



WHITE PAPER

Report on Caregiving Youth in the U.S.

Progress and Opportunity

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ABOUT THE CAREGIVING YOUTH RESEARCH COLLABORATIVE

The Caregiving Youth Research Collaborative (CYRC) is a U.S.-focused research network that aims to advance understanding of the lives of Caregiving Youth and their families. CYRC members work in higher education and clinical practices across the country with interdisciplinary professional expertise spanning the sciences and humanities.

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Executive Summary

Approximately 5.4 million children and adolescents in the United States support parents, grandparents, siblings and other family members who require care due to disability, chronic illness, age-related decline, and other mental and physical health conditions. However, their caregiving often goes unrecognized by healthcare professionals, educators, researchers, government agencies, the public, and the wider caregiving research community. In 2022, the National Strategy to Support Family Caregivers established young people as a federal priority for research and support across future caregiving initiatives. The current report was prepared to assist those goals by providing an expert review of existing research, practice, and policy designed to identify, understand, and support caregiving youth in the US.

Findings: Overall, this report suggests there has been meaningful progress over the past ten years in research, practice, and policy. However, substantial gaps remain in all areas:

Research: Advances in research include expanded practices and partnerships for estimating prevalence of youth caregivers among those who provide care for family members with disease-specific illnesses and/or geographic sub-populations. However, there is need for broad research on the impacts and outcomes of caregiving on the well-being and education of caregiving youth, including special populations but not limited to minoritized communities and veterans. Systematizing approaches to measurement and collecting data from young people would improve the evidence for augmenting understanding and support.

Practice: There is a growing number of practitioners who are advocating and creating services for caregiving youth and their families. These range from local and state-wide support in schools, research, and veteran organizations, to a dedicated national organization that contributes to a network of services and advocacy. The lack of formal professional education about caregiving youth, and resourcing to support limits the scope and scale of impacts.

Policy: There has been gradual recognition of young people as caregivers at the national level, accelerated by the inclusion of under-age 18 caregivers in the 2002 National Strategy to Support Family Caregivers. Some states have initiated important changes including inclusion in required curriculum and the consideration of a Caregiving Youth Bill of Rights. However, policy changes need to define and implement national standards for identifying and supporting all US caregiving youth.

Recommendations: To address gaps in research, practice, and policy we recommend three major areas of engagement to support caregiving youth

1. Conduct a national prevalence and impact study complemented by strategic investments in high-impact areas that are likely to have rapid and scalable effects on health, education, and future workforce policies.
2. Support states, local governments, schools, and healthcare providers to adapt existing services for caregiving youth and their families that have already been proven successful in the U.S. and internationally.
3. Form a National Task Force on Caregiving Youth to guide and coordinate research, practice, and policy along with multi-system and agency collaboration.

Introduction

This report provides a comprehensive review of advances in research, practice, and policy related to caregiving youth in the United States. The term “caregiving youth” (also “young carers” outside of the U.S.) refers to people under the age of 18 who provide care or support for family, relatives, or household members who require assistance due to chronic illness, age-related decline, or other medical or health need. It is estimated that there are between 1.3 million the (Hunt et al., 2005) and 5.4 million caregiving youth in the United States (AARP and National Alliance for Caregiving, 2020). As is the case for adult caregivers, caregiving youth have diverse experiences. Some might provide occasional support throughout the week as secondary caregivers, while others might provide near-constant support while serving as primary caregivers or caring for multiple people.

A growing number of countries in all regions of the world recognize that the concerns and experiences of caregiving youth are distinct from both older caregivers and their non-caregiving peers, but the U.S. has been critiqued for making little progress in moving from identification to further research or action (Becker, 2007; Leu & Becker, 2017a). Indeed, caregiving youth have not been integrated into adult caregiving research, youth-focused research, or policy considerations in the U.S. until very recently. For instance, the 2016 National Academies Consensus Study Report, *Families Caring for an Aging America*, was influential in identifying an emerging crisis of caregiving provision and support, but it did not include caregivers under the age of 20 (Schulz & Eden, 2016). At the time of writing, the recognition of caregiving youth at the federal level seems to be changing, but recognition must be followed by action. Throughout this report, the authors highlight many aspects of this change in research and advocacy efforts. Within national policy efforts, the U.S. Administration for Community Living’s National Strategy to Support Family Caregiving includes caregiving youth as a special population of concern, as does the White House (Executive Order 14095, 2023).

Reflecting upon the findings of this review, the authors note that innovations in both research and practice in youth caregiving and support are often overlooked by studies emphasizing national-level findings. This might be explained by the complexity and size of the U.S. because innovative work about and for caregiving youth that is not visible at national scales is present in regional and local networks, in state governments and departments of education, and within school districts. Nonetheless, the encouraging progress narrated in the following pages also reveals gaps in our understanding of the experiences and well-being of caregiving youth in the U.S., and the geographically limited support for young people who provide assistance for others who require care. In short, the size and complexity of the U.S. context should justify more, rather than less, attention at the national scale to ensure that all young people are adequately supported. As family caregiving in the U.S. reaches a tipping point in terms of demands upon labor, economy, and social resources, understanding caregiving by young people carries both social and ethical imperatives; socially, the reproduction of societies requires recognition and support

for those who give and receive care, and ethically, the growth of our communities today must assure that they support the flourishing of the next generation.

