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## The Role of Caregiving Youth in Multi-Generation Households

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BY CONNIE SISKOWSKI, RN, PHD





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Health-care disparities have existed for many years among older populations and minorities, affecting multiple generations within households — not solely those afflicted with an ailment. This has certainly been true of the COVID-19 pandemic, exacerbating a pre-existing national urgency to make systemic changes in health care among these demographics. Unfortunately, this focus on ill individuals fails to explore the impact of health conditions on the whole family, including children who often must step up to the plate and serve as caregivers for parents, grandparents, and siblings.

The term *caregiving youth* refers to the large and growing population of young people who must care for family members, even though they are under the age of eighteen and may still be in secondary schooling. These children must sacrifice their education, health,

well-being, and a more carefree childhood while fulfilling their dual roles as students and family caregivers. Caregiving youth provide care for family members with a broad spectrum of chronic health conditions. These family members may range from the youngest to the oldest, and often these caregiving youth are responsible for assisting more than one person.

Accordingly, aging-industry professionals need to be aware of this growing demographic in multi-generation households. They must recognize and understand the duties required of every family member, their concerns about the future, and their long-term planning needs. Proactively addressing these issues builds trust and furthers a productive relationship that is critical for success. We will begin by looking at how the composition of the American household has changed in recent years.

## Changes in Household Composition During the Past Decade

The numbers are large: more than sixty million people, or about 20 percent of the U.S. population, live in multi-generation households. According to the Pew Research Center, multigenerational families consist of more than two generations living under the same roof, including households with a grandparent and at least one other generation (Cohn & Passel, 2018). There are two types of multi-generation households. The first type, which comprises about two-thirds of these families, has a parent or parents of the child in co-residence. The second type is not inclusive of the child's parent. Of this second type of household, about 150,000 have grandfathers fulfilling the parenting role, a role as a single parent they may never before have filled.

During the past years, there have been profound worldwide changes in household composition, including a decrease in family size to 2.65 persons on average (Vanorman & Jacobsen, 2020). At the same time, we have seen increases in:

- **Single-parent households.** The U.S. leads the way with 23 percent of U.S. children under the age of eighteen living with one parent and no other adult. Globally, the average of single parent households is only 7 percent.
- **Multi-generation households.** These represent 20 percent of U.S. households in 2016, compared to 12 percent in 1980. Asian, Black, and Hispanic families all live in multi-generational households more often than non-Hispanic Whites.
- **Non-family households.** In 1960, non-family households accounted for 15 percent of all households, but as of 2017 that number has risen to 35 percent. A non-family household is one in which unrelated people are living together, such as an unmarried couple (Mather et al., 2019).

This change in the composition of households should concern planners of all types. What are the economic implications? What about the education of children? As our population ages, what happens to the housing market, health-care delivery, public and private health, and long-term care insurances? What is the effect on children when an accident or illness occurs in the family and a child is the only person available to provide needed care and support?

Both in the U.S. and globally, there is an increasing number of grandparents who are raising grandchildren without the child's parent. Several factors have propagated this change. Some grandparents would

rather raise their grandchildren than have them be in foster care. In other circumstances, parents lack the financial means needed to raise a child, commit physical abuse, or are absent due to incarceration or substance abuse, which may include opioids. Interestingly, the states with higher levels of opioid prescriptions are the same ones in which grandparent care is also higher (Anderson, 2019). Four states, all of them in the South, demonstrate this statistic. Alabama, Arkansas, Louisiana, and Mississippi each have nearly double the U.S. average rate of opioid prescriptions, or 65.4 per 100 residents.

The average annual income for a home with grandparents raising grandchildren is less than \$20,000 when only the grandmother is present. This low number is often related to a lack of education; about one-third of grandparents in this role are not high school graduates. Whether or not this shortage of schooling influences the education of the grandchild, especially with virtual learning, is currently unknown.

Federal, state, and local governments recognize foster families and provide them with access to many resources to benefit themselves and their foster children. However, when grandparents care for the child rather than a foster family, no resources or services are provided unless they have some legal guardianship status. For every child who is in the foster system right now, there are about twenty-five children being raised by their grandparents and/or an extended family support system. This is at a savings to taxpayers of more than six billion dollars.

