



# Social Policy Report

## The United States should recognize and support caregiving youth

**Emma Armstrong-Carter**, Stanford University

**Catherine Johnson and Julia Belkowitz**, University of Miami Miller School of Medicine

**Connie Siskowski**, The American Association of Caregiving Youth

**Elizabeth Olson**, University of North Carolina at Chapel Hill

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### ABSTRACT

In the United States, more than 5.4 million children and adolescents under age 18 provide care for family members who are aging or have chronic illness, disability, or other health conditions that require assistance. In this policy report, we describe youth's care for the family, and highlight the increasing prevalence, global challenges, and uneven successes of measurement and categorization. We briefly summarize research on how caregiving affects youth's academic, social, and emotional well-being. Next, we present novel, emerging evidence from the public school-based 2019 Youth Risk Behavior Survey for the State of Florida, which suggests that as many as 24% of middle school students and 16% of high school students provide at least some care to the family on a regular basis. Drawing on this evidence, we discuss targeted social programs which have been shown to promote the well-being of caregiving youth outside of the United States, as well as a 13-year-old school-based intervention in The School District of Palm Beach County, Florida. We conclude with specific recommendations for a path toward recognizing and supporting caregiving youth via policy and practice in the United States. Our aim is to increase the awareness and feasibility of identifying and supporting caregiving youth and their families via government-organized data collection and targeted social policies.

### Correspondence

Emma Armstrong-Carter (emmaac@stanford.edu)

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## FROM THE EDITOR

This *Social Policy Report* offers a discussion and analysis of a group of children that is rarely talked about in the U.S.—children who are caregivers for their parents, grandparents, siblings, or other family members. The interdisciplinary team of authors includes Emma Armstrong Carter, Ph.D. Candidate at the Stanford University Graduate School of Education, Catherine Johnson, MD/MPH student at the University of Miami Miller School of Medicine, Dr. Julia Belkowitz, Associate Professor of Pediatrics at the University of Miami Miller School of Medicine, Dr. Connie Siskowski, founder of the American Association of Caregiving Youth, and Dr. Elizabeth Olson, Professor of Geography and Global Studies at the University of North Carolina at Chapel Hill. Though they span several universities and disciplines, they share a passion for bringing attention to this largely overlooked group of children who care for others, either solely or with another family member.

As the authors point out, while caregiving youth have received growing attention in many other countries in Europe, Asia, and Africa, they have not been in any way on the U.S. policy or research agenda. They write, “the denial and subsequent invisibility of caregiving youth in the U.S. policy arena is mirrored in US research on caregiving trends and concerns, where children are primarily assumed to be care recipients and not caregivers.” This invisibility has distinct consequences. The authors provide an overview and analysis of the limited but important body of research documenting the toll of caregiving on children, such as increased stress and difficulties in school and in their social lives, all of which make them more vulnerable to physical and mental illness.

Not only are caregiving youth missing from the policy agenda, we do not have even good estimates of how many children are concerned here. The authors cite a variety of sociological factors that have influenced the rise of caregiving youth in the U.S. over the past several decades: the opioid crisis, which has sent many children into the homes of their grandparents rather than parents; the increases in multigenerational homes along with the aging of the general population; and increases in incarceration rates which deplete family resources both emotionally and financially. Most recently, the COVID-19 pandemic has left many children without adults to care for them. News articles have referenced children who become the caregivers for their families, but actual estimates of the number of children in this situation at a national level are not known. The authors note that a Youth Risk Behavior Survey recently administered by the Department of Health in Florida found that 24% of middle school and 16% of high school students provide some sort of care to a family member on a regular basis, and they highlight there are probably at least 5.4 million children who are active caregivers, if not two or three times this number in the wake of the pandemic. This number far exceeds the number of children who are in foster care or who are homeless, groups which receive far more policy attention.

Drawing on examples of recent actions taken in the UK, the authors call for more administrative data to identify, count, and assess the vulnerabilities of such caregiving youth, more qualitative research to provide insights on how to service the needs of these young people, and federal and school based studies to expand federal services and provide in-school support to caregiving youth. This is a timely and enlightening SPR about children we just don't talk about—a group that has been growing over the last two decades and that has in all likelihood experienced a drastic spike in growth as a result of the COVID-19 pandemic.

# The United States should recognize and support caregiving youth

Caregiving for a loved one is one of the most demanding, challenging, and rewarding human activities. Although children are commonly conceptualized as the recipients of care—rather than the givers—children all over the world participate actively in caregiving every day. In the United States (US), more than 5.4 million children and adolescents under age 18 provide care for family members who are aging or have chronic illness, disability, or other health conditions that require assistance (AARP & National Alliance for Caregiving, 2020). These “caregiving youth” often manage loved ones’ complicated daily tasks of living, including personal care, feeding, toileting, dressing, and administering medication (Kavanaugh et al., 2016). Although there is attention directed to this potentially vulnerable population internationally, young people under the age of 18 are largely absent from policy discussions related to the current and future landscapes of caregiving in the US. The US does not yet formally acknowledge or support caregiving youth within family caregiving services, which are only accessible to adults. Further, caregiving youth are a largely hidden population within schools, in that they are not formally identified or supported. Without sufficient support from school and social service policies, these youth are at heightened risk for academic, social, and emotional difficulties.

In this report, we review emerging evidence on the increasing prevalence of caregiving youth—that is, young people under age 18 who provide significant, ongoing care for a family member at home. We briefly summarize research findings which suggest that caregiving is closely tied to youth’s academic, social, and emotional well-being, and discuss the challenges and uneven successes of identifying, measuring, and categorizing caregiving youth. We then introduce one program which is providing ongoing, formalized support for caregiving youth in the US: the Caregiving Youth Project, a 13-year-old program that is operated in partnership with The School District of Palm Beach County, Florida (Cohen et al., 2011). We conclude with recommendations for recognizing and supporting caregiving youth via policy and practice in the US, particularly in the context of the COVID-19 pandemic and public health crisis. Our aim is to increase the awareness and feasibility of identifying and supporting caregiving youth and their families via government-organized data collection and targeted social policies.