The goal of this document is to summarize research, practice, and policy for and with caregiving youth in the U.S. It is organized into three main sections, each with specified recommendations, and concludes with three high-level priorities. The first section reviews data and evidence related to the prevalence of caregiving youth at subnational and national scales, as well as evidence from specific groups, including disease-specific caregiving populations. The second section considers evidence related to the impact of caregiving on young people's health, and education. The third section considers the policies and programs that are currently supporting caregiving youth and their families, including clinical interventions, school-based policies, nonprofit, and veteran-based programming and recreation opportunities tailored to caregiving youth.

The report was prepared by members of the Caregiving Youth Research Collaborative (CYRC) and represents a multiyear process consulting with scholars and practitioners working with caregiving youth in support or research roles. Members of the CYRC span 13 states plus the District of Columbia and Canada, and work in health and medical fields, social work, geography, education, veteran and military family services, and other areas. It includes members who have experience as caregiving youth, and as parents of caregiving youth. Support for CYRC and this report was provided by the Caregiving Youth Institute of the American Association of Caregiving Youth, and the College of Arts and Sciences at the University of North Carolina at Chapel Hill.

Prevalence of Caregiving Youth

Children and adolescents are unrecognized participants in the informal, unwaged family caregiving that millions of U.S. residents undertake to sustain their family members' daily living (Siskowski, 2006a). The limited data collected in the U.S. on general prevalence and the population dynamics and characteristics of caregiving is one consequence of this lack of recognition. In other nations, data on caregiving by children, adolescents, and young adults are collected routinely alongside other information deemed essential for evaluating population well-being (Hanson et al., 2023). In countries considered leaders in both research and support (Leu and Becker, 2019), prevalence studies have been followed by better understanding and policy responses. In the U.K., long considered a leader in supporting young carers, a 2023 nationwide survey by the charitable foundation, Carers Trust, revealed that young caregivers are struggling more than previously recorded, caring for more people while also facing financial constraints (Neale, 2023). In Australia, a study based on an educational bursary administered for young carers suggests that factors such as the time required for care, who requires care, household characteristics, gender, and educational access can shape the well-being of young caregivers (Moore et al., 2022).

In the U.S., the lack of recognition of the caregiving contributions of children and adolescents presents barriers to collecting accurate data on prevalence. The assumption among experts is an underestimate of both the number of youth caregivers and the diversity of care provided. Growing evidence from state and regional studies, disease-specific categories of care, and particular populations such as military families offer insight into the scope and characteristics of youth caregiving in the U.S. In the following pages, the authors review the evidence provided by national and regional studies, followed by research that focuses on specific populations. The section concludes with existing limitations to research on the prevalence of caregiving youth and recommendations for filling these gaps through future work.

Identifying and Defining Caregiving Youth: Academic Progress

Gathering data about caregiving youth in the U.S. has been challenged by the lack of understanding and recognition, and this is evident in and across research pertaining to both young people and caregiving more broadly. In the last 15 years, a series of scoping publications have reviewed mostly scientific studies that include or focus on the caregiving youth population. In 2010, a review paper published in the flagship developmental psychology journal highlighted the importance of understanding caregiving youth from a family systems and developmental perspective. The article argued that “despite the high numbers of children who provide care to family members in industrialized countries, relatively little is known about the impact of caregiving on children’s development” (East, 2010).

Academic researchers in social work published a scoping review of 22 studies about caregiving youth from 1996 and 2015 in peer-reviewed journals (Kavanaugh et al., 2016a). The review revealed that there were significant inconsistencies in how caregiving youth were defined and named. The authors also identified the importance of understanding the backgrounds of caregiving youth families, especially socioeconomic circumstances, racial and ethnic identities, and cultural values. They advocated for a greater understanding of how to support caregiving youth across schools and community settings (including medical clinics) via programs and policies (ibid). A subsequent 2021 review found continued inconsistency in the caregiving youth literature regarding terminology and limited advancement in research, programs, and policy (Hendricks et al., 2021). In 2022, Saragosa and colleagues reviewed 28 empirical studies about caregiving youth and concluded that caregiving experience is perceived by young people as challenging and complex, which could be improved with more informational navigation and emotional support (Saragosa et al., 2022). Finally, Doshi et al. (2021) highlighted several studies on caregiving youth and young adults, and concluded that, across studies, more support is needed for caregiving youth as they address challenges with stress, anxiety, and completing higher education.

