

# STATE OF AGING IN CENTRAL INDIANA



## SECTION 10 HEALTH CARE





Persona

ABRAHAM

70 years old

Lives with his partner

Retired small business owner

Abraham recently turned 70 and lives with his partner on the near-east side of Indianapolis in a home that they bought 25 years ago. After graduating from high school, working, and saving, Abraham became a small-business owner. He operated a laundromat, a thrift store, and then—for nearly 30 years—a small neighborhood bar. He sold the bar and retired after suffering a fall down a small set of stairs, which injured his knee and required surgery. The fall left him unable to stand for more than a few minutes, or walk more than short distances, without significant pain—which made it impossible for him to keep working at the bar.

Social Security benefits make up nearly all of their household income of nearly \$35,000. The small retirement nest egg he built during his working years was drained by the costs of surgery, physical therapy, and related expenses not covered by Medicare. He also takes two prescription drugs to lower his cholesterol and his blood pressure. His primary caregiver for nearly 30 years, who retired 15 months ago, also diagnosed Abraham with pre-diabetes and said he needed to change his diet to avoid developing type 2 diabetes.

Since his surgery and subsequent retirement, Abraham has been covered by both Medicare and Medicaid, which means that most of his healthcare costs are currently covered. Yet he still faces serious health-related stressors and challenges.

Personas are sketches of fictional people that represent real challenges and circumstances highlighted in this report. They are a useful way to imagine how these statistics impact the lives of individuals and families.

One is that he has no hope of recovering the full mobility and mostly pain-free life he had before his fall, and he fears that another fall could leave him wheelchair-bound. A second challenge is that, as a gay Black man, Abraham has not developed a trusting relationship with the new primary care physician he has seen (just twice) since his former caregiver retired. He learned as a young man to be intensely private about his personal life, and he waited several years to reveal his sexual orientation to the previous caregiver. He has not yet done so with the new one. One result is that he feels less motivated to schedule or keep regular doctor appointments, which means he misses out on the kind of preventive care that might slow the progression of his prediabetes and mitigate his risk of heart disease.

A third challenge is that Abraham is suffering from depression as he struggles to adjust to retirement, limited mobility, and chronic pain. His lack of a strong relationship with his new primary caregiver is one obstacle to securing a referral to a mental-health professional. The stigma he has encountered as a gay man is another obstacle. He is very aware that counseling could help him cope with his depression. But connecting with a therapist, much less being vulnerable about his struggles, seem like insurmountable challenges.

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+

---

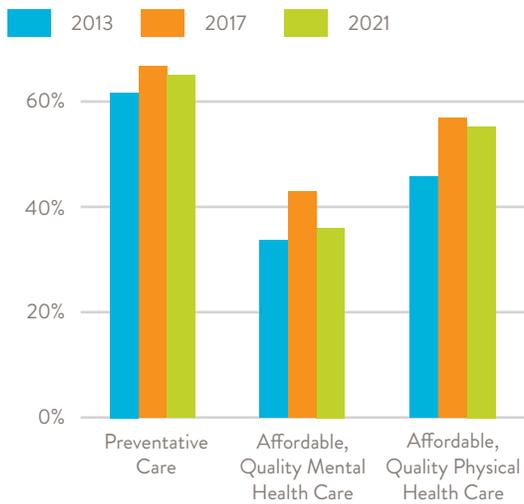
# HEALTH CARE

The health-related needs of older adults are often more complex because of advanced chronic disease and associated disability and require additional attention to care coordination. This section of the report discusses availability and use of health care, home-based services, and community-based services. Key findings include:

- Most older adults in Central Indiana feel preventative and physical health care is broadly available, but the share who have problems affording health care is on the rise, according to a 2021 survey.
- Providers identify falls, mental health, dementia, and fragmented care as issues that need more resources and attention.
- Recipients of home- and community-based services report positive outcomes for hospital discharges and chronic conditions. Medicaid reforms in Indiana could expand access to these services.
- Low-income and other vulnerable Medicare recipients in Central Indiana visit hospitals and emergency rooms more frequently than other Medicare recipients.
- Indiana's ratio of residents to physicians improved by 20% between 2016 and 2021, but rural areas are still lacking health care providers.

## Older adults in Central Indiana feel health care is broadly available, and mental health services are somewhat available.

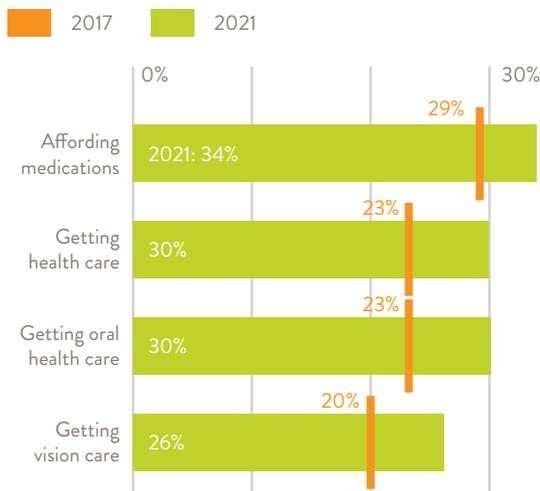
Percent of CASOA respondents who say availability is good or excellent for...



Source: CASOA, 2021

## Still, more older adults in Central Indiana have trouble getting the health care they need compared to 2017.

Percent of CASOA respondents who report at least a “minor” problem with the following



Source: CASOA, 2021

Chronic disease in older adults is often accompanied by disability, high health care utilization, and high health care costs.<sup>1</sup> A significant issue that arises with aging and advances in medical capabilities is how to balance the goals of maximizing quantity of life versus quality of life.

