

FOCUS AREA 3

Investing in Caregivers



Caregivers of all ages are the backbone of Illinois' long-term care system. More than 2.2 million Illinoisans – more than three quarters of whom are women – provide unpaid care to aging loved ones, individuals with disabilities, and others in need. They represent almost one quarter of all adults in the state. On average, family caregivers are 49 years old and care for someone who is 66. Many caregivers (57%) work, and one in five provide 40 or more hours of care a week. Caregiving can be a positive experience, but for many it often comes at a cost. Family or volunteer caregivers report higher levels of stress, depression, and chronic health conditions than the general population.

At the same time, paid caregivers – direct care workers, home care aides, home health aides, certified nursing assistants, and personal attendants – deliver essential frontline care but often work part-time, are paid low wages, receive limited benefits, and face excessive workloads.

This leads to high turnover. According to PHI, a national advocate for the direct care workforce, in Illinois 89% of these caregivers are women, 58% are people of color, and 21% are immigrants. Given the challenges of their work and the limited salaries, 36% of this workforce lives in or near poverty (defined as having household income less than 200% of the federal poverty level), and 49% rely on public assistance programs to make ends meet.

To address these challenges, Illinois' Multisector Plan is aligning with national best practices, recommendations from family caregivers, as well as leaders in the caregiver services network, and the recommendations of the federal RAISE Family Caregiving Advisory Council. This Focus Area outlines six statewide strategies, which should be implemented using accessible and culturally responsive tools.

Strategies

For a full description of these strategies, associated actions, outcomes, and metrics, please see Appendix A.3.

- Help all Illinois caregivers recognize their vital caregiving role, stay connected to ongoing support, and raise awareness among the public and employers about the essential contributions and challenges of caregivers.
- Expand the number of people and processes necessary to support caregivers.
- Expand access to programs, services, supports, and products for all caregivers to meet specific family caregiver needs, and increase availability of paid caregivers.
- Reduce financial challenges associated with unpaid caregiving, particularly for lower- and middle-income caregivers.
- Promote research, identification, and adoption of evidence-based practices in caregiver support.
- Develop recruitment and retention measures to ensure a robust paid caregiver workforce that is qualified and supported.



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What We'll Measure

- Percentage of individuals aged 15+ who reported providing unpaid care or assistance to an older adult
- Prevalence of select chronic conditions (e.g., hypertension, diabetes, arthritis, etc.) among individuals caring for an older adult
- Percentage of caregivers of older adults reporting fair, good, or excellent self-rated health
- Percentage of caregivers who report experiencing mental distress and/or being diagnosed with depression
- Number of personal care and home health aides per 1,000 older adults

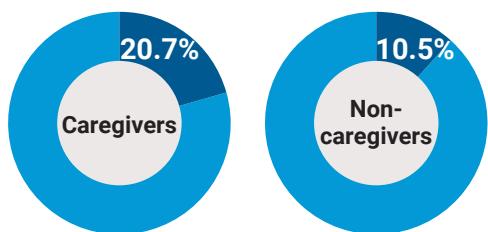
Currently 16.5% of Illinoisans provide unpaid care to an older adult and paid direct care workers in the state have lower average hourly wages than other comparable entry-level jobs.

Illinois by the Numbers

23% of adults, or almost 1 in 4, were caregivers for a family member or friend in 2025.

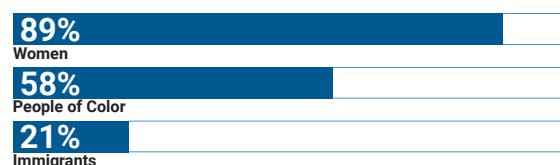


That translates to over 2.2 million adults.



Caregivers in 2021 were twice as more likely to report at least 1 poor physical or mental health day in the previous 2 weeks compared to non-caregivers.

89% of paid caregivers in Illinois were women in 2023, 58% were people of color, and 21% were immigrants.