National Studies and Identification

At the time of this report, there has been one national survey focused on caregiving by youth in the U.S. (Hunt et al., 2005), and one national survey which, though focused on adult caregivers, included the opportunity to identify family members under 18 as caregivers. This original study sought to overcome the barriers to identification through systematic survey work, subsequently providing evidence on caregiving youth in the U.S. At least 1.3 to 1.4 million children ages 8–18 years were found to be undertaking some form of caregiving for family or household members in 2005. A second stage of this study, conducted by phone, included additional questions related to the general household arrangement and caregiver characteristics; behavior problems; allocation of time by young person; “mood” and feelings; and school and educational experiences. Key findings include: when caregiving youth live in lower-income and/or in single-parent households, over half help the care recipient with an activity of daily living such as bathing, dressing, toileting, mobility, or feeding. These caregivers also help communicate with medical professionals, give medicine, and spend more time doing regular household tasks. Furthermore, caregivers show tendencies to demonstrate anxious or depressed behavior as compared with non-caregiving peers (ibid).

In 2020, the American Association for Retired People (AARP) and the National Alliance for Caregiving (NAC) released a research report, *Caregiving in the U.S.*, which estimated that there are now more than 5.4 million youth under age 18 who regularly provide care along with another adult (AARP and National Alliance for Caregiving, 2020). This study was noteworthy because youth are generally excluded from national studies of caregiving for adults in the U.S. The findings suggested a significant increase in the prevalence of caregiving youth in the U.S., and a substantial increase since the first report. This is especially notable given that the AARP-NAC report covers only caregivers of adults, thus excluding sibling caregiving, and does not include children and grandchildren who live in single-parent and grandparent head-of-household homes, such as in homes where a grandparent is raising a grandchild. Moreover, the signal of increasing numbers of adult family caregivers overall, and additional increases for caregiving youth, mirrors findings in the U.K. where there has been a dramatic rise in the number of youth caregivers in the past two decades (Joseph et al., 2020).

The 2005 and 2020 studies used random sampling techniques to survey families nationally about their experiences with caregiving, with small samples (less than 2000 households for each study). As such, experts estimate that the most recent numbers may reflect approximately half of the actual prevalence of caregiving youth in the U.S. today (Levine, 2020; Olson & Siskowski, 2018). Future research can offer new data and methodology to address these underestimates and understand how and if caregiving by youth has changed since the Covid-19 pandemic (Lewis, 2021).

State and Regional Studies

Florida and Rhode Island currently lead the nation for rigorous prevalence studies of caregiving youth and their experiences. Both states include a single survey item to identify caregiving youth in existing school-based surveys, and findings suggest that as many as 24% of children and adolescents are involved in caregiving (Armstrong-Carter et al., 2021, 2022).

For the first time in the U.S. in 2019, the school-based Florida Youth Risk Behavior Survey included a question about caregiving by public middle and high school students. The question was included and vetted by the U.S. Centers for Disease Control and Prevention (CDC) through their partnership with the Florida Department of Health and Florida Department of Education and supported by the American Association of Caregiving Youth. The survey identified caregiving youth among a sample of 10,880 youth in Florida (Armstrong-Carter, Siskowski, et al., 2022) and found that 24% of middle school students and 16% of high school students provide some type of care at least once a week for someone in their family (Armstrong-Carter, Siskowski, et al., 2022). This work in Florida has provided a model for other states and schools to identify caregiving youth.

Inspired by the efforts and outcomes in Florida, in 2021, the Rhode Island Department of Education adopted a similar method in their school-based assessment. A survey of more than 48,000 middle and high school students across the state found that 29% of children were caregiving for part of the day, and 7% of children were caregiving for most of the day (Armstrong-Carter et al., 2023).

It is important to note that the estimates from Rhode Island are comparable but differ slightly from those of Florida because of differences in the survey instruments and the wider social and health contexts of the two studies. The survey item in Rhode Island included both caregiving youth (caregiving due to a medical condition) and what would normally be considered as babysitting for a sibling in the absence of a medical condition. Additionally, the Rhode Island survey allowed for specification of “most” or “part of the day,” with nearly 30% of caregiving youth spending part of the day caregiving, and 7% providing care for most of the day. Finally, the Rhode Island survey was administered during the COVID-19 pandemic in 2021, and pandemic conditions likely influenced the results. For example, more students may be caregiving (at least for part of the day) due to pandemic-associated increases in family illness, financial stress, and school closures. Overall, these differences suggest the need for both greater systematization of survey approaches and for more data so that other intervening variables, such as contextual characteristics of state educational systems, might be taken into account.

Population Specific Research

Efforts are being made to identify and support caregiving youth through health-oriented organizations that have begun to gather data and orchestrate efforts to recognize youth and children performing vital caregiving services, including veteran and disease-specific organizations in the U.S. These organizations support the

person living with chronic or acute illness or disability while often providing critical education and engagement for family caregivers of all ages. Here, the authors review a sample of veteran and military families, clinical settings, and disease-specific organizations that have gathered data to better understand the prevalence of caregiving youth.