## AVAILABILITY OF HEALTH CARE

Central Indiana is fortunate to have an abundance of health care professionals and health care organizations. The region has more geriatric specialists relative to other areas of the state. (See Data Appendix.) The majority of Central Indiana respondents to the Community Assessment Survey for Older Adults (CASOA™) age 60 and older reported feeling that health care is broadly available.<sup>2</sup>

However, as with the rest of the country, the number of health care professionals and health care organizations specializing in the care of older adults is not adequate for the aging population.<sup>3</sup> In Indiana as of 2021, the ratio of residents per physician in rural areas is 1,070:1 as compared to urban i.e., 433:1.<sup>4</sup> These ratios both improved by at least 20% since 2016, but these disproportionalities adversely affect the access to care in rural counties where the point of care for most older residents is their primary care practitioner. The lack of availability of specialized geriatric services in these primary health care provider shortage areas coupled with other socio-economic factors like low income further deteriorates the possibility of geriatric health care access.<sup>5</sup> Shelby County, for example, has only one healthcare system serving its entire population and no geriatric services available. (See Data Appendix.)

In interviews, professionals providing health care and social services to older adults in Central Indiana communicated the need for additional resources to address several issues, including:<sup>6</sup>

- Falls and the fear of falling (see Health Outcomes section for associated statistics)
- Mental health and emotional issues in older adults, including depression and schizophrenia (see Health Outcomes section for associated statistics)
- The need for memory care programs and better treatment and support for persons living with dementia and their caregivers

- Fragmented care and the lack of coordination between hospital discharge planners and community-based case managers

These shortcomings in health care for older adults have been recognized nationally and have led to the Age-Friendly Health Systems initiative of the John A. Hartford Foundation and the Institute for Healthcare Improvement (IHI), which aims to build a social movement so all care with older adults is age-friendly.<sup>7</sup> Becoming an Age-Friendly Health System entails reliably providing evidence-based elements of high-quality care, such as knowing and acting on what matters to the older person, along with critical geriatric care concepts related to medication, mentation, and mobility. Several hospitals and clinics in Central Indiana have been recognized by the Institute for Healthcare Improvement as an Age-Friendly Health System. (See Data Appendix.)

In addition, several of the larger health systems in Central Indiana have established specialized geriatric services proven to result in better outcomes for older adults with complex needs. These services typically involve a team of health care professionals such as a physician, nurse, and social worker. They can also include geriatric emergency department programs, Acute Care for Elders (ACE) hospital consultation, hospital-to-home care transitions programs, outpatient consultation for falls and memory assessment, and office and in-home primary care. Details about the availability of these services in the healthcare systems in Central Indiana are provided in the appendix.

As adults age, integration of health care and social services becomes more important for achieving optimal health outcomes, yet fragmentation of care remains a problem (and an opportunity). In response to the need for more integrated care, CICOA Aging & In-Home Solutions is working closely with an increasing number of hospitals to embed social services staff. In two hospitals, CICOA staff are collaborating with hospital discharge planning teams to improve care transitions and prevent hospital readmissions. CICOA also has taken the lead in Central Indiana to increase awareness and provide education about dementia through the Dementia Friends Indiana program.

Several hospitals in Central Indiana are working with CICOA to become a Dementia Friends Indiana Hospital and requiring staff to become more familiar with how to appropriately care for persons with dementia. (See Appendix.)

The number of geriatrics health care professionals and services has grown in Central Indiana which has helped to address these issues. However, there is still limited capacity compared to the need that exists. For example, a geriatrician is a physician who is specially trained to evaluate and manage the unique health care needs and treatment preferences of older adults. In 2018, there were only 87 board certified geriatricians in practice across all of Indiana.<sup>8</sup> This reflects a nationwide issue.<sup>9</sup>

Both Indiana University School of Medicine (IUSM) and St. Vincent Hospital offer training programs for physicians desiring to specialize in geriatric medicine. IUSM also hosts a U.S. Health Resources and Services Administration funded Geriatrics Workforce Enhancement Program that aims to provide education and training in geriatric care principles to medical, nursing, and social work trainees as well as staff of local primary care practices.

## LONG-TERM SERVICES AND SUPPORTS

Long-term services and supports (LTSS) are the personal care assistance that many people need as they grow older.<sup>10</sup> LTSS includes assistance with self-care tasks, like bathing and dressing, and with daily living tasks, like cooking or managing medication. This work is provided by both paid and unpaid caregivers. Older adults who need assistance with activities of daily living may receive help from family members, friends, paid helpers, community organizations, or government programs. The two main models of LTSS are home and community-based services (HCBS) and institutional care such as provided in nursing homes.<sup>11</sup> HCBS include assistance at home and in other community settings such as an assisted living facility or adult day program.<sup>12</sup>

## HOME- AND COMMUNITY-BASED SERVICES

Many older adults in Central Indiana have problems maintaining their home and performing daily activities. They require support from home- and community-based services, such as Indiana's Community and Home Options to Institutional Care for the Elderly and Disabled program (CHOICE)<sup>13</sup> and the Medicaid Aged and Disabled Waiver (Waiver) program.<sup>14</sup> The Waiver program provides home and community-based services (HCBS) to supplement informal supports for people who would require care in a nursing facility. Services offered under the CHOICE and Waiver programs include transportation, meals,

personal care assistance with activities of daily living, home modifications, personal emergency response system, caregiver support, respite care, adult day services, and assisted living including memory care (Waiver only). In 2019-2020, individuals in Indiana receiving home- and community-based services under the publicly funded CHOICE or Waiver program experienced positive outcomes. Around 85% of these individuals felt supported enough to go home after discharge, had someone follow up after discharge, and knew how to manage their chronic conditions (see chart on right).

Assisted living is for people who need help with activities of daily living, but not as much help as a nursing home provides. Assisted living residents usually live in their own apartments or rooms and share common areas. They have access to many services, including up to three meals a day; assistance with personal care; help with medications, housekeeping and laundry; and social and recreational activities. There are numerous opportunities for assisted living in Central Indiana, including several facilities covered under the Waiver program and some that have a secure memory care unit for persons living with dementia.

The Program of All-Inclusive Care for the Elderly (PACE) model, also offered by Indiana Medicaid, serves individuals ages 55 or older who are certified by the state to need nursing home care, able to live safely in the community with supports, and live in a PACE service area. PACE is responsible for delivering all medical and supportive services and coordinating the enrollee's care under Medicare and Medicaid to help them maintain independence in their home as long as possible. Central Indiana has one PACE program serving residents of Johnson County and parts of Marion County.