## Federal Help for Grandparents Raising Grandchildren

President Clinton signed the first National Family Caregiver Support Program (NFCSP) in December of 2000, granting funding to support families and informal caregivers tending to their loved ones at home (Administration for Community Living, 2021). Program funding is tied to the Older Americans Act and thus there are age limitations. Furthermore, funding is distributed to states by the Administration on Aging and then the state Elder Affairs Departments. The NFCSP specifically includes support for grandparents raising grandchildren if age requirements are met. In 2020, a 10 percent cap on programs for grandparents raising grandchildren was eliminated, thereby making more dollars available. However, states must provide a 25 percent match for the federal dollars received.

One of today's challenges is that many younger grandparents are eliminated from support, because they must be at least fifty-five years old. The eligibility

definition from the Federal Law reads (Federal Law Summary, 2020):

*“... a grandparent or step-grandparent of a child, or a relative of a child by blood, marriage or adoption, who is fifty-five years of age or older and, (A) lives with the child; (B) is the primary caregiver of the child because the biological or adoptive parents are unable or unwilling to serve as the primary caregiver of the child; and (C) has a legal relationship to the child, such as legal custody or guardianship, or is raising the child informally.”*

There are five areas of federal funding support:

- information,
- help in acquiring services,
- counseling and training,
- giving the caregiver a break (respite), and
- other flexible supplemental services for the benefit of the caregiver.

### Caregiving Youth in the U.S.

However, no benefits exist when a child in these circumstances must care for the grandparent. The population of children as caregivers is significant to the future of our country even though they have yet to be recognized by policy, professionals, or the public. A joint report by AARP and the National Alliance for Caregiving (2020) stated that among caregivers of adult family members, there are from 3.4 to 5.4 million children under the age of eighteen years assisting with the provision of care. This report excludes caregiving youth from single-parent or grandparent households in which the child or grandchild is the sole provider of care. A report for the Bill and Melinda Gates Foundation (2006), *The Silent Epidemic*, documented that among young adults who dropped out of high school, 22 percent said it was to care for a family member (Bridgeland, Dilulio, & Morison, 2006). Should a child have to drop out of school because of family caregiving responsibilities?

Caregiving youth are sometimes referred to as being “parentified” (forced to be parents) because of their responsibilities and the complexities of the tasks they perform that mirror those of adult family caregivers. The extent of care and time spent caring for family members varies among this cohort. Some assist with activities of daily living (ADL)s such as bathing, feeding, and mobility help. Others are responsible for instrumental activities of daily living (IADL)s ranging from translation and household tasks to medication and treatment administration and management.

### ONE CHILD'S EXPERIENCE

Jeremy's single mom left for work early in the morning. A seventh grader, Jeremy's role was to care for his great-grandmother, including making her breakfast and assuring she took her medications before he left for school. Sometimes this would take longer than usual, and he would miss his school bus. Jeremy started a downward spiral of missing school, and then not wanting to go at all. But thanks to the work of the American Association of Caregiving Youth (AACY) that included a home visit, the school began to understand what was going on, and things changed. With support and recognition, Jeremy's life began to turn around. Alternate transportation to school on those late mornings was acquired. Jeremy learned he was no longer alone. His story and life events continued to happen, yet he got through it with the help he needed and today remains in touch with the AACY, which can be found at [aacy.org](http://aacy.org).

More complicated tasks such as suctioning, wound care, and tube feeding that in the past have been relegated to health-care workers are now performed by family caregivers of all ages. Fully 20 percent of *adult* family caregivers report they have never received information or help about providing care, much less child carers (AARP Public Policy Institute, 2020). The responsibilities can be overwhelming and even traumatic to an adult — and perhaps more so to a child. Sometimes the inability to achieve cooperation from the care receiver adds to the stress of the work and may result in guilt, with long- and short-term psychological ramifications.

Nevertheless, caregiving by persons of any age is not all negative. Caregiving provides purpose, builds resilience, and teaches time management by handling multiple responsibilities. When caregiving youth graduate from high school they often realize their life skills are superior to those of their peers.

### Home Health Care and Long-Term Care Support

Increased recognition of the role of the family caregiver led to the creation of the state-by-state Caregiver Advise, Record, Enable (CARE) Act. The CARE Act was created to assist caregivers when their loved ones go to the hospital and eventually transition back home. CARE first became a law in Oklahoma in

2014, and by 2020 was in the books in forty states (Reinhard, Young, Ryan, & Choula, 2019). This law stipulates that the family caregiver is to be named on the electronic medical record of the patient. However, minors who are caregivers are not covered, nor is the law fully implemented. Still, CARE promises improvement in the potential for continuity of care and the engagement of a whole health-care team, which includes family caregivers, and should ultimately improve outcomes. As technology advances and medical records incorporate in-home care, there will be increased demands on family caregivers, including children. Ideally each patient will soon have a universal care plan tailored to the individual and family; and the family caregiver, including minors, will be noted on the electronic medical record in all fifty states. A knowledgeable advisor or professional care manager can expedite needed and timely interventions to limit adverse outcomes for the care receiver.