Veterans And Military Families

In 2017, *Improving Support for America's Hidden Heroes: A Research Blueprint* was released by RAND corporation for the Elizabeth Dole Foundation and identified the need to consider child and adolescent caregivers in veteran and military families. The blueprint involved a process that involved convening multiple panels of caregivers, caregiving researchers, and service providers to review available caregiving research at the time, resources, and help outline a plan for future work. Of note was the panel's interest in identifying the impact of caregiving on the children of caregivers, often called "the forgotten secondary caregivers" (pg. xii, Tanielian et al. 2017). Recommendations included assessing the consequences of caregiving on children in caregiving homes and establishing a research center of excellence within the military and veteran caregiving community to help foster research collaborations and collect data to better document and understand the needs of military and veteran caregiving families.

In 2019, the VA established the VA Elizabeth Dole Center for Excellence for Veteran and Caregiver Research (VA Dole COE), which brings researchers together from five VA health centers across the United States in collaboration with other research partners including the Elizabeth Dole Foundation to conduct research on caregiving. In 2020, the VA Dole COE began work to identify youth in veteran caregiving homes, developing critical research partnerships to reach caregiving families and leading pilot studies in various states in which the VA Dole COE operates, including Texas (U.S. Department of Veteran Affairs, 2020) and Utah (Kalvesmaki, 2021).

Further recognition of military and veteran youth caregivers has grown extensively. In 2021, Mathematica released a large-scale report highlighting the unmet needs of "Hidden Helpers", the term used to describe caregiving youth and children in military and veteran homes (Malick et al., 2021). Analyzing data from 2015–2019 American Community Survey (ACS), the report estimated that there were approximately 2.3 million caregiving youth within veteran families. In addition, the report highlighted results from interviews with youth caregivers on the nature of their role and the toll it can take on their physical and mental health. In tandem with the release of the report, on November 10, 2021, the White House issued a directive pledging support for children in military and veteran caregiving families and providing research support for VA and partners to continue studying the impacts of caregiving on military-connected children (White House Press Release, 2021).

A selection of family-oriented veteran service organizations and the VA are now incorporating data collection on and about youth caregivers into existing programs for military connected children. These include the VA Dole COE, Military Child Education Coalition and EDF's Hidden Helpers Coalition.

Healthcare Settings

Caregiving youth may be known to a few individual healthcare providers, but there is not broad recognition of caregiving youth in the medical community. Nor are there national guidelines known to this team of authors regarding the inclusion of the topic into the curricula of nurses, physicians, and/ or other healthcare providers. This represents an untapped resource for identifying caregiving youth through both adult and pediatric practices to facilitate connecting to available youth support services.

In a yet unpublished study conducted between March 2021 and March 2022, high school aged students at three Title I school-based health clinics in Miami, Florida, completed a survey regarding their caregiving responsibilities in the home alongside validated mental health screening measures including those for depression, anxiety, anxiety related to COVID-19, and a broadband measure for general mental health concerns. Among the 102 students surveyed, 40 (39%) reported some type of caregiving in the home. While further research is needed to understand these outcomes better, these early findings provide support for the concept that caregiving youth can be identified through screening questions in a healthcare setting.

Disease Specific Research

Research within specific illnesses allows for a deeper understanding of how the illness influences care and the type of symptomatology that leads to higher care needs, informing the development of targeted support, education, and the opportunity to work directly with disease-based organizations to build in and incorporate youth programming.

Huntington's disease and Amyotrophic lateral sclerosis (ALS). Scholars have examined youth caregiving in the context of complex neurological disorders, requiring daily, often 24-hour care, with no treatment or cure, including Huntington's disease (HD) and Amyotrophic lateral sclerosis (ALS). Research within these illnesses describes a constellation of complex care tasks ranging from feeding, bathing, and toileting to constant watching and waiting for falls and illness progression (Kavanaugh, 2014; Kavanaugh et al., 2020). Care is undertaken by youth as young as 8 years of age, for as often as 5 hours a day. Given the outwardly stigmatizing symptoms, including the use of power-driven devices, communication devices, and gait impairment, many youth have few resources and experience social isolation within peer groups and from adults, both in the health care and school systems (Kavanaugh et al., 2015).

Additionally, situating research within autosomal dominant (Huntington's) and those with genetic variants (ALS), allows for a deeper exploration of the potential for genetic implications and how being a young caregiver for a genetic illness impacts the well-being of caregiving youth (Dondanville et al., 2019), parent/child conflict (Kavanaugh, 2014) and personal concerns for the future.

Given the lack of treatment or cure for illnesses such as HD, end-of-life issues are an ever-present reality for young caregivers. Research suggests that

youth understand that end of life is near for their parents with HD, and parents may have specific wishes or choices when it comes to end of life decisions. However, many youth have never discussed these with their parents, describing respect for the parent's wishes, feeling their opinion was not valued, and a general avoidance of End-of-Life issues (Kavanaugh et al., 2015). This includes an unexpressed worry of "what's going to happen to me?"