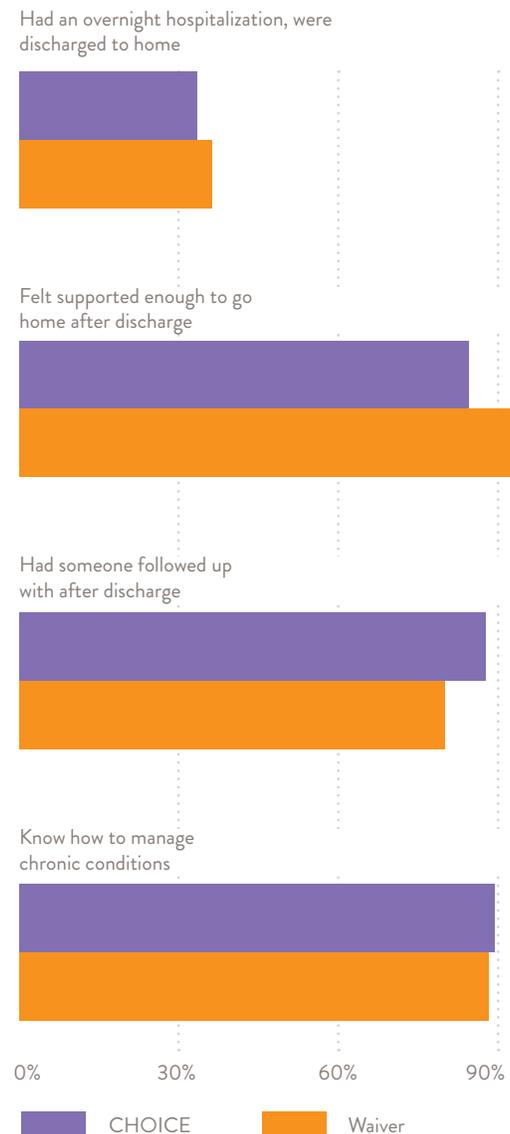
### EXPANSION OF HOME- AND COMMUNITY-BASED SERVICES

The Indiana Family and Social Services Administration (FSSA) is implementing reforms to the administration of long-term care under Medicaid with a goal to lower costs per person and deliver more care and services at home. Twenty-five other states have implemented similar reforms, called managed LTSS (mLTSS) programs.<sup>15</sup>

The case for reform is driven by demand for HCBS and growing costs. An FSSA presentation outlining reforms states that most people prefer home-based care but few receive it, and costs for institutional care are

## Most home- and community-based service recipients experience positive outcomes related to hospital discharges and chronic conditions.

Percent of Indiana statewide HCBS waiver recipients who...



Source: 2019-2020 National Core Indicators for Aging and Disabilities © (NCI-AD)

disproportionately high. LTSS spending accounts for a quarter of Medicaid costs in Indiana, and most of that cost is institutional care.<sup>16</sup>

Traditional Medicaid payments for LTSS services operate under a fee-for-service model, just like a typical private insurer: Providers agree to be reimbursed at a contracted rate for certain services. Indiana's managed LTSS will operate under a risk-based managed care model. Under mLTSS, the state will sign a contract with "managed care entities" (MCE). The MCE will provide care through their own networks of providers and hospitals, and the state will pay an MCE a fixed annual fee for each Medicaid patient. These payments are linked to patient outcomes rather than services, which shifts a share of the financial risk from state and federal government to health care providers. Proponents of this model say it incentivizes quality, affordable care because profit is driven by reduced costs and positive patient outcomes.<sup>17</sup> Some critics are concerned this reform will exacerbate an LTSS workforce shortage and increase the burden on family caregivers. (See the Caregiving chapter for more details.)

FSSA anticipates the mLTSS program will launch in 2024 and will serve over 120,000 Hoosiers in the initial years of its implementation. By 2029, FSSA expects it will serve 165,000 Hoosiers.

## NURSING HOME CARE

Most nursing home care is custodial care such as help with activities of daily living (like bathing, dressing, using the bathroom, and eating). Many nursing homes are certified to provide skilled nursing care (like changing sterile dressings). Nursing homes that participate in Medicare or Medicaid are included in Nursing Home Compare, a rating system from the Centers for Medicare & Medicaid Services (CMS). The rating system provides residents and their families with a summary of three dimensions of nursing home quality: health inspection results, staffing data, and quality measure data. The goal of the rating system is to help consumers make meaningful distinctions among high- and low-performing nursing homes. Among the many nursing homes in Central Indiana, approximately one of every four facilities currently has a five-star overall rating.

## LTSS STATE SCORECARD

The AARP Public Policy Institute periodically publishes the LTSS State Scorecard to provide state and federal policy makers and consumers with information they need to assess their state's performance across multiple dimensions and indicators, learn from other states, and improve the lives of older adults, people with disabilities, and their families.<sup>18</sup> Compared to the 2017 LTSS State Scorecard, Indiana's overall ranking in 2020 was up to 44 from 51, and Indiana improved on indicators under two of the five dimensions: affordability and access (Indiana ranks 41) and quality of life and quality of care (Indiana ranks 19). Indiana ranks lowest (51) in support for family caregivers. For the dimension of choice of setting and provider, Indiana ranks in the bottom quartile (48) receiving particularly low scores for a) the percentage of Medicaid and state LTSS spending for HCBS vs. nursing home care, b) the percentage of Medicaid LTSS users receiving HCBS vs. nursing home care and c) adult day services supply. Planning for the next LTSS State Scorecard is underway, and will provide updated data covering the impact of the pandemic.

## LOW-INCOME AND OTHER VULNERABLE OLDER ADULTS

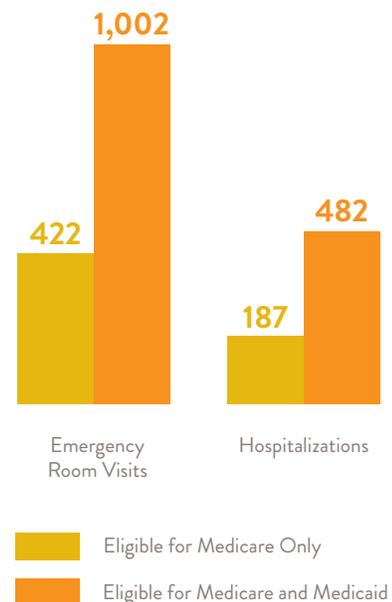
Older adults in Central Indiana have concerns about the expense associated with health care access, eligibility for Medicaid (e.g., "making too much money" to be eligible), inadequate health care coverage by Medicaid and Medicare, and cost of medications.<sup>19</sup> See the Financial Stability section of the report for additional discussion.