More than 5.4 million children under age 18 are caregivers for a family member.

## Caregiving Youth

The term “caregiving youth” refers to people under the age of 18 who assume caregiving responsibilities for someone at home who has a medical condition or is experiencing functional decline with aging. Although almost all children and adolescents provide at least some help to the family (Armstrong-Carter et al., 2019), caregiving youth are distinct because they care specifically for a family member or members who live with a medical condition (e.g., chronic physical or mental illness, disability) or aging-related condition which requires significant support in order to

undertake everyday activities (Becker, 2007). In other words, similar to adult family caregivers, whether a youth is a caregiver or not is commonly determined by the *needs of the person they care for*. In the US, most caregiving youth (72%) care for a parent or grandparent, whereas others care for a sibling (11%) or other individuals in the home including great-grandparents (Hunt et al., 2005). Caregiving youth is a time-varying and context-specific category because the circumstances within families vary greatly and health care issues are often dynamic and change over time.

Like adult caregivers, caregiving youths' experiences are heterogeneous. The specific care tasks which caregiving youth perform often vary based on the functional status of the family member (e.g., AARP & National Alliance for Caregiving, 2020; Hall & Sikes, 2017). Caregiving youths' tasks can range from supporting activities of daily living, such as dressing, bathing, and eating, to other instrumental tasks of daily living such as shopping, transportation, or administering medicine (Kavanaugh et al., 2016). Many caregiving youth also provide significant, ongoing emotional support, particularly when a family member is struggling with a terminal or mental illness (Mechling, 2011). Caregiving tasks also vary in intensity and timing. Caregiving youth might support family members in this critical work for as little as an hour each day, or provide over 40 hours of caregiving each week in addition to their school work (Hunt et al., 2005). One quarter (25%) of caregiving youth are the only person in their household who provide care for their loved one (Hunt et al., 2005).

Youth who provide care are more common in families that either cannot or choose not to seek formal respite care or other available supports. There is some evidence that caregiving youth are also more likely to be girls compared to boys, and older children or young adolescents, compared to younger children (Joseph et al., 2019; Agnes Leu et al., 2018). Moreover, racial minority groups and families who face financial hardship are overrepresented among youth who provide the most care (Hunt et al., 2005). Lower-income homes are less likely to have long-term care insurance and have fewer financial resources for hiring in-home help. They are also more likely to be headed by a single parent or grandparent, or have both parents working. In these circumstances, caregiving tasks for a grandparent or other sick relative are more likely to fall on the child (Hunt et al., 2005). Consistent with this arrangement, many caregiving youth live in "Grandfamilies," at home with a grandparent. They may also live in a "Sandwich Generation Household," characterized by three—or even four—generations living together. Overall, which children provide care, and the nature of that care, varies across individual differences in cultures, communities, and household structures (Joseph et al., 2019; Agnes Leu et al., 2018).

## Caregiving Youths' Academic, Social and Emotional Experiences

A small but growing empirical literature from the fields of psychology, social work, medicine, and geography has begun to document how caregiving by youth impacts their physical and emotional well-being and academic opportunities (Armstrong-Carter et al., 2019). This work has revealed mixed findings. Some studies suggest that youth caregivers gain confidence, empathy, and practical skills which promote resilience over time (Cohen et al., 2012; Shifren & Chong, 2012) and simultaneously report both satisfaction and burden associated with their caregiving activities (Siskowski, 2006). Conversely, other studies

reveal that caregiving youth disproportionately experience mental and physical health problems, and face restricted employment and educational options during transitions to adulthood and throughout the life course (see Armstrong-Carter et al., 2019 for a review). Reported challenges include frustration, anxiety, and depression, which caregiving youth are more likely to experience compared to their non-caregiving peers (Cohen et al., 2012; Shifren & Chong, 2012). In part, this stress is associated with balancing multiple conflicting responsibilities, including both caregiving and school work (Siskowski, 2006). Consider, for example, a child who would like to focus at school on his or her schoolwork or friends, but is worried about his aging grandmother at home alone—if she will be able to take her medicine without him, or who will help her if she falls. Similarly, caregiving tasks and worries may conflict with time for homework, sleep, or relaxation, which over the long-term, are foundational for children’s well-being across domains. Conflicting responsibilities may also be particularly challenging during the developmental transition to social interconnection with peers which occurs across childhood and adolescence (Armstrong-Carter et al., 2019). As such, the impact of caregiving as a child varies across context and developmental period, and depends on the available supports and resources which can mitigate challenges (Järkestig-Berggren et al., 2019).

Who young people care for and the requirements of that care further shape their experiences. Consistent with developmental psychology research on the intergenerational transmission of traits, youth caring for adults with mental illness are more likely to develop mental health problems, compared to youth caring for adults with physical illness (Mechling, 2011). Indeed, perceived burden and stress among caregiving youth is positively correlated with the duration and intensity of care they provide (Hibbert, 2010; Shifren & Chong, 2012). In particular, children in families of low socioeconomic status are likely to be negatively impacted by the emotional difficulties of caregiving (Cohen et al., 2012), because the stresses associated with providing care as a child while simultaneously facing financial strain are particularly acute and confound one another (Cohen et al., 2012).