Cancer. Of the 17 million cancer cases diagnosed worldwide each year, 25% occur among individuals likely to be raising children (parents aged 20-54) (World Health Organization, 2020). Cancer is an illness that affects the whole family system, and consequentially, families must reorganize their functioning, roles, and responsibilities (Faulkner & Davey, 2002; Huizinga et al., 2011). Due to the debilitating and often prolonged effects of diagnosis and treatment, children of parents with cancer may assume a caregiving role---providing multifaceted, extended care without reduction of other family, home, school, or work-related responsibilities (Maguire et al., 2013). Despite a large body of research existing on caregiving in oncology, most of this information pertains to the experiences of adult caregivers. Caregiving youth are contrastingly overlooked (Tan et al., 2023). They provide care without the same education, support, and acknowledgment that their adult caregiver counterparts receive (Hendricks et al., 2021). This paucity is especially evident in the oncology space where, to date, no research has specifically investigated caregiving youth in oncology, despite evidence of youth providing support to their parent with cancer, and no targeted interventions exist (Justin et al., 2021). While interventions exist to broadly support children who have a parent with cancer, no interventions are specifically tailored to address the unique consequences and needs resulting from adopting a caregiving youth role. This absence of research reduces our ability to intervene and support youth in this role and creates an inequity between adults and caregiving youth with respect to the acknowledgment of their caregiving role and the services available to them.

Caregiving Youth and COVID-19

Research into the impact of the COVID-19 pandemic and related social distancing measures is still ongoing, especially for long-term impacts on the well-being and education of children and adolescents in the U.S. Qualitative data from a study of Latino and African-American young caregivers for a grandparent with Alzheimer's Disease and Related Dementias during Covid-19 (Johnson et al., 2023) detailed the complex experience of care and the emotional toll on young caregivers when they are either isolated from the care recipient or isolated with the care recipient. Regardless of the isolation state, young caregivers described heightened levels of worry and anxiety for their care recipient, given the lack of access to care and services, that were previously available. Additionally, as with all youth during the COVID-19 pandemic, young caregivers transitioned to online courses. However, this experience was more complicated and often required turning off the camera and missing class to provide care for their family member(s) in the home.

There is still a need to assess the impacts of the pandemic on caregiving youth. The differentiated negative mental health impacts on youth who felt isolated or unconnected from school (Jones et al., 2022; Panda et al., 2021) would suggest that caregiving youth's general sense of isolation could have been exacerbated during this time.

College Students

Caregiving youth rarely stop caregiving after they turn 18, and there has been a growing interest among scholars to understand the link between higher education and caregiving student success, particularly amongst young adults. However, only a portion of this research specifies the age of students, and so it is difficult for most to decipher if the results differ across different age groups. This research is nonetheless relevant because caregiving can be an integral part of the transition to adulthood for some youth, influencing both their decisions about the future and their well-being as they pursue further education.

A study of 353 college students in a large, urban, public university in the southern U.S. in 2009 found that 21.52% of students were either current caregivers or had been in the past (Greene et al., 2017). Most caregiving students cared for a parent, followed by a grandparent. They mostly cared for one person, but often cared for two or more people. About half of caregivers began caregiving responsibilities between 16 and 20, and about a third began between 11 to 15. Most caregiving students were caregiving for 0 to 5 hours on a normal day in college, with up to one-fifth of caregiving students were caregiving for more than 8 hours per day on the weekend. Caregivers frequently helped their loved one walk, and with feeding and dressing. They also served as companions, gave emotional support, cleaned the home, and completed laundry. They were involved in organizing help from others, coordinating appointments, and administering medical care (Greene, Cohen, et al., 2016). In 2022 a survey of caregiving undergraduate and graduate students at the University of North Carolina Chapel Hill Found 5.6% of students sampled identified as caregivers (Armstrong-Carter, Panter, et al., 2022). And the University of Wisconsin at Milwaukee (UWM), a large, urban, open access university, found 11% of students who identified as caregivers, were providing care for a parent or grandparent (Kubszack, Lewandowski and Kavanaugh, 2023 under review).

Demographic Insights: Race, Gender, and Age

The studies mentioned above reveal both the limitations and the promise of understanding the demographic characteristics of caregiving youth. Of special concern is the intersectionality of age, race, gender, class, and other dimensions of difference in relation to the frequency, quality, and outcomes of being a caregiving youth. At the present time, there is a consensus across research that differences in the interaction between multiple identities – such as being a Latinx girl or a Black male teenager – matter to the kinds of care that is expected. The age of the caregiver also influences the kinds of support provided to the household. Even less is known about possible differences between rural and urban caregiving youth.

Existing studies that focus on dimensions of difference are scarce and limited, but the evidence suggests a need to expand research on intersections between caregiving by young people and the identities that shape other aspects of their lives.

Race and ethnicity

Existing research suggests that caregiving youth are more likely to come from historically underserved racial and ethnic groups in the U.S. The Florida school-based study found that middle and high school students from Latinx and Black backgrounds provided higher levels of caregiving to chronically ill or elderly parents and grandparents compared to those identifying as being from white non-Latinx, Asian, or “Other” ethnicities (Armstrong-Carter, Siskowski, et al., 2022). Replicating findings from Florida, research in Rhode Island also found that caregiving youth are disproportionately from historically underserved groups. Asian, Black, Latinx, Native/Pacific Islander, and multiracial youth were significantly more likely to provide caregiving for family, compared to white non-Latinx youth (Armstrong-Carter et al., 2023).