Medicare and Medicaid are separate government-run health insurance programs serving two different populations. While Medicare provides health coverage to people 65 years and older and people with disabilities, Medicaid provides health coverage to low- or very low-income individuals. Individuals who are eligible for both Medicare and Medicaid benefits, referred to as "dually eligible," make up about 17% of total Medicare enrollment.<sup>20</sup>

Dually eligible individuals tend to have more chronic medical conditions and greater levels of physical disabilities and mental illness than persons with Medicare only.<sup>21,22</sup> In addition, those who are dually eligible visit the emergency department (ED) and are hospitalized at more than twice the rate of those that have Medicare only.

Low-income Medicare recipients visit hospitals and emergency rooms more than twice as frequently as those who are not low-income.

Incidence of ED visits and hospitalizations in Central Indiana per 1,000 people per year



Source: CMS, 2020

Nationally, the proportion of dually eligible beneficiaries of color increased from 41% in 2006 to 48% in 2018.<sup>23</sup> In Indiana, approximately 80% of those dual eligible are White while 15% are Black, which is disproportionate to the total White and Black population.<sup>24</sup>

Hospital readmissions are often avoidable and may indicate a lack of coordination of medical care, or inadequate follow-up after patients leave the hospital. In 2020, the 30-day all-cause readmission rate for 65 to 74-year-olds in Indiana was 16%, equal to the U.S. rate. Indiana and U.S. rates have been steady since at least 2015.<sup>25</sup>

Older adults with dementia<sup>26</sup> are also known to have higher hospitalization rates than those without dementia. A study at Eskenazi Health, a health care system in Indianapolis, demonstrated that older adults with dementia had more than twice the number of hospital admissions and care transitions compared to older adults without dementia.<sup>27</sup>

Local providers also expressed concern about the barriers experienced by the older adult LGBTQ+ population, who experience difficulties finding and accessing basic health care in Indiana for a variety of reasons. First, there is a limited presence of health care providers who specialize in LGBTQ+ specific health care. This is particularly the case for transgender people who struggle to find health care practitioners with knowledge regarding medical transition. Furthermore, one LGBTQ+ informant expressed concern regarding accessibility of general health care needs<sup>28</sup> because of visible discomfort on the part of the health care provider. This person's experience aligns with findings in the research literature.<sup>29, 30</sup> To learn more, see "Highlighting Equity" on disparities in health care access and quality for LGBTQ+ older adults.



## HIGHLIGHTING EQUITY

### HEALTH CARE ACCESS AND QUALITY CONSIDERATIONS FOR LGBTQ+ OLDER ADULTS

Compared to their non-LGBTQ+ peers, LGBTQ+ older adults experience higher rates of disability, poor physical health, and psychological distress.<sup>31</sup> Using the social-ecological framework<sup>32</sup>, we highlight some factors that can influence LGBTQ+ healthcare access and outcomes in Central Indiana.



#### INTERPERSONAL FACTORS:

##### *Fear of disclosing sexual orientation or gender identity:*

Many LGBTQ+ older adults experience fear or bias when disclosing their LGBTQ+ status to healthcare providers. One national study found that 15% of LGBTQ+ older adults were fearful about accessing health care services outside of the LGBTQ+ community, and nearly one quarter had not revealed their sexual orientation or gender identity to their primary care provider.<sup>33</sup> Many LGBTQ+ older adults grew up in a time where non-heteronormative behavior could result in imprisonment, violence or loss of freedom, which led many to hide their sexual orientation or gender identity from others, including health providers.

##### *Provider bias:*

Providers can also demonstrate negative behaviors toward LGBTQ+ older adults, further demotivating these individuals to self-disclose their sexual orientation or gender identity. These negative behaviors of healthcare providers can either be intentional, such as refusing care or joking about the patient with other staff members, or unconscious, such as assuming that the patient's married partner is of the opposite sex. LGBTQ+ older adults' non-disclosure of their sexual orientation or gender identity may cause adverse health outcomes, such as a delay in diagnosing significant medical issues.<sup>34</sup>



#### ORGANIZATIONAL FACTORS:

##### *Lack of LGBTQ+-inclusive health services:*

Another factor that influences LGBTQ+ older adults' health care in Central Indiana is the lack of guidelines and services for LGBTQ+ care in healthcare systems. The Human Rights Campaign's Healthcare Equality Index 2020, which evaluates healthcare facilities' policies and practices on LGBTQ+ patient inclusion and equity, only designated two Central Indiana healthcare facilities, Eskenazi Health and the VA Richard L. Roudebush Medical Center, as "LGBTQ+ Healthcare Equality Leaders." This designation means that these facilities have LGBTQ+-inclusive policies around patient and employee non-discrimination and family visitation, provide LGBTQ+- specific patient services

and support, and engage with the LGBTQ+ community through initiatives, events, or marketing.<sup>35</sup> In contrast, three healthcare facilities in Central Indiana do not have an LGBTQ+-inclusive patient nondiscrimination policy, and one does not have an equal visitation policy for family members.<sup>36</sup>

#### *Limited medical education inclusive of LGTB+ issues:*

Another organizational concern is the lack of education inclusive of LGBT+ people provided in U.S. medical schools. A 2018 report from the Association of American Medical Colleges found that while three quarters of medical schools included some LGBTQ+ health themes in their curriculum, roughly half said that this education consisted of three or fewer lectures, group discussions, or other learning activities.<sup>37</sup> This lack of comprehensive medical education leaves many providers feeling inadequately trained to care for their LGBT patients. A 2018 survey of over 600 medical students found that 80% of respondents felt “not competent” or “somewhat not competent” in treating LGTBQ+ patients.<sup>38</sup>