## Increased Prevalence Over Time

To date, there is one national survey focused on caregiving by youth in the US (Hunt et al., 2005). This provided foundational evidence on caregiving youth in the US, by reporting that there were at least 1.3–1.4 million children ages 8–18 years who were doing some type of caregiving for family in 2005. A more recent study focusing on adult family caregivers who provide care for adults estimated that there are now more than 5.4 million youth under age 18 who regularly provide care along with another adult (AARP & National Alliance for Caregiving, 2020). This study was noteworthy because youth are generally excluded from national studies of caregiving in the US. Moreover, this study demonstrated a sharp increase in the prevalence of caregiving youth in the US in the past 15 years. This finding mirrors prior evidence from the United Kingdom (UK), where there has been a dramatic rise in the number of youth caregivers in the past two decades (Joseph et al., 2019). However, this most recent US study does not include children and grandchildren who provide care for their parents and grandchildren alone (i.e., without an adult providing any care), for instance in homes where grandparents are raising their grandchildren. In light of this

methodology, experts estimate that the most recent numbers may reflect only about half of the actual prevalence of caregiving youth in the US today (Levine, 2020; Olson & Siskowski, 2018).

The overall economic contribution of family caregiving in the US has been a concern of policy makers who aim to reveal the true value of this care to the nation's economic health. Indeed, the increasing prevalence of caregiving by young people has significant impacts beyond the household. An estimate of the economic value of youth caregiving in the US was calculated as approximately \$8.5 billion in 2012 (Viola et al., 2012). The economic value today would be much higher. The flipside of these economic contributions is the life-long impacts upon earnings when youth and young adults make decisions about further education and careers based on caring responsibilities. For instance, caregiving youth and their families are more likely, compared to non-caregiving families, to live in poverty concurrently and in the future, and encounter financial and social barriers to educational opportunities (Hunt et al., 2005).

## **Social and Demographic Change Contribute to the Increase in Caregiving Youth**

Policy makers, advocates, and researchers have been pointing to an emerging care crisis in the US, where both labor markets and social services fail to adequately support individuals who require sustained care. This lack of support to family caregivers in general is largely due to austerity measures combined with the undervaluation of care work (Dahl, 2017). In light of these exacerbated structural conditions, the increasing prevalence of caregiving youth seen over the last two decades and will likely continue to increase.

Both accelerating demographic changes and Adverse Childhood Experiences contribute to the increase in caregiving youth. First, demographic changes include the *aging population* of baby boomers which is spurring demands for in-home care including complex care, and an increasing reliance on informal, younger family caregivers (Schulz & Eden, 2016). This is punctuated by *increasing life-expectancy*, even among those who are suffering from age-related illness, thus increasing the duration of care for caregivers. Second, new or intensified Adverse Childhood Experiences are related to the *opioid epidemic*, which impacts parents and causes children and adolescents to increasingly move in with grandparents who tend to have greater care needs (Anderson, 2019). Similarly, *teenage pregnancy* and *parental incarceration* also prompt children to move in with older relatives who have greater care needs. Finally, the *COVID-19 pandemic* has likely dramatically increased the prevalence of caregiving youth and intensified the challenges that they face. When taken alongside of the structural characteristics of depleted social services, uneven health care access, and racialized patterns of health disparities in the US, the burden of caregiving for individuals with chronic health conditions continues to shift toward families, particularly those with the fewest resources available to balance care with other aspects of household production and earnings (Schulz & Eden, 2016). This makes the US a unique context for caregiving youth, and so here we elaborate on each of these broad trends that indicate some of their distinctive characteristics, experiences, and burdens in the US.



## **Aging population and increase in multigenerational homes**

In the US, the marked demographic shift to an aging population contributes to a reliance on informal younger caregivers in the home. The number of aging adults—largely baby boomers—is rapidly increasing (US Census Bureau, 2020a). In 2019, there were 54 million adults aged 65 and older (US Census Bureau, 2020a), and this population is expected to increase to 72.8 million by 2030—more than one in five US residents (Schulz & Eden, 2016). Of these older adults, 66% rely exclusively on help from family caregivers to support their physical health and daily functioning (Schulz & Eden, 2016). As the population of older adults increases, the number of individuals typically considered in the “primary caregiving years” (adults ages 45–64) is projected to decline (AARP & National Alliance for Caregiving, 2020). If the projections are even partially accurate, there is an impending shortage of informal adult family caregivers to assist the aging population, made even more critical by a parallel shortage of formal caregivers who are hired in from outside the home (AARP & National Alliance for Caregiving, 2020). As a result, care burdens are already intensifying, and are shared among multiple members of the household, including young children (AARP & National Alliance for Caregiving, 2020).

As the demand for caregiving for aging adults increases and the availability of adult family caregivers relatively decreases, youth below the age of 18 are increasingly taking up care responsibilities. This pattern has been exhibited and studied in the UK and other countries that have undergone similar demographic shifts in recent years (Joseph et al., 2019). Caregiving youth are most common in multigenerational homes. For example, 8.7 million adult family caregivers for aging adults also have children below the age of 18 living at home (Schulz & Eden, 2016). Today, about 7.8 million children across the country live in households headed by grandparents or other relatives (Generations United, 2020). Even when there are not additional burdens, aging adults are highly likely to receive care from more than one family caregiver (Schulz & Eden, 2016). In particular, parents from multigenerational households who are single, working, or experiencing multiple conflicting responsibilities tend to share caregiving responsibilities with other family members in the home, including young children (AARP & National Alliance for Caregiving, 2020).

Overall, these data suggest that the aging population and an increase in multigenerational households are creating conditions in which children are increasingly assuming caregiving roles (Armstrong-Carter et al., 2019). This may be particularly common in rural areas of the US, which are aging at faster rates compared to urban regions, and have more limited access to medical and social services (Peterson & Rieck, 2017). The lack of services represents an additional barrier for caregiving youth aiming to support the health of their loved one or loved ones (Carers Trust, 2020).