Though these studies engage with limited populations, they reflect broader trends that the authors see in family caregiving in which Black and Latinx caregivers tend to experience more significant care burdens, higher financial impacts, and higher levels of stress than white or Asian populations (AARP and National Alliance for Caregiving, 2020). In the sample of college students, caregiving students were disproportionately women, graduate students, enrolled part-time, and from lower socioeconomic status backgrounds, as indexed by receiving need-based financial aid in the form of a Pell Grant. The authors of this report note that there is little known about caregiving youth among Indigenous American/American Indian communities, but caution that any research with Indigenous American caregivers requires a community-lead approach that is deeply attentive to political sovereignty, cultural safety, and a deep historical understanding of the relevant community.

Gender and Age

In addition to differences by race and ethnicity, a few studies have revealed gender and age differences in students’ experiences of providing caregiving for the family. In the Florida study, boys and younger children provided more caregiving compared to older children and girls, contrasting societal stereotypes of girls and older individuals as caretakers (Armstrong-Carter et al., 2022). In other research, girls and older adolescents completed more frequent household chores compared with boys and younger children (Armstrong-Carter et al., 2019a; Tsai et al., 2013). Girls also provided more emotional support to family compared to boys, although there were no age differences in emotional support (ibid). In other research, there has been evidence that cultural expectations and norms might influence expectations that girls support care within the home (Diaz et al., 2007). There is little known about caregiving by LGBTQIA+ youth in relation to frequency or characteristics.

Differentiation of caregiving by age has received little analytic attention, though there is some evidence that age difference shapes the intensity and character of support provided. In Florida, for example, caregiving was associated

with an unbalanced/unhealthy diet among older youth (i.e., high schoolers) but not among younger children (i.e., middle schoolers) (Armstrong-Carter et al., 2023). The reasons for this outcome are unclear, but other studies of youth nutrition suggest that older caregiving youth may have additional responsibilities that serve as barriers to engaging in healthy eating routines (Bridgeland et al., 2006). For instance, adolescents and older children have more homework and are more likely to work outside the home for supplemental income (ibid) while young children who are more reliant on family routines in the home (French & Stables, 2003).

Recommendations for Improving Prevalence Data

There are several high-level recommendations for enhancing the research landscape at the end of this report. For researchers working on prevalence studies, several key insights emerge from the review of literature.

1. **Disseminating methods for better detection.** The precedents set by existing studies highlight the promise of leveraging existing school-based state-wide surveys to collect new information about the experiences and needs of caregiving youth in other states. The United States does not uniformly require identification of caregiving youth within educational or social services (Armstrong-Carter et al., 2019). States and school districts do not typically collect information about caregiving students in the Youth Health Risk and Behavior Surveys. The school-based surveys of Florida and Rhode Island are potential models for identifying caregiving students through researcher-practitioner partnerships that facilitate analysis of collected data and provide consultation on specific needs.
2. **Expanding analyses that allow for differentiation within the caregiving youth population.** A key priority for future research will be to understand the interactions between caregiving and other youth characteristics, including socio-economic status, gender, race/ethnicity, and age. Many studies, particularly prior to 2015, were limited to qualitative, or small or quantitative samples with restricted statistical power (see Kavanaugh et al., 2016b for a scoping review). Recent large-scale studies have collected information in schools directly from students' self-report, but it can be difficult for researchers to establish partnerships that allow for access to identifiable data. It is highly probable that family socio-economic status partially confounds findings from prior research about the association between caregiving as a child and children's well-being because caregiving youth likely come disproportionately from families and communities with low socio-economic status (Hunt et al., 2005).

3. **Standardizing questions for identification.** Establishing a standardized series of questions to guide best practices in population-level research should be a priority for the research community. The absence of a “gold standard” for measuring the presence of caregiving youth in the population complicates national comparisons and limits the opportunity for districts or schools to easily administer reliable data collection to improve practice (Armstrong-Carter et al., 2021a). Standardization might require multiple, rather than single-item, questions that can better distinguish between types and intensity of caregiving undertaken by young people.

Impacts of Caregiving

There is ample evidence that, like adult caregivers, caregiving youth have a diversity of positive and negative experiences due to their caregiving, with a diverse range of outcomes. Caring for a family member who needs support can help a young person develop life skills such as household management, empathy, and resilience (East, 2010). Caring labor can also generate pride, purpose, and responsibility when tasks are age-appropriate and not overwhelming in terms of intensity or time commitment. However, caregiving can also impede activities that young people require to flourish, adding to the pressure of school and work, and limiting access to leisure time and friendships outside the home (ibid). Stress and time spent caregiving can exacerbate existing disparities in children’s well-being and educational opportunities (Armstrong-Carter et al., 2021b). Researchers are beginning to understand how activities undertaken by caregiving youth, such as using unfamiliar medical devices, administering medication, or supporting intimate tasks such as toileting and/or bathing, can induce stress, trauma, or physical strain. They are also examining the conditions under which caregiving takes a toll upon school attendance and focus, and other aspects of child and adolescent life that enhance physical and psychosocial well-being.