#### **POLICY FACTORS:**

##### *Lack of healthcare policies that explicitly protect LGTB+ individuals:*

The lack of health care policies that explicitly protect LGTB+ individuals has a negative effect on this population. For example, Indiana’s Medicaid program has no explicit policy for transgender health coverage and care, which can create barriers to health care for transgender people receiving Medicaid in the state. In contrast, 23 states, plus Puerto Rico and the District of Columbia, currently have an explicit policy for transgender health coverage and care in their Medicaid programs. Additionally, 24 states and the District of Columbia have laws preventing health insurers from “explicitly refusing to cover transgender-related health care benefits.” Indiana has not passed these protections.<sup>39</sup>

# DATA APPENDIX

## Specialized Geriatric Services Offered by Health Systems in Central Indiana

Health System and County	Geriatric Emergency Department	Acute Care For Elders (ACE) Inpatient Consultation	Geriatric Psychiatry Inpatient Unit and/or Consultation	HELP Program (Hospital Elder Life Program)	NICHE (Nurses Improving Care for Health System Elders)	Care Transitions Program (Hospital-to-Home)	Nursing Facility Program
Ascension St. Vincent (Marion, Hamilton County)	✓	✓	✓		✓	✓	
Community Health (Marion, Hamilton, Johnson County)	✓	✓	✓	✓	✓	✓	✓
Eskenazi Health (Marion County)		✓		✓	✓		✓
Franciscan Health (Marion, Johnson County)							
Hancock Regional Hospital (Hancock County)							
Hendricks Regional Health (Hendricks County)							
Indiana University Health (Marion, Boone, Hamilton County)		✓				✓	✓
Johnson Memorial (Johnson County)							
Major Hospital (Shelby County)							
Riverview Hospital (Hamilton County)							
Witham Health Services (Boone County)			✓				
Richard L. Roudebush VA Medical Center (Marion County)		✓				✓	

Age-friendly hospitals are defined by Institute for Healthcare Improvement. Dementia-friendly hospitals are defined by CICOA. All other parameters were sourced from key informant interviews.

Health System and County	Geriatrics Outpatient Consultation	Geriatrics Outpatient Primary Care	Geriatrics Home-Based Primary Care	GRACE Team Care (Geriatric Resources for Assessment & Care of Elders)	PACE (Program for All-Inclusive Care of the Elderly)	Dementia Friends Indiana Certified hospital/ clinic	Age-Friendly Health System
Ascension St. Vincent (Marion, Hamilton County)	✓	✓				✓	✓
Community Health (Marion, Hamilton, Johnson County)	✓		✓				✓
Eskenazi Health (Marion County)	✓	✓	✓			✓	✓
Franciscan Health (Marion, Johnson County)					✓		
Hancock Regional Hospital (Hancock County)						✓	
Hendricks Regional Health (Hendricks County)							✓
Indiana University Health (Marion, Boone, Hamilton County)	✓			✓			✓
Johnson Memorial (Johnson County)							
Major Hospital (Shelby County)							
Riverview Hospital (Hamilton County)							
Witham Health Services (Boone County)						✓	✓
Richard L. Roudebush VA Medical Center (Marion County)	✓	✓	✓	✓			

# Download the data used in this chapter.

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



## ENDNOTES

- 1 Vincenzo Atella et al., "Trends in Age-related Disease Burden and Healthcare Utilization," *Aging Cell* 18, no. 1 (February 2019), <https://doi.org/10.1111/accel.12861>
- 2 Community Assessment Survey for Older Adults™. National Research Center Inc., 2021. <https://cicoa.org/news-events/research/casoa/>.
- 3 "Geriatricians," accessed January 25, 2021, <https://www.advisory.com/Daily-Briefing/2020/01/21/geriatricians>.
- 4 "Bowen Center Information Portal," accessed April 18, 2022, <https://bowenportal.org/index.php/indiana-physician-workforce/>.
- 5 John W. Rowe, "The US eldercare workforce is falling further behind," *Nature Aging* 1, 327-329 (2021), <https://doi.org/10.1038/s43587-021-00057-z>
- 6 Thirty-five key informant interviews with caregivers and service providers 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.
- 7 "What Is an Age-Friendly Health System? | IHI - Institute for Healthcare Improvement," accessed January 25, 2021, <http://www.ihl.org/Engage/Initiatives/Age-Friendly-Health-Systems/Pages/default.aspx>.
- 8 "Current Number of Board Certified Geriatricians by State 8 1 19.Pdf," accessed January 25, 2021, <https://www.americangeriatrics.org/sites/default/files/inline-files/Current%20Number%20of%20Board%20Certified%20Geriatricians%20by%20State%208%201%2019.pdf>.
- 9 Rowe, "The US eldercare workforce is falling further behind"
- 10 "What Is the Lifetime Risk of Needing and Receiving Long-Term Services and Supports?," ASPE, April 4, 2019, <https://aspe.hhs.gov/basic-report/what-lifetime-risk-needing-and-receiving-long-term-services-and-supports>.
- 11 "LTSS Overview | CMS," accessed January 27, 2021, <https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-TA-Center/info/ltss-overview>.
- 12 "Home & Community Based Services | Medicaid," accessed January 27, 2021, <https://www.medicaid.gov/medicaid/home-community-based-services/index.html>.
- 13 CHOICE is an acronym for the program's full name Community and Home Options to Institutional Care for the Elderly and Disabled. The CHOICE program is administered through Indiana's 16 Area Agencies on Aging. The CHOICE program provides home- and community-based services to assist individuals in maintaining their independence in their own homes or communities for as long as is safely possible.
- 14 Indiana Medicaid pays for services for individuals who choose to remain in their home as an alternative to receiving services in an institution, such as a nursing facility. These services are referred to as home and community-based services. These programs are intended to assist a person to be as independent as possible and live in the least restrictive environment possible while maintaining safety in the home.
- 15 Indiana Family and Social Service Administration. *Managed Long-Term Services and Supports*. Accessed May 13, 2022, <https://www.in.gov/fssa/long-term-services-and-supports-reform/managed-long-term-services-and-supports/>
- 16 Indiana Family and Social Service Administration. *Managed Long-Term Services and Supports Stakeholder Update*. November 3, 2021. Accessed May 13, 2022, <https://www.in.gov/fssa/long-term-services-and-supports-reform/files/mLTTSS-Design-Book-Presentation-11.3.21.pdf>