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Focus Area: Investing in Caregivers

Where Illinois Stands

More than 2.2 million Illinoisans provide unpaid, regular care for a family member or friend. Among this group, 14.6% are aged 15+ and provide unpaid care to an older adult aged 65+. Rates of major chronic conditions (e.g., hypertension, heart disease, etc.) are comparable for Illinois caregivers and non-caregivers, with two exceptions: caregivers are 1.6 and 1.25 times more likely to have asthma and arthritis compared to non-caregivers. Additionally, Illinois caregivers are more likely to report poor self-rated health than non-caregivers (20.3% compared to 14.3%, respectively) and 1 in 5 caregivers report experiencing mental distress. The prevalence of depression among Illinois caregivers is 23.7% compared to 14.6% among non-caregivers.

Regarding paid caregivers, Illinois has 48 home health care workers per 1,000 older adults (ranked 21 of 50 states). The average for the U.S. is 62 home health care workers per 1,000 older adults, and the highest-ranking state is New York at 156 home health care workers per 1,000 older adults. With older adults projected to make up nearly a quarter of Illinois' total population by 2035, growing and investing in a highly trained and adequately compensated caregiving workforce is critical to addressing their health and social needs. Currently, direct care workers in the state have lower average hourly wages than comparable entry-level jobs, and Illinois ranks among the bottom half of states (28) in providing competitive wages.

What We'll Measure

- Percentage of individuals aged 15+ who reported providing unpaid care or assistance to an older adult
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Strategy 1: Caregiver Outreach and Awareness

Help all Illinois caregivers recognize their vital caregiving role, stay connected to ongoing support, and raise awareness among the public and employers about the essential contributions and challenges of caregivers.

Actions

- Develop EngAge Central (See Special Initiatives, Page 28) as a user-friendly hub of resources including but not limited to an evidence-based assessment tool, caregiver resources including support groups and online webinars, Area Agencies on Aging resource database, and educator resources. (**Short-term**)
- Work to develop and launch a statewide comprehensive caregiver awareness campaign using storytelling, data, and

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culturally responsive messaging to help caregivers of all ages self-identify and access support through EngAge Central. **(Short-term)**

Strategy 2: Caregiver Infrastructure

Expand the number of people and processes necessary to support caregivers.

Actions

- Align cross-agency efforts and ensure Illinois' participation in national caregiver initiatives and funding opportunities. Leverage state and federal resources to blend and braid state and federal funding to expand and better coordinate support for Illinois caregivers in alignment with the federal RAISE Family Caregivers Act. **(Short-term)**
- Explore the establishment of a statewide Caregiver Advisory Council that reflects geographic, racial, ethnic, and LGBTQIA+ diversity, includes representation across all income levels and age groups – including the growing population of youth caregivers – to ensure meaningful caregiver engagement and the development of person-centered services that are responsive to all communities. **(Short-term)**
- Improve partnerships and efficiencies across all levels of government, healthcare systems, and community organizations to promote caregiver best practices in the aging, disability, and veterans' services networks, and paid caregiving organizations. **(Long-term)**
- Explore innovative models that encourage and connect caregivers. **(Long-term)**

Strategy 3: Services and Supports for Caregivers

Expand access to programs, services, supports, and products for all caregivers to meet specific family caregiver needs, and increase availability of paid caregivers.

Actions

- Explore options to fund and strengthen the Illinois Family Caregiver Act, passed in 2004, which aligns with federal Older Americans Act funding. **(Short-term)**
- Strengthen the Illinois CARE Act through new provisions such as adding oversight and accountability measures to ensure unpaid family caregivers and family of choice caregivers are included in care plans and/or discharge plans at the consent of the care recipient. **(Short-term)**
- Work with academic partners to develop a respite curriculum for nursing students and launch a pilot to pair nursing students with caregivers in need of respite. **(Short-term)**
- Enhance coordination among Home and Community-Based Services (HCBS), veterans' services, and Area Agencies on Aging services to provide better coordinated and accessible caregiver support to meet growing caregiver needs. **(Short-term)**
- Work to expand and align training, compensation, education, counseling, benefits, and support for all caregivers. **(Mid-term)**
- Improve partnerships and communication between caregivers and healthcare providers, including doctors, hospitals, social workers, nurses, rehabilitation facilities, physical therapy providers, and long-term care facilities. **(Mid-term)**
- Improve framework coordination, outreach, and expansion for caregiver support across multiple state agencies like