In this section, the authors review existing and emerging research on the impacts of caregiving for U.S. caregiving youth. The authors have included insights from recent research on young adults who are enrolled in college or post-high school education where they point to key areas for future investigation. The interdisciplinary character of the research in the U.S. has yielded important insights over nearly twenty years of investigation. In addition to federal research dollars from the National Science Foundation (NSF) and the National Institutes of Health (NIH) in the form of grants secured by researchers or research teams. Other funding for research has been secured from federal or state agencies, and from national non-profit research and advocacy organizations.

Educational Impacts

An important aspect of youth caregiving that is beginning to be uncovered are the hidden costs for young people who are caregivers. The paucity of research linking students’ experiences of caregiving to their educational and emotional outcomes

partially stems in a large part from a lack of systematic data collection on caregiving students in the United States (Armstrong-Carter et al., 2021a). Researchers have found that for caregiving youth, educational outcomes, and the ability to pursue one's own professional and financial goals can be impeded by the nature of needing to be available to family members for their caregiving needs.

Evidence from Grades K-12

Schooling can exert significant pressure on young people and families that have greater caregiving needs. This may be especially of concern if households experience other forms of housing insecurity, poverty, or non-citizenship status. Zaff et al. (2016) found that young people who provide care for families either through direct caregiving or through waged employment may determine that attending school impedes their ability to provide needed income or care. The researchers note that the educational system in the U.S. regularly lacks the knowledge or awareness of students who must provide care for family members and, consequently, fail to put in place mechanisms to support their completion.

The Family Health Section of the 2002 What Works Survey conducted in Palm Beach County, FL with over 12,000 public middle and high school students reported that more than half of students had someone in their home or close by who needed special medical care. More than one in three students reported that because of caregiving they either missed school, did not complete homework, had trouble focusing or some combination of these three academic challenges (Siskowski, 2006).

Evidence from Higher Education

Armstrong-Carter et al. (2022) surveyed college-aged students at UNC-Chapel Hill, a competitive R1 University. They found that caregiving for chronically ill or older adults was associated with lower grade point averages. Caregiving students also noted being distracted by their caregiving, making it difficult to concentrate on their studies and to juggle the burdens of caregiving at home while also being a university student. Circumstances such as the COVID-19 pandemic added stress for students who worried about providing care for vulnerable family members while being exposed to possible infection on campus.

The University of Wisconsin at Milwaukee (UWM), a large, urban, open access university, found 11% of students who identified as caregivers were providing care for a parent or grandparent. Being a caregiver required them to put off going to school, extend their school experience, or struggle to keep up with course content. This data is being used by the UWM to create new supports specifically for these young adult caregivers, including faculty education programs, resources for respite and a designated study and rest area within the university library (Kubszack, Lewandowski and Kavanaugh, 2023 under review)

There is growing interest in the role that caregiving plays in the completion of degrees and time to obtain a degree in higher education. The Chronicle of Higher Education assembled a panel of experts in 2020 to discuss the findings of an AARP report which found that 70% of students with caregiving responsibilities perceive that

it has an impact on their academic success (AARP & The Chronicle of Higher Ed, 2021). Overall, the balance of current evidence suggests that students in higher education who are caregivers have different experiences than their non-caregiving peers, although understanding prevalence and impact is still limited given existing data. The few studies that have been conducted at institutions of higher education in the U.S. suggest that research could reveal different trends in both prevalence and outcomes according to student population and type of institution (e.g., community colleges).

Health and Well-being

Research on the psychological and physical health of caregiving youth suggests some persistent themes but also highlights differentiation according to the types and duration of care, the socioeconomic status of the family, cultural acceptance and support for care, and other factors. Even with heterogeneity in mind, most studies confirm that caregiving youth experience similar stresses as are evident in research on adult caregivers, as well as positive outcomes of providing care.

Mental, Social, and Emotional Health

Similar to the adult-caregiving literature, studies reflect both positive and negative effects on mental health for caregiving youth and young adults in education (Cohen et al., 2012; East, 2010; Hunt et al., 2005; Shifren & Kachorek, 2003). Although the 2005 National Survey was conducted more than a decade ago, findings from this survey and concomitant media attention brought awareness to the effects of caregiving on children's behaviors and emotional well-being. For example, according to parents' reports, youth caregivers were more likely to show anxious and depressed behavior as compared to non-caregivers (Hunt et al., 2005). In Florida, caregiving youth experienced significantly more ongoing emotional problems compared to their non-caregiving peers, such as suicidality, self-harm, ongoing sadness, and depressive symptoms (Armstrong-Carter et al., 2022). In Rhode Island, caregiving youth were 15% more likely to experience ongoing sadness for two or more weeks compared to their peers who were not caregivers (ibid). Though there are many challenges facing caregiving youth, one ongoing study into the everyday geographies of caregiving youth (E. Olson, National Science Foundation # 1853260) reveals that youth who understand the importance of their caregiving create and value networks of care, find pride in the care they provide to their families and friends, and value the skills that they learn from their caregiving.

