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LIFE & WORKTURNING POINTS

Caring for Family Doesn't Have to Be Unpaid Work

Interest in providing financial support for family caregivers is growing due to the workforce crisis in the care industry



By Clare Ansberry

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Family caregivers, long the backbone of the country's long-term care system, are increasingly tapping public and private resources to get paid for caring for loved ones.

During the pandemic, Sheila D. Johnson, 55 years old, of Richmond, Va., couldn't get skilled nurses to help with her brother, Kevin McCain, who is paralyzed and lives with her. She had to quit her job to take care of him.

"I still needed to work and have income so I decided I might as well try to get paid," says Ms. Johnson, who began researching and found a Medicaid program that would allow her to earn income for providing care. She is paid \$12.70 an hour by the managed care company handling the Medicaid program for 56 hours of care a week, which is about 40% less than she was earning from her bakery and doing social media for a farm market, but it helps. "Our expenses on the electric side are really high," she says, noting that her brother has a ventilator and oxygen machine that runs 24 hours a day.

"I think paid family caregivers are the way of the future," says Denise Brown, owner of the Caregiving Years Training Academy, which offers a planning tool for families exploring potential compensation options, including Medicaid, long-term-care insurance, and the U.S. Department of Veterans Affairs, that allow eligible family caregivers to be reimbursed.

Some families, who have the resources, are using their own money to hire children, nieces, nephews and grandchildren. "Rather than trying to find a direct care worker, who may or may not be available or reliable, families will instead hire a family member" says Ms. Brown, who suggests those families consult elder law attorneys and financial planners.

An estimated 48 million Americans provide care without pay to an adult family member or friend, according to Caregiving in the U.S. 2020, a report by AARP and the National Alliance for Caregiving.

Many of these family caregivers assumed the role during the pandemic, as private caregivers left what is a demanding and low-paying profession. Often, these caregivers—the majority of whom are women—have to leave their own job, creating a financial strain on their households.

Interest in providing financial support for family caregivers, including compensation, is growing due to the workforce crisis, long Covid and the growing gap between the number of people needing care and those available to provide it, says Lance Robertson, a director in healthcare for the consulting firm Guidehouse, and former U.S. assistant secretary for

aging. “Family members are right there. They’re equipped and capable. If we lose them, it will worsen the workforce crisis,” he says.

Many family caregivers are eligible for hourly wages, most often through state Medicaid plans, but don’t know it exists or how to navigate the often complicated process. Coverage, eligibility and benefits vary by state and sometimes by county. Some states require family members to take training courses. Others won’t pay a spouse or legal guardian or a family member, who lives in the same house. Hourly pay is often based on the average local wage for a home care aide.



The median hourly wage for home health and personal care aides is about \$14 an hour.

“We found that 80% of family caregivers don’t know they can get paid,” says Maggie Norris, founder of recent start up Aidaly, which helps family caregivers access compensation from public and private sources, and manage paperwork. Aidaly has about 2,280 caregivers enrolled in two markets, Miami-Dade and Phoenix, and most are adult daughters living in the home with their parents, says Ms. Norris.

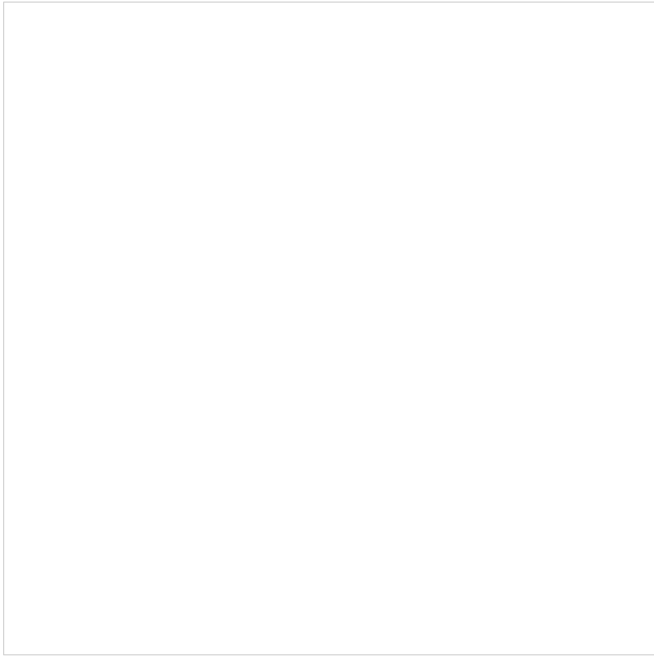
While many caregivers don’t know they can be paid, there are also those who feel guilty accepting it.

“I felt terrible taking money,” says Connie Hoyt, 72, who takes care of her granddaughter, Airian, 29, who has spina bifida, is paralyzed from the waist down, and lives with Ms. Hoyt and her husband, Bob, in their double-wide ranch home in Clearfield, Pa. Airian’s mom, Bobbi Jo Jones, who is the youngest of Connie’s four daughters, died in April of a heart attack.