## **Increasing life-expectancy and age-related illness**

The average life-expectancy and the number of age-related illnesses is increasing in the US, also driving up the need for families to find affordable caregiving solutions for longer periods of time (Schulz & Eden, 2016). For example, with increasing life expectancy and medical advances, dementia and early-onset dementia are on the rise

(AARP & National Alliance for Caregiving, 2020). In parallel, the number of children living with a parent or grandparent with dementia is steadily increasing (Hall & Sikes, 2017), without substantial changes in policies for respite or long-term care accessibility (Schulz & Eden, 2016). In these household structures, children may increasingly assume caregiving themselves, particularly in homes where there is not another adult present, or the other adult is employed (AARP & National Alliance for Caregiving, 2020; Hall & Sikes, 2017). In contrast to countries with more comprehensive and robust public health systems, in the US the lack of universal health care, combined with associated opportunities for managing complex disease at home, exacerbate the conditions under which youth are increasingly caring for older relatives.

### **The opioid epidemic and increase in multigenerational homes**

Another contributing factor to the increase in caregiving youth in the US is the opioid epidemic and other substance misuse ramifications. Across the country, older adults and grandparents assume guardianship of children whose parents are reliant on opioids and other prescription medications (Anderson, 2019). Today in the US, at least 2.6 million children are raised by grandparents, a figure which has doubled since the 1970s, and increased 7% in the last 5 years alone (US Census Bureau, 2020b). On average, these aging adults receive little institutional support for taking care of their grandchildren, and often begin to require care themselves over time (Schulz & Eden, 2016). Although as early as 2000 the National Family Caregiver Support Program, which was attached to the Older Americans Act, provided for grandparents raising grandchildren, it lacked forethought about what happens when/if the grandparent became ill (Olson, 2019). In these environments, children often begin to provide care for their aging guardian (Olson & Siskowski, 2018). Indeed, states with high opioid prescribing rates have higher rates of grandparents responsible for grandchildren (Anderson, 2019). Moreover, multigenerational homes due to opioid addiction are regionally concentrated in the rural parts of the US South, where physical health is poorer on average, and health care is less accessible compared to some other parts of the country (Anderson, 2019).

### **The role of adolescent pregnancy and incarceration**

Similar to the opioid epidemic, other adverse childhood events—including adolescent pregnancy and parental incarceration—contribute to changes in household structure, such that youth are likely to care for aging relatives. Adolescent pregnancy has decreased over recent decades in the US, but is still relatively common compared to other high-income nations (Smith et al., 2018). Adolescent mothers often move in with older relatives who have greater care needs, including the child's grandparents, to manage finances and receive social and emotional support (Smith et al., 2018). As in other scenarios, youth who live with grandparents are then more likely to provide care as the grandparent ages or experiences illness or disability. Adolescent pregnancy remains more common in low-income communities and communities of color, primarily in Latinx and Black youth (Smith et al., 2018). Latinx families have the highest prevalence of unpaid care for aging family for both economic and cultural reasons, and there is some evidence that family care produces better outcomes for some portions of the Latinx US community, compared to non-Latinx communities (Rote et al., 2019).



However, both Latinx and Black caregivers experience higher burdens of caregiving than White Americans (Alzheimer's Association, 2020). The stresses of caregiving may compound the stresses of institutional barriers and discrimination.

Another factor that prompts youth to live with aging relatives is the historically and internationally unprecedented incarceration rate in the US (Travis et al., 2015). An estimated five to eight million children have an incarcerated parent (most often a father), not including parents under probation or parole (Murphey & Cooper, 2015). When parents—particularly from single parent homes—are incarcerated, children often move in with grandparents (Travis et al., 2015). One in ten children of male prisoners live with grandparents, and around half of the children of incarcerated mothers live with grandparents (Travis et al., 2015). This disproportionately affects children from historically marginalized racial/ethnic groups, and children in low-income communities and rural areas where relatively fewer institutional supports are available (Travis et al., 2015). As such, increasing incarceration rates in the US represent another scenario in which children move in with grandparents and may take on caregiving responsibilities as their grandparents age or develop health conditions.

### **The COVID-19 Pandemic**

The current *COVID-19 pandemic* has likely dramatically increased the prevalence of caregiving youth. Moreover, as practitioners consider the ways in which COVID-19 has changed all children's daily experiences, the impacts of the COVID-19 virus as well as social distancing measures are likely to be unique for caregiving youth and their families. There are at least four key implications specifically when there is a concomitant health condition of a family member. First, more youth may be faced with taking on caregiving responsibilities, some for the first time, as COVID-19 causes family members to become ill. For instance, one longitudinal study of a community sample found that adolescents provided more help to family members and others individuals with health conditions in the first few weeks of lockdown, compared to before lockdown (van de Groep et al., 2020). Children and adolescents who live with older adults, or adults who have pre-existing medical conditions, may be particularly likely to begin caregiving as a result of the pandemic.

Second, the COVID pandemic has created a range of new pressures upon caregiving youth globally. A UK-based survey investigated the impact of COVID-19 among 961 "carers" ages 12 to 17 years (Carers Trust, 2020). This report revealed that 58% increased the amount of time they spent caring since the start of the COVID-19 pandemic. Moreover, 66% are more stressed and more worried about the future, many experienced financial burdens (50%), and some also had difficulties obtaining necessary medicines and supplies for themselves or their loved one (11%; Carers Trust, 2020). These pressures are compounded by protective measures, including social distancing, that may result in increased time spent caregiving, inability to leave home to take a break, reduced family income with resultant basic resource shortages, and heightened concern about the future (Carers Trust, 2020).

Third, COVID-19 has eliminated many opportunities for caregiving youth to "get away" and recharge aside from their caregiving tasks. Almost 20% of youth in the UK reported

that time away from the person they care for was an important coping mechanism for them, especially during lockdown, and difficulty getting away was also negatively impacting their education (Carers Trust, 2020).

Fourth, COVID-19 has removed children from in-person schools, where they can—at least theoretically—be identified and supported by other adults and mentors. In the UK, schools are integral to providing “young carers” (i.e., caregiving youth) with access to informational and emotional support. With schools moving online, many may go unidentified and unsupported, and it is unclear whether they will finish schooling or find time to complete academic assignments (Siskowski, 2006). One new, ongoing qualitative study in Palm Beach County, Florida is evaluating the impacts of social distancing upon the provision of services to caregiving youth. We (the authorship team) has preliminary qualitative research which reveals complex effects upon youth caregiving families that range from job insecurity and job loss to significant challenges in participating in virtual education (this work is currently ongoing).

