

ILLINOIS CAREGIVER ASSISTANCE AND RESOURCE PORTAL

Public Act 103-0588

Formerly HB 4677, Sponsored By Rep. Moeller/Sen. Villanueva

CAREGIVER'S CHALLENGES

AARP IL's 2024 Pathway of Care report highlighted caregivers' struggle to access trusted long-term care resources and information.

Information Gathering & Planning—Finding care resources

Challenges

- Tight time constraints
- Inadequate information sources and community resources
- Hard, lonely work



ILLINOIS CAREGIVER PORTAL

- The portal will serve as a “one-stop shop” for caregivers, providing easy access to a broad spectrum of resources, including state, federal, nonprofit, and professional caregiving information.
- Centralized, virtual portal for caregivers and all Illinois residents to access information on nursing home care, home and community-based services, veteran resources, and federal information.
- Equipping caregivers with a user-friendly virtual portal for navigating caregiving services, care resources, and local/state and federal programming in collaboration with Area Agency on Aging and 2-1-1 call center.
- The IL Dept. on Aging will manage the pilot program and coordinate with aging, disability, and veteran state agencies.
- Subject to appropriation. Supported by the IL Dept on Aging.

AT A GLANCE

ILLINOIS CAREGIVERS¹

- 1.29 million caregivers
- 1.21 billion care hour/year
- \$17.70 value per hour
- \$21 billion unpaid labor/year
- Over \$7,200 typical out-of-pocket caregiving costs/year in the U.S.

CAREGIVER'S VOICE

“I have spent countless hours, researching things for myself and my mom and dad. Just trying to see what we have available for us is a difficult thing to do.”²

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Trigger—An older family member or friend gets hurt or their disease/illness progresses. Need to find an immediate care solution.



Challenges:

- Need to find an immediate care solution
- Reaching agreement on care and financing care

“He went into the hospital. I could not help him by myself at home. I could not help him get up or down...” —Peoria County Caregiver

Experience with Long-Term Care—

Use of long-term care in the community and in nursing homes



Challenges & Bright Spots:

- Negative experiences more common among low-income families in Illinois
- Adult day care & similar programs highlighted as a “lifeline” for families
- Varied experiences with home health care, but many had positive experiences with Illinois’s Self-Directed Assistance program
- Initial transition into nursing home care challenging

Information Gathering & Planning—Finding care resources



Challenges:

- Frustration with lack of trusted information sources to help with search
- Process of finding care is lonely and difficult
- Cost of care is a key concern
- Many families feel lower-cost options limited to lower-quality services and facilities

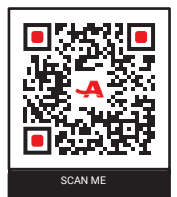
“It’s like a maze to figure out. Insurance doesn’t tell you anything about anything. So you have to call and plan everything out yourself.” —DuPage County Caregiver

“I wish there was a counselor that specializes in talking to family members in my situation... It would be nice if it was all wrapped up in one nice, helpful little package.” —Madison County Caregiver



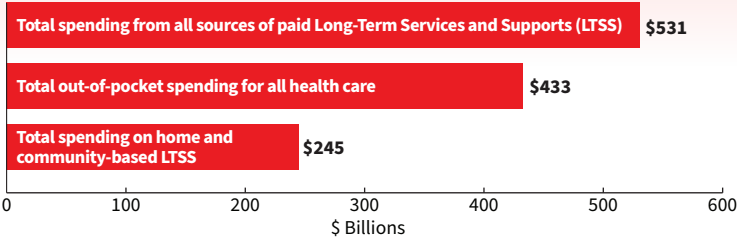
“We finally found a third [home health aide], and she is wonderful. So after three different times, we did find a person with this agency who knew exactly what to do.” —Peoria County Caregiver

“I was not as pleased with all of the facilities on an equal basis. As far as upkeep of the facility, and interacting with some of the staff on the visit... Especially within my community.” —Cook County Caregiver



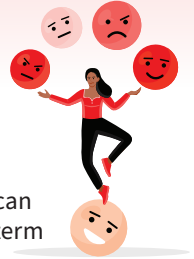
In 2021, about 38 million Americans spent 36 billion hours caring for adults with chronic, disabling, or serious health conditions. The estimated economic value of this care is **\$600 billion**.

Estimated value of caregiving relative to other spending.

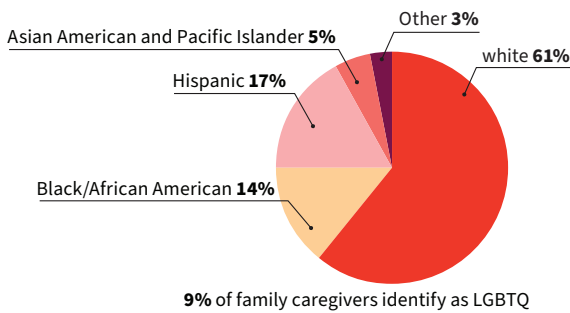


60% of caregivers juggle work and care.

- ▶ **60%** of caregivers worked a full-time or part-time job.
- ▶ **40%** of caregivers cite the emotional stress of juggling caregiving with paid work as biggest challenge.
- ▶ Career disruptions and breaks due to caregiving can lead to substantial economic risk and even long-term financial struggles for caregivers.



Today's family caregivers are diverse.



Sandwich Generation Caregivers face dual-generation care demands.

- ▶ Caring for *both* an older family member or friend and children or grandchildren results in a higher level of **emotional & financial strain**.
- ▶ **30%** of all caregivers are caring for two generations.
- ▶ They increasingly include Gen Z and millennial caregivers.
- ▶ They are often balancing work with caregiving.



Diverse caregivers have distinct care experiences.

- ▶ Black/African American and Hispanic/Latino caregivers are more often involved in **high-intensity caregiving**.
- ▶ Black/African American caregivers often receive **no paid or unpaid caregiving help**.



- ▶ Hispanic/Latino caregivers are more often younger and **caring for children, too**.
- ▶ Asian American caregivers report feelings of having **no choice** in providing care.
- ▶ LGBTQ caregivers more often experience **high financial strain**, feelings of isolation, & high emotional stress tied to their role.

Six recommendations to support unpaid family caregivers:

Implement the National Strategy to Support Family Caregivers.



Support family caregivers when caring for someone in the hospital and as they transition home through the CARE Act.



Offer caregiver tax credits or other reimbursement programs to offset the costs of family caregiving.



Strengthen paid family leave and paid sick leave to help family caregivers balance care and work responsibilities.



Expand respite care services that give family caregivers a hard-earned break.



Include family caregivers in care through caregiver training & education and caregiver assessments that connect them to supports and services.