Ms. Hoyt didn’t know that she could be a paid caregiver for Airian until someone at a spina bifida clinic told her about a Medicaid program that would allow Airian to hire her own caregivers, including family members.

“I’m not going to be here forever,” says Ms. Hoyt, who has fallen and broken her leg twice. Last year, she had a heart attack and recently, she was diagnosed with kidney failure. “I realized I need to get this set up for her for the time when I can’t take care of her,” says Ms. Hoyt. Other family members, who live nearby, could step in and be paid.

Ms. Hoyt, who worked nights cleaning at a local hospital until she broke her leg, gets paid an hourly rate of \$11.20 for 12 hours a day, which helps pay for gasoline to take Airian to the spina bifida clinic in Pittsburgh, a five-hour round trip, and to take her bowling and to movies with her boyfriend, who is also paralyzed, and to Special Olympics competitions. Airian’s gold medals from swimming hang on her wall.



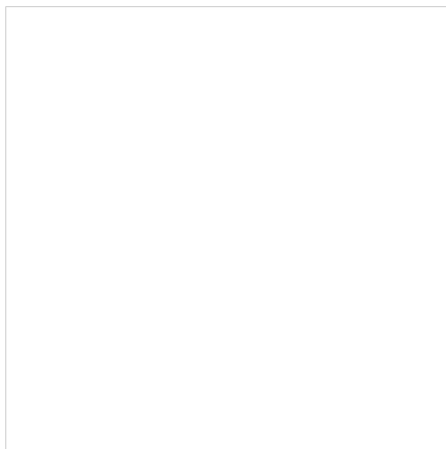
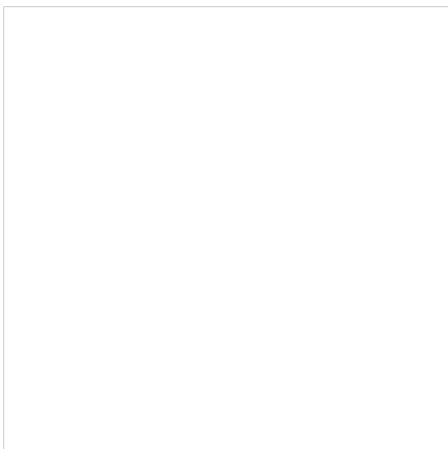
A memorial decal showing Airian Hoyt with her mother, Bobbi Jo Jones, who died in April after a heart attack. The Hoyts outside their home.

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Barbara Corley, of Circleville, Ohio, gets paid to provide care three days a week for her sister, who is spastic quadriplegic, through Ohio's Medicaid waiver program. Ms. Corley, who left her full-time job with a prosthetic manufacturer during the pandemic to become a certified caregiving consultant, also has a contract with her county.

"There's a real effort in our county to get family caregivers whenever possible," says Ms. Corley, in part because agencies can't find workers and also know the families are struggling financially. Ms. Corley guides other families through the Medicaid waiver certification process, telling them where to get CPR training and background checks.

"Just because you're a family member doesn't mean they send you a blank check," says Ms. Corley, who is an independent provider and gets paid a higher hourly rate—\$21 to \$22 pretax—than family members who work for an agency and are paid between \$12.50 to \$15 an hour pretax.



Barbara Corley, in red, takes care of her sister three days a week, while her mother handles the other days. The sisters do their nails together.

BARBARA CORLEY (2)

Some families who don't qualify for public programs or have long-term-care insurance but do have financial resources hire family members to provide care.

One daughter, in her late 50s who didn't want her last name used because her parents weren't deducting taxes, quit her job at a day-care center because her parents needed help and didn't want strangers taking care of them.

"My parents just weren't comfortable having someone come into the home," says the woman, who lives in northern Illinois. She and her husband were putting three children through college. "I had a certain salary I needed to maintain and my parents said they would pay me that," she says. Her siblings supported the arrangement, which caregiving experts say is critical.

Her mom died in August and she was able to have more time with her. She is now caring for her dad. "I'm extremely grateful and lucky," she says.

Resources for Caregivers

- **Medicaid:** All 50 states and the District of Columbia offer some type of self-directed Medicaid services for long-term care that allow qualified individuals to manage their own care, rather than have an agency manage their care. That can include hiring a family member, but rules and criteria vary from one state to another.
- **Department of Veterans Affairs:** Veterans are eligible for various programs, including veteran-directed benefits that allow them to manage their own care, and can include hiring and paying for in-home caregivers who are family members.
- **Long-term-care insurance:** Long-term-care insurance policies often cover some costs for home healthcare and personal care services, but not all policies will cover paying a relative for care. Check with the agency who sold the policy to see if family care is covered.
- **Private Pay:** The Family Caregiver Alliance, a nonprofit caregiver support organization, offers suggestions on drafting a personal care agreement between the caregiver and care recipient.
- **The National Alliance for Caregiving**
- **The Rosalynn Carter Institute for Caregivers**

Write to Clare Ansberry at clare.ansberry@wsj.com