- 17 ASHP. *Capitated & Risk Sharing Models FAQ*. July 2016. Accessed May 13, 2022, <https://www.ashp.org/-/media/assets/pharmacy-practice/resource-centers/ambulatory-care/capitated-and-risk-sharing-models-faq.ashx>
- 18 "LTSS 2020 Short Report PDF 923.Pdf," accessed January 25, 2021, <http://www.longtermscorecard.org/~media/Microsite/Files/2020/LTSS%202020%20Short%20Report%20PDF%20923.pdf>.
- 19 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. The 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.
- 20 Dual Eligible. The Henry J. Kaiser Family Foundation. Accessed June 7, 2022. <https://www.kff.org/tag/dual-eligible/>.
- 21 "Coordinating Physical and Behavioral Health Services for Dually Eligible Members with Serious Mental Illness," Center for Health Care Strategies, December 11, 2019, <https://www.chcs.org/resource/coordinating-physical-and-behavioral-health-services-for-dually-eligible-members-with-serious-mental-illness/>.
- 22 "Medicare-Medicaid Enrollee Information National, 2012," 2012, 6.
- 23 CMS, "Medicare-Medicaid Dual Enrollment 2006 through 2018," Data Analysis Brief (Centers for Medicaid and Medicare Services, September 2019), <https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/DataStatisticalResources/Downloads/MedicareMedicaidDualEnrollmentEverEnrolledTrends-DataBrief2006-2018.pdf>.
- 24 "Dual Eligible Beneficiaries by Race/Ethnicity," KFF (blog), May 31, 2018, <https://www.kff.org/other/state-indicator/dual-eligible-beneficiaries-by-re/>.
- 25 "Explore Hospital Readmissions - Ages 65-74 in Indiana | 2020 Senior Health," America's Health Rankings, accessed January 25, 2021, [https://www.americashealthrankings.org/explore/senior/measure/hospital\\_readmissions\\_sr/state/IN](https://www.americashealthrankings.org/explore/senior/measure/hospital_readmissions_sr/state/IN).
- 26 "What Is Dementia?," Alzheimer's Disease and Dementia, accessed January 25, 2021, <https://alz.org/alzheimers-dementia/what-is-dementia>.
- 27 Christopher M. Callahan et al., "Transitions in Care among Older Adults with and without Dementia," *Journal of the American Geriatrics Society* 60, no. 5 (May 2012): 813–20, <https://doi.org/10.1111/j.1532-5415.2012.03905.x>.
- 28 For example, going to the doctor, getting an eye exam, etc.
- 29 Utamsingh, P. D., Richman, L. S., Martin, J. L., Lattanner, M. R., & Chaikind, J. R. (2016). Heteronormativity and practitioner-patient interaction. *Health communication*, 31(5), 566–574. <https://doi.org/10.1080/10410236.2014.979975>
- 30 Bonvicini K. A. (2017). LGBT healthcare disparities: What progress have we made?. *Patient education and counseling*, 100(12), 2357–2361. <https://doi.org/10.1016/j.pec.2017.06.003>
- 31 Charles A. Emlet, "Social, Economic, and Health Disparities Among LGBT Older Adults," *Generations* (San Francisco, Calif.) 40, no. 2 (2016): 16–22.
- 32 University of Washington School of Medicine, "Social Ecological Model | Ecology of Health and Medicine," August 12, 2017, <https://blogs.uw.edu/somehm/2017/08/12/social-ecological-model/>.
- 33 Mary Beth Foglia and Karen I. Fredriksen-Goldsen, "Health Disparities among LGBT Older Adults and the Role of Nonconscious Bias," *The Hastings Center Report* 44, no. 0 4 (September 2014): S40–44, <https://doi.org/10.1002/hast.369>.

- 34 Foglia and Fredriksen-Goldsen.
- 35 "HEI-2020-FinalReport.Pdf," accessed January 25, 2021, <https://hrc-prod-requests.s3-us-west-2.amazonaws.com/resources/HEI-2020-FinalReport.pdf>.
- 36 "HEI Interactive Map - HRC," accessed January 25, 2021, <https://www.hrc.org/resources/hei-map>.
- 37 "Keeping Our Promise to LGBTQ+ Patients," AAMC, accessed January 25, 2021, <https://www.aamc.org/news-insights/insights/keeping-our-promise-lgbtq-patients>.
- 38 "Medical Students Push For More LGBT Health Training To Address Disparities," NPR.org, accessed January 25, 2021, <https://www.npr.org/sections/health-shots/2019/01/20/683216767/medical-students-push-for-more-lgbt-health-training-to-address-disparities>.
- 39 "Movement Advancement Project | State Profiles," accessed January 25, 2021, [https://www.lgbtmap.org/equality-maps/profile\\_state/IN](https://www.lgbtmap.org/equality-maps/profile_state/IN).

# STATE OF AGING IN CENTRAL INDIANA



## SECTION 11 CAREGIVING

June 2022





Persona

## MARIA AND GEORGE

58 and 60 years old

Married couple

Care for grandchild and parent

Maria and George are a married, Latinx couple living on the near-southside of Indianapolis. George, 60, has been a middle-school teacher in the Indianapolis Public Schools system for 30 years. Maria, 58, was a homemaker and the primary caregiver for the couple's three kids, all of whom are grown and have moved out of the house.

To supplement George's income, Maria occasionally takes on work from a housecleaning service owned by a longtime friend of hers from church. Maria is also a caregiver for the couple's granddaughter, Elisa, the only child of one of their daughters. Elisa goes to daycare during the work week, but George and Maria watch her some weekend afternoons—when their daughter is running errands or needs a break—and on workdays, when Elisa needs to be picked up from daycare and her parents are running late.