In sum, the COVID-19 pandemic is likely to have a lasting impact on the number and scope of children living with family members who are ill and require care, and is potentially contributing to the daily pressures of caregiving youth who are now confined to the home. To date, the findings from the UK represent the only known quantitative evidence on how “young carers” have been impacted by the coronavirus. Additional insights will be revealed through the Me-We Project, a research and intervention-based project funded by the European Union involving research in six European countries, and which has included remote interventions during social distancing and lock-down measures (The Me-We Project, 2020). Comparable research investigating how COVID-19 impacts the prevalence and experiences of caregiving youth in the US is a top priority for improving the well-being of these children and their families.

We focus above on a few key contributors to the increase in caregiving youth (i.e., aging population, increasing life expectancy, opioid epidemic, teenage pregnancy, parental incarceration, and the COVID-19 pandemic), but there are many other important factors.

There are a few key contributors to the increase in caregiving youth: an aging population, increasing life expectancy, opioid epidemic, teenage pregnancy, parental incarceration, and the COVID-19 pandemic.

For instance, caregiving youth are particularly common in homes where one or more relative is a current or former member of the military (Ramchand et al., 2014). Lack of insurance coverage in the US—corresponding to less managed professional care at home—also creates contexts for informal caregiving youth to step in and assume caregiving roles. In addition, increases in conditions such as autism contribute to more and more youth caring for older and younger siblings and other family members (Schulz & Eden, 2016). Similarly,

increases in mental illness across the country may also mean that more youth are caring for family members struggling with addiction, depression, and anxiety (Olfson et al., 2017).

## Policies to Support Caregiving Youth

As the numbers of caregiving youth grow, so should advocacy for legislation and supportive policy on their behalf. In the US, children and adolescents are largely unrecognized participants in the informal, unwaged family caregiving that millions

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of US residents undertake to sustain their family members daily (Olson & Siskowski, 2018). While a growing number of European, Asian, and African countries recognize that the concerns and experiences of caregiving youth are distinct from both older caregivers and their non-caregiving peers, the US has been comparatively slow in moving from identification to further research or action

(Levine, 2020; Olson & Siskowski, 2018). National and regional responses elsewhere have generated priorities for identifying, evaluating, and mitigating potential barriers to education, human rights, and social and political participation (Joseph et al., 2019; Agnes Leu et al., 2018). For example, in the UK and Australia, as well as in many lower-income nations, caregiving youth are the subject of considerable research and are recognized by schools and governments (Joseph et al., 2019; Leu et al., 2018). They also receive institutional support through laws and government policies designed to protect them and help meet their needs (Leu & Becker, 2019).

The UK has been identified as especially protective for youth who are caregivers through their inclusion in national caregiving legislation including special provisions under the Children and Family Act (Joseph et al., 2019). In the UK, the rights of “young carers” (the name given to this group in the UK)

The invisibility of caregiving youth in the US policy arena is mirrored in US research on caregiving trends and concerns, where children are primarily assumed to be care recipients and not caregivers.

are recognized and upheld to varying degrees by national governments, caregiving advocacy groups, health care services, and schools. This model of institutional recognition contrasts with current US practices, where federal programs such as the National Family Caregiver Support Program exclude family caregivers who are under the age of 18 from receiving supports afforded to those over 18 (Olson, 2019). Caregiving youth have also been conspicuously absent from research or educational curricula on the emerging caregiving crisis in the US. They generally are not formally recognized by professionals who work with youth (e.g., pediatricians, nurses, school social workers, guidance counselors, school administrators, teachers) as students who might be vulnerable or require special supports to ensure full and equal access to education. The

Caregiving youth are recognized neither as caregivers nor as potentially vulnerable youth.

denial and subsequent invisibility of caregiving youth in the US policy arena is mirrored in US research on caregiving trends and concerns, where children are primarily assumed

to be care recipients and not caregivers. Caregiving youth are recognized neither as caregivers nor as potentially vulnerable youth, and many have been historically unacknowledged and misunderstood (Olson, 2017).

## **An Intervention in Florida: The Caregiving Youth Project**

Despite these challenges, there are success stories of supporting caregiving youth in the US. One key example is the American Association of Caregiving Youth, the only organization in the US dedicated to providing support to all caregiving youth regardless of the condition of the care recipient or financial status. In response to the challenges caregiving youth face, the Association established the first US Caregiving Youth Project in partnership with The School District of Palm Beach County, Florida in 2006, to identify and support caregiving youth. The Caregiving Youth Project launched its first program in Boca Raton Community Middle School and has expanded regionally (Cohen et al., 2011). Since its inception, the Project has provided support services for nearly 1800 youth and their families from 6th grade through 12th grade graduation. Even though these children juggle school work and significant responsibilities at home—combined with structural inequalities of coming from primarily minority and low-income homes—their average high school graduation rate during the past six years is 98% (American Association of Caregiving Youth, 2020). More than 90% of these students go on to post-secondary education, and many seek a career in health care, a needed labor force as the US population ages.

The Caregiving Youth Project is designed to support children via schools and districts, and thus provides professional services in school, out of school, and at home. It provides students and their families with a myriad of needs-driven services with other local and national collaborating partners. Through family specialists and a grade-specific curriculum, the program offers in-school skills building groups, lunch and learn sessions, and educational workshops. Home assessments by a social worker validate the caregiving status, link families to respite and resources, and evaluate the need for in-home academic support and/or special projects. Out-of-school sponsored activities include wellness days, picnics, college preparation, and supports for students and families to take advantage of other available resources. Program participation voluntarily continues in high school, with students spending an average of 5.46 years in the program. A mentoring program prepares caregiving youth for graduation and further steps to achieve future goals. Moreover, the program implements an evaluation-based model to address caregiving ramifications including isolation, anxiety, and depression, which hinder the child's academic performance along with psychosocial, emotional, developmental, and physical health (Cohen et al., 2011).