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respite care services, HCBS, volunteer programs, legal and guardianship supports for families (e.g., special needs trusts, wills, ABLE accounts, supported decision-making.) (**Long-term**)

Strategy 4: Financial and Workplace Security for Caregivers

Reduce financial challenges associated with unpaid caregiving, particularly for lower- and middle-income caregivers.

Actions

- Explore opportunities to recognize or exempt caregivers from negative or unintentional impacts of changes in federal work requirements for programs like SNAP and Medicaid. (**Short-term**)
- Create opportunities for individuals subject to the recently enacted federal work requirements to maintain Medicaid eligibility (paid direct care workers and individuals between the ages of 18 and 64) for volunteer service, paid work opportunities, or a combination of both. (**Short-term**)
- Promote current paid leave policies and conduct research into the feasibility of paid family and medical leave programs, including funding models to ensure that employee caregiving responsibilities are recognized. (**Short-term**)
- Expand financial planning education, access to basic legal services, and resources for caregivers through state agencies and employers. (**Short-term**)
- Encourage employers, including the State of Illinois, to adopt caregiver-friendly workplace practices such as supportive human resources policies and services, caregiver toolkits, flexible schedules, Employee Resource Groups, and access to caregiver navigation services. (**Mid-term**)
- Explore ways to support unpaid caregivers who are self-employed, part-time, or working informal gig jobs as they are often excluded from employer-based benefits. (**Mid-term**)
- Identify ways to better support direct care workers (e.g., providing respite, in-home care, and transportation assistance) independently hired by older adults and family caregivers to determine ways to support them in the health care system, with particular attention to racialized caregiving inequities. (**Long-term**)

Strategy 5: Data, Research and Evidence-Based Practices

Promote research, identification, and adoption of evidence-based practices in caregiver support.

Actions

- Explore methods to expand, manage, collect, and analyze statewide caregiver data, disaggregated by race, region, and caregiving type to track needs and outcomes to facilitate measuring, demonstrating, and communicating the impact and return on investment (ROI) of caregiver services compared to more costly facility costs. (**Short-term**)
- Work to standardize evaluation and reporting tools across state agencies and partners to strengthen evidence-based practices along with increasing transparency by publishing publicly available and disaggregated caregiver data to inform policy and program design. Ensure data collection captures diverse caregiver experiences including race, ethnicity, age, geography, income, location of caregiving and caregiving type. (**Mid-term**)
- Work toward continued funding of the Behavioral Risk Factor Surveillance System (BRFSS) caregiving module with the Centers for Disease Control as a pilot program. Engage the Illinois Department of Public Health to share a summary brief for public dissemination. (**Long-term**)

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Strategy 6: Paid Caregiver Support

Develop recruitment and retention measures to ensure a robust paid caregiver workforce that is qualified and supported.

Actions

- Develop a core training curriculum for direct care workers that transfers from employer to employer and equips workers to provide care across waiver populations. **(Short-term)**
- Establish a direct care worker or community healthcare worker credential that could be referenced within waivers including specialized training to continue career growth and development of career ladders. **(Short-term)**
- Ensure payment rates for home and community-based service providers are competitive to attract and retain paid caregivers. **(Short-term)**
- Explore financial relief programs at the federal and state levels to help build financial security for homecare and adult day center workers. **(Mid-term)**
- Collaborate with community colleges and nursing schools to create curricula and clinical opportunities that cultivate career pathways to home and community-based services. **(Mid-term)**

**Citations can be found on page 54 of the full Plan.*