George's mother, Sofia, is 85 and beginning to experience the early stages of dementia. She lived alone for several years, in her own home not far from Maria and George, after her husband died. But a year ago, after she was unable to renew her driver's license because of failing eyesight, living alone became increasingly dangerous and impractical. With their kids raised and gone, Maria and George had two spare bedrooms, and it made sense for them to take her in. With George still working full-time, Maria provides the vast majority of care for Sofia. The experience has been deeply rewarding on many levels. Maria's social circle

Personas are sketches of fictional people that represent real challenges and circumstances highlighted in this report. They are a useful way to imagine how these statistics impact the lives of individuals and families.

has expanded as she takes Sofia to events for seniors at the local community center. The two are regulars, as well, at the bi-monthly lunch for seniors at their Catholic Church. The lunches offer good opportunities to talk with friends and meet new people. Maria also feels a strong sense of pride and fulfillment in being a critical source of support to her husband—who struggles to adjust to this new phase in his family’s life—and his mother.

Yet the caregiving has created some new anxieties and hardships for Maria. One is that she is unable to help out as much with her granddaughter. With her early-stage dementia and poor eyesight, Sofia needs nearly constant attention. Picking up Elisa at daycare—and watching her on weekends—has become more difficult and requires much more planning than it used to. Caring for Sofia also means that Maria is able to accept fewer jobs with her friend’s cleaning service, which is now only possible when George is free and can care for his mother. So, in addition to depriving Maria of a chance to get out of the house occasionally—something she enjoys very much—caring for Sofia has had a negative impact on the family’s income. At the same time, it has increased their expenses. This combination of stresses is leading Maria to lose sleep. She worries about not only the couple’s finances in the near-term but how Sofia’s dementia will affect her and George’s relationship and finances over the coming years.

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+

---

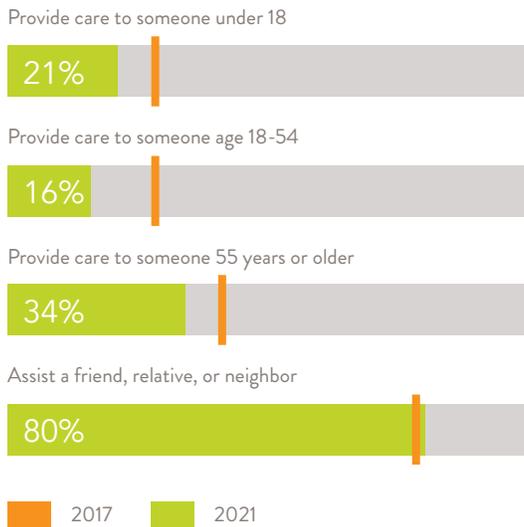
# CAREGIVING

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 report assisting a friend, relative, or neighbor.
- One third of older adults provide care to someone age 55 or older.
- As many as one fifth of older adults in Central Indiana are physically, emotionally or financially burdened by caregiving responsibilities, but this has fallen slightly since 2017. Most adults do not believe support services are available for caregivers.
- Between 2017 and 2021, there was a decline in the share of adults reporting caregiving for other adults in the past week and feeling burdened by caregiving responsibilities.
- A national survey found that caregivers' mental health took a significant toll during the pandemic. Among respondents at least half report adverse mental health conditions such as anxiety, depression, or PTSD. Furthermore, around 30% of caregivers considered suicide.

## The share of older adults who report caring for someone and feeling burdened by caregiving fell.

Percent of Central Indiana CASOA respondents who...



\*In 2013 and 2017, these questions referred to individuals age 55 or older, age 18 to 54, and under 18.

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



Source: CASOA, 2021

## 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 assisting a friend, relative, or neighbor.<sup>1</sup>

The share of older adults who report providing at least an hour of care to someone in the past week is significantly lower than the 2017 CASOA survey. This could be due to changes in the survey questions. The 18 to 54 age range was formerly 18 to 59, and 55 or older age range was formerly 60 or older. This could also be impacted by the COVID-19 pandemic. Surveys were conducted in the fall and winter of 2021, when the U.S. was in the midst of a COVID-19 surge. This could have temporarily reduced older adults' ability to care for others as they practiced social isolation.

“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.

Caregivers are a diverse group. Some are paid while many are not. Some are parents of children, some are children of the older adults they are caring for, and others are community members that volunteer to help provide care.

One in six American workers provide care, with caregiving more common among people with lower incomes: 21% people earning \$36,000 per year provide care compared to 15% of those who earn above \$90,000.<sup>2</sup> A larger share of Black (21%) and Latinx individuals (20%) provide care than White individuals (17%). (See "Highlighting Equity" for more information about Latinx caregivers.)

While caregivers are diverse, the responsibility falls more heavily on those who are low-income and are people of color. These groups already face adverse health outcomes

“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

which were exacerbated by systemic problems caused by the COVID-19 pandemic.

There are some promising ways to reduce these added stressors and complications for both caregivers and older adults, such as increasing communication using technology, assisting with activities of daily living such as grocery shopping, and providing caregivers with the support they need.<sup>3</sup>

Reforms to Indiana’s long-term support services (LTSS) system will impact family and friends who are caring for older adults. (See the Health Care chapter for details about this reform.) The managed LTSS (mLTSS) reform in Indiana has raised some concerns. Under the current system, family and friends provide the majority of the LTSS in-home and community-based care. Some critics are concerned this reform will exacerbate the persistent and growing LTSS workforce shortages.<sup>4</sup> There is fear that this will increase the burden on family caregivers. Some are concerned mLTSS prioritizes reduced costs for the government more than providing quality health care for older adults.<sup>5</sup> Critics say managed care entities have an incentive to offer low quality of services and deny procedures to boost profits. There is also pushback from healthcare providers due to low reimbursement fees and increased administrative burden.<sup>6</sup> Indiana FSSA is attempting to allay these concerns by holding stakeholder meetings and soliciting feedback from all the involved entities.

## IMPACT ON CAREGIVER

The impact of caregiving on the caregiver is significant, and informants to this report say that it is not unusual for the caregiver to suffer along with their friend or loved one.<sup>7</sup> 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 indicate positive benefits most frequently when caregiving was a newer or short-term experience or when the individual was not the sole caregiver. Caregivers report 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 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.