The Caregiving Youth Project has demonstrated that when caregiving youth are recognized and supported, some of the main challenges that are reported by caregiving youth can be mitigated. Caregiving youth who participate in the program emphasize that the program makes them feel less alone and more valued in their role and helps them learn the skills they need to manage their responsibilities. They report increased skills and confidence, less isolation, and better family and peer relationships in end of year surveys. They and their families learn skills and access resources that enable them to more effectively balance stressors and conflicting responsibilities. There is economic and

**Table 1. The prevalence and frequency of youths' caregiving activities from a 2019 school-based survey of middle school and high school students in Florida**

	Middle School	High school
Sample N	5,156	5,703
Grades	6 - 8	9 - 12
Age	$M = 13, SD = 1, R = 10 - 16$	$M = 16, SD = 1, R = 12 - 18$
% Female	51%	52%
Care (any)	23.6%	16.4%
Care 0 days per week	9.2%	13.2%
Care 1–2 days per week	10.5%	8.0%
Care 3–5 days per week	5.5%	3.5%
Care 6–7 days per week	7.6%	4.9%
No one in family or home who needs care	67.2%	70.3%

Note. Percentages that do not sum to 100% are due to a small amount of missing data ( $N = 580$  students). *M*, Mean; *SD*, standard deviation; *R*, Range.

The Caregiving Youth Project has demonstrated that when caregiving youth are recognized and supported, some of their main challenges can be mitigated.

societal value to the student and the economy for caregiving youth to graduate from high school without the negative ramifications of caregiving on their health and in their lives (Cohen et al., 2011).

## The Need for Administrative Data on Caregiving Youth to Inform Policy

### The urgency of large-scale data collection

In order to design policies and revise existing policies that can support caregiving youth, there is an urgent priority for government-organized, large-scale data collection. A single item included in the Census—though notoriously difficult to negotiate—would be one approach. While offering the potential for nationally representative figures, collecting this information in the Census also has limitations. In the UK, for example, the number of caregiving youth identified through census survey resulted in underrepresentation, in part because parents do not have complete insight or understanding of their children's caregiving roles (particularly when the parent him/herself is ill or disabled), or how caregiving impacts their children (Joseph et al., 2019). In the absence of national data collection, local government and school-based studies may provide more accurate estimates of the prevalence of caregiving youth. Prevalence studies are crucial because they convince policy makers that interventions are urgent. Moreover, there is a need to provide further evidence of what we already



suspect: that caregiving can be difficult for children much in the way that it can be difficult for adults, which can result in lack of sleep, problems in school, or isolation and stress.

### **Qualitative focus groups**

Qualitative interviews and focus groups may provide additional insight into how best to support caregiving youth. For example, ongoing qualitative, participatory studies demonstrate how diverse methods can be used to provide crucial insights into the experiences of caregiving youth, and which policies can support them. One recent study used semi-structured interviews of 28 caregiving youth in the US (Nickels et al., 2018). This approach revealed that youth require significant organizational and administrative skills in order to administer medication to their loved ones, but have a wide range of knowledge about how to do so effectively. Most youth have not had formal training on how to ensure that their loved one receives the correct dosage on time, and how to monitor side effects; this poses significant health and safety risks. Many caregiving youth are aware of these challenges and difficulties, which contributes to why administering medications can be a highly emotional task. This study illustrates how caregiving responsibilities represent a unique hardship for youth, and highlights the need for support and research from the medical, health care, legislative, and public health communities.

### **School-based surveys and the role of schools**

A promising school-based approach to assessing the prevalence and correlates of youth caregiving emerged this past year. In the spring of 2019, the Center for Disease Control approved a question about caregiving for inclusion in the “Youth Risk Behavior Survey.” The Department of Health in Florida administered the Youth Risk Behavior Survey to almost 11,000 students in public middle schools and high schools. A single item assessed youth caregiving: “During an average week, how many days do you provide care for someone in your family or household who is chronically ill (lasts 3 months or more), elderly, or disabled with activities they would have difficulty doing on their own?” As shown in Table 1, approximately 24% of middle school students and 16% of high school students are providing some type of care at least once a week for someone in their family or home who is chronically ill, elderly, or disabled and who needs care. This startling number far exceeds the combined total of children of all ages in foster care (19,000) or who are homeless (95,000) in this same time period. Extrapolated across Florida, these numbers would reflect more than 290,000 caregiving youth in Florida public schools. Most importantly, this study demonstrated the feasibility of estimating the prevalence of caregiving youth with a single item included in government-sanctioned surveys. Including similar measurements of caregiving on widely administered national and state surveys of youth would contribute significantly to the potential for interdisciplinary scholarship and policy.

### **The challenges of identifying caregiving youth**

Research to date has highlighted at least two central challenges for measuring and categorizing caregiving youth. First, a standardized toolbox is urgently needed. In the absence of national surveys in the US, data collection has focused on identifiable

populations, such as young people who care for a family member with a particular illness (Kavanaugh et al., 2018), or geographically specific research and interventions (Assaf et al., 2016). While large quantitative surveys of caregiving youth have been conducted in other countries (Joseph et al., 2019), US-based research features small samples and is often qualitative or retrospective, which can be biased and limit generalizability (for a review, see Armstrong-Carter et al., 2019). Moreover, since most studies of caregiving youth were pioneered abroad (Leu & Becker, 2019), the reliability of common prevalence surveys has not been fully documented in the US context. For example, the UK-based Multidimensional Assessment of Caring Activities references “decorating rooms” and “having a wash” (Leu & Becker, 2019)—language unfamiliar to most children in the US. Perhaps because of this, quantitative researchers in the US have used diverse clinical assessments designed to assess the activities, stress, and relationships of adult caregivers. This methodological variation makes it difficult to interpret and compare study findings and can lead to ad hoc designs for researchers who lack reliable or validated survey instruments to incorporate into their research.