As the population of older adults increases, where is the health care and allied labor force to support their needs? When caregiving youth are valued and supported in school and at home, many more of them will graduate and seek a career in health care. It is both logical and prudent to support a young population that has been successful in its dual student and caregiver roles by encouraging future careers in related fields.

### Economic Contribution of Caregiving Youth

The financial contribution to the economy of more than 50 million adult family caregivers is estimated to be at least \$470 billion annually. This value is calculated based on the extent of care that would need to be provided if a family member was not in that role. The most recent estimates of the contribution of caregiving youth is based on 2005 data that found there were at least 1.3 million children aged eight to eighteen in that role. The estimated annual value of caregiving by youth in the United States at that time was \$8.5 billion (Viola, Arno, Siskowski, Cohen, & Gusmano, 2012). Today, the numbers of caregiving youth are at least four times greater and the hourly wage value is higher, especially with more complex care being given. Additionally, the former data is exclusive of care in single-parent/grandparent households.

There are other hidden costs when evaluating the sheer economic value of youth giving care to family members. The increased duties at home can impact achievement in the child's educational setting. When a child underachieves at school or drops out, there are affiliated societal costs such as lower taxable income,



higher rates of teen pregnancy, increased crime and disease, and ultimately system dependency.

### Having a Plan B

It is clear that life happens, even for the most mature, invincible family caregiver. Falls may result in significant injury, chronic illnesses can progress, motor vehicle accidents may result in traumatic injury, and/or the aging process can result in severe functional decline. Children trying to cope with sudden or increasingly difficult caregiving responsibilities become more vulnerable. They may feel an enormous burden, buttressed by the underlying stress of wondering who will take over their job if something happens to them.

Minimizing stress is critical to the well-being of a family caregiver of any age. Thus, written arrangements for who will take over, even temporarily, if something unforeseen happens is one way of reducing anxiety and concern for the Plan B person as well as the care receiver. The plan to help assure continuity of care should include:

- **A daily schedule of the care receiver:** times for activities, favorite TV shows or movies, rest times, meals, and socialization so that structure and regular routines with likes and dislikes continue. This is especially important for children with special needs or those who have cognition impairments.
- **Medication administration and management:** what to take when and why, as well as with meals or foods to avoid. The pharmacy contact

information and prescription drug plan numbers should also be included.

- **Primary and specialty physician information**, along with a preferred home health-care provider and any pertinent medical information, including health plan coverages.
- **Emergency contact information** for anyone involved.

## Needed Advocacy, Research, and Legislative Support

Currently, no legislation includes recognition and support of caregiving youth, even when a grandparent raising them becomes ill. On behalf of our nation's multi-generational families and especially for the youth whose role reverses from being cared for to taking care of a loved one, as an advisor for families, you can take an active role.

- Be aware of long-term family health situations and the effects on the whole family, especially on children and their education.
- Know that parents and grandparents, themselves overwhelmed, may not realize how family health situations affect their children.
- Foster relationships with schools and community support services to strengthen caregiving families.
- Advocate for caregiving youth with legislators, religious and business leaders, the public, and in educational and professional groups.

## Conclusion

The composition of families is changing more rapidly than policy and pertinent legislation. There is a pervasive need for educated advisors who can provide guidance to individual families, as well as for community and religious leaders to take a proactive role in future planning that must include protective safeguards. There are still many unknowns and much to learn about caregiving youth and their value to their families, as well as to society. It is only with government support and recognition that these student carers will be able to thrive. Change must come in the form of legislation passed on their behalf. As a society and as a country, if one believes that children are our future, action must be taken now. •CSA



**Connie Siskowski, RN, PhD** was educated at Johns Hopkins, New York University, and Lynn University. Connie's doctoral research uncovered the high prevalence of caregiving by students in Palm Beach County, FL. In 1998 she established what is now the American As-

sociation of Caregiving Youth of which she is currently president. Connie has contributed to multiple publications. Awards include an Ashoka Fellowship, Purpose Prize, Distinguished Alumna Award (Johns Hopkins University), Top Ten CNN Hero, a star on Boca Raton's Walk of Recognition, and a faculty appointment to the RAISE Family Caregiving Advisory Council. 561.391.7401 (w) · 561.715.6531 (m) · [www.aacy.org](http://www.aacy.org)

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