## IMPACT OF COVID-19 ON CAREGIVERS

The COVID-19 pandemic has caused severe harm to most industries and that includes caregiving for older adults. Caregivers were already a vulnerable group under immense pressure before the virus, but they were pushed even further during the pandemic. A Centers for Disease Control and Prevention (CDC) survey found that caregivers' mental health took a significant toll during this time. Among respondents at least half report adverse mental health conditions such as anxiety, depression, or PTSD. Furthermore, around 30% of caregivers considered suicide. Half of caregivers responsible for both children and adults considered suicide.<sup>8</sup> For comparison, a survey from the Substance Abuse and Mental Health Administration in 2015 found the rate at which the general population thought about committing suicide was much smaller (4%).<sup>9</sup>

### 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.

### Positive Impact

Aging in place  
Increased longevity

### Negative Impact

Neglect  
Abuse

Informants report that “aging in place” is a well-understood concept. People want to stay in their own homes as independently 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.

**“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.<sup>10</sup> 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.<sup>11</sup> 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.<sup>12</sup> 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.)

## 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 agree 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)<sup>13</sup> and Indiana 211.<sup>14</sup> Informants also report 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, Duett, to match people who need in-home care with providers.<sup>15</sup>

**“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**

### 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)



## 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.<sup>16</sup> Although Latinx caregivers report higher levels of caregiving satisfaction than White caregivers, 44% report feeling stressed and overwhelmed by their caregiving responsibilities.<sup>17</sup> Latinx individuals also spend more time and money caring for their loved ones than average.<sup>18</sup> 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.<sup>19</sup> Studies have shown that caregivers of people with dementia experience greater caregiver burden, with roughly 25% providing at least 40 hours of care per week to their loved one, compared to only 16% of other caregivers.<sup>20</sup>



#### *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.<sup>21</sup> As a result, one study found that Mexican-American caregivers were the least likely to use formal care for their loved one compared to others.<sup>22</sup> 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.<sup>23</sup>



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

Only around half of Latinx older adults are proficient in English,<sup>24</sup> and 57% of Latinx adults report 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% felt that these services would provide the food they were used to eating.<sup>25</sup> Additionally, Latinx caregivers felt they had a lack of understanding of topics around caregiving, with 41% stating they do not understand government programs such as Medicare and SSI, compared to 27% who share that they encountered issues with finding educational resources. When asked what Spanish-language resources would be helpful for Latinx caregivers, roughly half mention trainings on stress management, government programs, and caregiving techniques.<sup>26</sup>

## ENDNOTES

- 1 National Research Center Inc., “Community Assessment Survey for Older Adults: 2021 Report Results for Central Indiana” (Boulder: CICOA Aging and In-Home Solutions, 2021), <https://cicoa.org/news-events/research/>.
- 2 Peter Cynkar and Elizabeth Mendes, “More Than One in Six American Workers Also Act as Caregivers” (2011), <https://news.gallup.com/poll/148640/one-six-american-workers-act-caregivers.aspx>
- 3 Anna Garnett, Melissa Northwood, and Ruhenna Sangrar, “Older caregivers struggling with extra burdens of home care during COVID-19” (2021), <https://theconversation.com/older-caregivers-struggling-with-extra-burdens-of-home-care-during-covid-19-152373>
- 4 Managed Long Term Services and Supports: Status of State Adoption and Areas of Program Evolution (n.d.). Retrieved May 31, 2022, from <https://www.macpac.gov/wp-content/uploads/2018/06/Managed-Long-Term-Services-and-Supports-Status-of-State-Adoption-and-Areas-of-Program-Evolution.pdf>
- 5 Fred J. Hellinger, (1998). The Effect of Managed Care on Quality: A Review of Recent Evidence. *Archives of Internal Medicine*, 158(8), 833–841. <https://doi.org/10.1001/archinte.158.8.833>
- 6 How Have Long-Term Services and Supports Providers Fared in the Transition to Medicaid Managed Care? A study of Three States. (n.d.). ASPE. Retrieved May 31, 2022, from <https://aspe.hhs.gov/reports/how-have-long-term-services-supports-providers-fared-transition-medicaid-managed-care-study-three-1>
- 7 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.
- 8 Mark Czeisler, Elizabeth Rohan, Stephanie Melillo, et al., “Mental Health Among Parents of Children Aged <18 Years and Unpaid Caregivers of Adults During the COVID-19 Pandemic — United States, December 2020 and February–March 2021” (2021), <https://www.cdc.gov/mmwr/volumes/70/wr/mm7024a3.htm>
- 9 Kathryn Piscopo and Rachel N. Lipari, “Suicidal Thoughts and Behavior among Adults: Results from the 2015 National Survey on Drug Use and Health” (2016), <https://www.samhsa.gov/data/sites/default/files/NSDUH-DR-FFR3-2015/NSDUH-DR-FFR3-2015.htm>
- 10 Mark S. Lachs, Christianna Williams, Shelley O’Brien, Leslie Hurst, Ralph Horowitz, “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>.
- 11 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>.
- 12 Toshio Tatara et al., “The National Elder Abuse Incidence Study,” n.d., 136

- 13 "CICOA Aging & In-Home Solutions | Indianapolis, IN," accessed February 16, 2021, <https://cicoa.org/>.
- 14 FSSA, "Indiana 211," accessed February 16, 2021, [www.in211.org](http://www.in211.org).
- 15 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>.
- 16 "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>.
- 17 Sunshine M Rote, Jacqueline Angel, Heehyul Moon, Kyriakos Markides, "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>.
- 18 "Status of Hispanic Older Adults: Insights from the Field," 2018, 28.
- 19 "Status of Hispanic Older Adults: Insights from the Field."
- 20 Henry Brodaty and Marika Donkin, "Family Caregivers of People with Dementia," *Dialogues in Clinical Neuroscience* 11, no. 2 (June 2009): 217–28.
- 21 Yvette G. Flores, Ladson Hinton, Judith Barker, Carol Franz, Alexandra Valasquez, "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>.
- 22 Rote, et al., "Caregiving Across Diverse Populations."
- 23 Flores, et al., "Beyond Familism."
- 24 "Status of Hispanic Older Adults: Insights from the Field."
- 25 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/>.
- 26 "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.