Second, measuring youth’s caregiving can be challenging because it exists on a continuum ranging in complexity and timing, and overlaps with other contextual challenges. Almost all children and adolescents provide some domestic assistance to their families that extends from helping with daily chores to taking care of siblings to providing ongoing care for a sick or disabled family member (Armstrong-Carter et al., 2019). Youth’s household contributions vary and may increase with family need (Tsai et al., 2013). This variability makes it difficult to pinpoint exactly which children might benefit from social policies and institutional supports.

## **Policy Recommendations**

To conclude this article, we offer recommendations for recognizing and supporting caregiving youth via targeted social policies and practice in the US. In particular, we highlight potential policies in the government, school, medical, and non-profit sectors. Examples from the UK provide compelling, evidence-based ways in which the US can and should recognize and support caregiving youth.

### **How local and federal governments can support caregiving youth**

The absence of caregiving youth from national surveys means that this population has been largely omitted from both state and national discussion and policy. In the US, the responsibility for addressing the unmet needs of family caregivers is largely delegated to the individual states (Olson, 2019). Although the known prevalence of caregiving youth is substantial enough to justify further research and intervention, these youth are excluded from benefits provided to older caregivers under the National Family Caregiver Support Program for which one must be at least 18 years of age.

Existing social programs that support family caregivers should be updated to include young people under age 18. For example, in 2018, after advocacy on their behalf, the RAISE Family Caregivers Council has now been directed to include and recognize caregiving youth in the US (Olson & Siskowski, 2018). This law directs the Department

of Health and Human Services to develop, maintain, and update a national Family Caregiving Strategy. Recent collaborations with the Centers for Disease Control for school-based surveys demonstrate that such government-sanctioned progress is feasible. Moreover, there is reason to believe that caregiving youth would use and benefit from services afforded to older caregivers in the US, if they are given access. In the UK, 24% of caregiving youth use local caregiving services, including online (Carers Trust, 2020). These necessary supports can only happen if states and the federal government adjust the age limitations currently placed on who is considered a caregiver and extend access for people under the age of 18 to institutional supports.

### **How schools can support caregiving youth**

Schools are integral for identifying and supporting caregiving youth in the UK and other high-income nations, via school social workers or health workers, who count them locally and nationally (Leu & Becker, 2019). The US needs comparable policies and interventions to educate and empower school staff—including school nurses, counselors and administrators—to address the needs of this population in schools and at home. Given the lack of exposure and awareness surrounding this group of potentially vulnerable youth, it is unlikely that school social workers and other staff are trained to recognize or support young children who provide care.

Federal and state policies require that schools routinely identify other vulnerable populations of students who may benefit from additional services—for example, students who have learning disabilities, are homeless, or are in foster care. Students who are caregivers should be afforded comparable recognition and services. To achieve this, states should include youth caregiving questions in surveys like the Youth Risk Behavior Survey, or support districts which may anticipate high prevalence of caregiving youth due to the factors described in this report.

For practitioners working directly with caregiving youth, the most effective way to support student-caregivers will vary by the individual family circumstances. Identifying caregiving youth is critical because they have particular needs in the school context. For instance, they report needing additional course extensions and flexibility with classes (Siskowski, 2006). Some caregiving youth may not be able to meet after school for group work because they return home to care for their loved one. If this is an issue, alternative assignments should be available. As another example, if a caregiving youth must take their care recipient to urgent care the night before an exam, the exam could be delayed to another day. The Caregiving Youth Project has also advocated for youth to be able to count caregiving as part of their service hours requirement for high school graduation. In addition, caregiving youth report needing more time for themselves to effectively manage stress (Levine et al., 2005). School-based or after school support groups should be extended for caregiving youth, mirroring the approach of the Caregiving Youth Project. One solution may be online groups. These are just a few examples of some of the ways that institutions as a whole—and teachers and administrators individually—should be flexible to meet the needs of student caregivers. Overall, lessons gleaned from successful interventions can make the task of supporting caregiving youth and their families less daunting for school-based practitioners who are often poorly resourced

for the scope and intensity of the challenges they face in supporting children and adolescents with complex needs.

In short, schools are mandated to accommodate children with various documented needs and circumstances, and those invested in youth well-being should insist that similar provisions be extended to caregiving youth to facilitate these students' social and academic success. Otherwise, these students will continue to be at risk of academic difficulties and not finishing high school (Bridgeland et al., 2006; Siskowski, 2006). Teachers and administration should recognize student-caregivers and work with them to extend deadlines and leave and be flexible in response to their needs. Given that caregiving youth are more likely to be from racial minority groups and low socioeconomic status backgrounds (Joseph et al., 2019), supporting their academic success in these ways may help to mitigate pervasive educational disparities in the US.

### **How medical providers and health care services can support caregiving youth**

Research on caregiving youth should provide a basis for medical policies, services, and interventions. First, interventions aimed at supporting caregivers can significantly improve the quality of care delivered, as well as improve the well-being and quality of life for both caregivers and care recipients (Schulz & Eden, 2016). For example, since its inception in 2001, the Project CARE in North Carolina has targeted dementia-specific services to address the needs of family caregivers and caregiving communities (Project CARE, 2020). Recognizing caregiving youth can help other comparable projects to more accurately characterize the needs of their target population. Moreover, supporting the needs of caregivers of all ages can help such projects to achieve their goals of promoting sustainable, compassionate, family-based care.

Second, providers of medical and social services for children and adults should be educated to be aware of caregiving youth and their potential needs. Caregiving youth's role is often unseen or unacknowledged by medical professionals (Nickels et al., 2018). Education about caregiving youth should be incorporated into the curriculum for all health care workers. In particular, education for physicians, physician assistants, and nurse practitioners from Family Medicine and Pediatrics is crucial because these providers are on the front lines for assessing the needs of youth and families. Without an understanding that caregiving youth exist and what their needs may be, medical providers cannot accurately understand many child and adult patients' daily experiences, and thus may overlook their needs. For example, caregiving youth report needing support obtaining medical assistance, such as accessing information about keeping the care recipient safe and managing behaviors and treatment plans, talking with physicians, and even making end of life decisions for their loved one (Nickels et al., 2018). In order to promote the well-being of these children and their families, it is crucial that medical providers across the board understand the types of care that youth provide, and the challenges and barriers they face.

Finally, the national academies and organizations that establish best practice in pediatric and adult specialties should formally recognize and provide recommendations to identify and support caregiving youth. Through this top-down approach, medical providers can join other disciplines that are already engaged in research and activism. The Veterans

Association—which provides a significant proportion of medical care across the US—has already taken crucial first steps by acknowledging the contributions of youth who care for former military members in their homes (Bristol, 2019). Health care organizations, certification boards, and practitioners can advance this work by participating in and supporting research on caregiving youths’ experiences across medical settings. For instance, one of the many ways that caregiving youth contribute is by helping their families navigate medical services including doctor appointments, pharmacies, or completing medical and insurance paperwork (Kam & Lazarevic, 2014; Katz, 2014). This may also include translating for family members in medical settings, particularly among minority or recently immigrated families (Kim et al., 2018). Across clinical contexts, there should be specific best-practice recommendations for identifying caregiving youth, through formalizing screening tools or other standardized procedures. Continuing education programs or certificates may be another way of facilitating providers’ understanding and awareness of this population.

### **How non-profit organizations can support caregiving youth**

Non-profits that target a wide range of social issues and populations also have an opportunity to support caregiving youth. For instance, the Dole Foundation, which supports adult caregivers for military families, has recently extended their services and recognition to caregiving youth (Elizabeth Dole Foundation, 2020). Similarly, PsychArmor, a nonprofit in California, provides free education courses for caregiving youth in military families (PsychArmor, 2020). Such work exemplifies how organizations that are not explicitly focused on caregiving youth can recognize and include caregiving youth in their agendas and services. This will promote not only the well-being of caregiving youth, but also the effectiveness of the missions of non-profit organizations across diverse sectors. Other examples of promising steps in the non-profit sector include important collaborations between disease-specific non-profit associations and researchers, such as resources produced in collaboration with the association for Amyotrophic Lateral Sclerosis (ALS) (Kavanaugh et al., 2018).

## **Conclusion**

A significant and growing population of children below age 18 provides care for family members who need considerable, ongoing care due to normative aging processes, chronic illness, or disability. Across the US, there is increasing reliance on caregiving youth who have not traditionally been recognized (Schulz & Eden, 2016). In many communities, caregiving is becoming a reciprocal, bidirectional task in which children provide care for older and younger family members (Armstrong-Carter et al., 2019). As the US population ages, and caregiving shifts from institutional to home-based care, the prevalence and burdens on caregiving youth will likely continue to increase (Levine, 2020; Olson & Siskowski, 2018). Nonetheless, 71% of caregiving youth report that providing care makes them feel good about themselves (Kavanaugh et al., 2016).

Recognizing and supporting caregiving youth through schools and local and national data collection and policies is critical for the short-term and long-term well-being of these children, their families, and the country. If government and social policies are not



Recognizing and supporting caregiving youth through schools and local and national data collection and policies is critical for the short-term and long-term well-being of these children, their families, and the country.

revised to include caregivers younger than age 18, more than five million young people and their families will continue to fall between the cracks of caregiver support (AARP & National Alliance for Caregiving, 2020). We call upon all advocates of children to acknowledge and build policies in support of caregiving youth and their families and to secure their future in America.

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## Author Bios

**Emma Armstrong-Carter** is a PhD Candidate at the Stanford University Graduate School of Education. She studies children's incredible capacity to support and help family, friends and strangers. Prior to Stanford, Emma was an undergraduate student and research associate at the University of North Carolina at Chapel Hill. She has published widely on topics related to child and adolescent development, including youths' prosocial behaviors, stress-physiology, and experiences of environmental adversity. Emma's research has also emphasized the importance of research-practice partnerships and involving local communities closely throughout the research process.

**Catherine Johnson** is currently a dual-degree MD/MPH student at the University of Miami Miller School of Medicine. She works with the American Association of Caregiving Youth as part of her masters capstone project.

**Dr. Julia Belkowitz, MD, MPH** is an Associate Professor of Pediatrics, University of Miami Miller School of Medicine. Dr. Belkowitz received her bachelor's degree in psychology at the University of Michigan and her medical degree at Jefferson Medical College. She completed her pediatric internship and residency at Jackson Memorial Hospital, and is currently an Associate Professor of Pediatrics at the University of Miami Miller School of Medicine, where she also serves as the Assistant Dean for Student Affairs. Her other responsibilities also include serving as an advisor for students completing their public health capstone experiences. Dr. Belkowitz also works to raise awareness about the issue of caregiving youth through mentorship of trainees, advocacy and research.

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

**Dr. Elizabeth Olson, PhD** is Professor of Geography and Global Studies and Chair of the Department of Geography at the University of North Carolina at Chapel Hill. She holds an MA in Political Science/Public Policy and a PhD in Geography, both from the University of Colorado at Boulder. Prior to joining UNC in 2012, she worked at Lancaster University and the University of Edinburgh in the United Kingdom, where she developed many of her interests in the intersections between care, ethics, young people, and geographies of inequality. Her current research engages these themes through care ethics and the experiences of youth who are caregivers. She has published widely on topics related to normative ethics in geography, the geographies of religion and spirituality, and youth and young people, and is co-editor of *Religion and Place: Landscapes, Politics and Piety* (2012) and the *Routledge Handbook of Gender and Feminist Geographies* (2020).



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