In the previously mentioned unpublished survey of children in the Miami school-based clinics, as compared to children who did not report caregiving in the home, caregiving youth had statistically significant higher scores on scales for depression, disturbed thinking regarding COVID-19, and overall mental health concerns. When evaluated for clinically relevant scores, caregiving youth were more likely to screen positive for depression. Analysis examining mental health as related to the level of caregiving responsibilities, including time spent and extent of caregiving tasks did not differ by the Level of Responsibility, except for the measure

for anxiety related to Covid-19. This suggests that any level of caregiving may be associated with poorer mental health outcomes among caregiving youth. This would appear to correspond with other research on adolescents who help the family more with instrumental activities of daily living, including household tasks, not necessarily caregiving (Fuligni, 2011).

Sleep

Though all caregiving has some impact for youth, complex and intense care needs for illnesses such as ALS present different degrees of challenges, because 24-hour care can impact young caregivers' sleep and well-being. In a pilot study of age and gender-matched young caregivers and non-caregiving controls, young caregivers had more disruptive and less consistent sleep than their non-caregiving peers (Kavanaugh et al., 2021). The next phase of this research is assessing the moment of care, what care type and when it is being conducted, and how those combine to impact young caregiver well-being. This data will inform specific interventions for care tasks, and understand which ones are more impactful and which ones may need more specific support (Sommers et al., 2023).

Recommendations for Advancing Understanding of Caregiving Impacts

The momentum of research on the impacts of caregiving on young people's well-being has accelerated as more researchers are trained to conduct research on and with caregiving youth. Nonetheless, our review also reveals the limitations of existing research and the need for enhanced investment to better understand the impacts of caregiving upon young people. This is especially urgent given that research to date suggests clear and distinctive impacts of caregiving on young people's ability to engage in the activities that are necessary for well-being and success; they are a unique population, and their experiences must be included if researchers are to comprehensively understand family caregiving in the U.S., or address inequalities in education, health, and well-being.

1. **Supporting interdisciplinary research to understand disparities in health, education, housing and environment, and social and political engagement.** Progress towards understanding the impacts of care upon young people requires an interdisciplinary approach that can capture the various aspects of youth well-being from physical health, to emotional and psychological safety, to full access to participate in education. Given the shortage of holistic information about the well-being of caregiving youth, integrating caregiving youth into broader studies of the social determinants of health, particularly in communities that suffer from health disparities and related health injustices, offers the potential to expand understandings of impact.

2. **Enhancing opportunities for novel partnerships.** Considering the challenges of identifying caregiving youth in the U.S., partnerships between schools, health care providers, and community groups are essential for advancing understanding of impacts. Community-based partnerships also can ensure that all communities might benefit from research insights and investments. This can include making research tools more readily available and maintaining access for other researchers outside of higher education and encouraging the inclusion of questions about young people in research about family caregiving. Concerted and coordinated efforts to share best practices regarding issues such as sharing student or patient information in ways that protect confidentiality would accelerate our understanding of the needs of caregiving youth and translating research into practice more effectively and efficiently.
3. **Investing in high-risk, high-reward research and research with special populations.** Research with caregiving youth should be considered high risk and high reward; with limited understanding of this population and limited existing data, even exploratory research is likely to yield impactful results. Foundations and federal agencies should be educated to understand the value of investing in exploratory or high-risk research with caregiving youth. Likewise, special populations, especially those that are currently under-represented in research or that have the potential of disproportionately high caregiving impacts, should be supported as priorities for further research and understanding.

Policies, Programs, and Practice

A diversity of programs and policies exist to support caregiving youth in the U.S., including clinical interventions, school-based policies, nonprofit and VA-based programming, and recreation opportunities tailored to caregiving youth. In this section, the authors offer a more engaged discussion of the kinds of policies and practices that are being designed and implemented to provide direct support to caregiving youth and their families, and also to the professionals who encounter the population. The authors begin by framing the policy and legislative context in the U.S. and then offer overviews and call-out boxes describing the diversity of formalized practices that have been developed in different spheres that service caregiving youth families.

Recognition and Rights

The relatively slow pace of federal, state, or local recognition of caregiving youth is shaped by the social and political histories of childhood in the U.S. As Olson (Olson, 2019b) explains, child labor laws that were enacted during the late 19th and early 20th century coincided with the emergence of the new fields of public health, home economics. These trends domesticized – and to a large part hid – the caring labor of

both young people and women through much of the 20th century. Federal legislation enacted through the latter half of the 21st century represented a shift in recognizing the importance of family caregiving. Legislation from the Older Americans Act of 1965 to the Family Medical Leave Act of 1993 expanded the recognition of adult family caregivers, their rights, and the services they required for support; children and adolescents were excluded due to the identification of caregivers as adults, or over the age of 18 years. Since that time, work by researchers and advocates to expand the age boundary to include children and adolescents as caregivers in both policy and public consciousness has produced important shifts, albeit still largely in process at the time of this report.

Though the failure of the U.S. to ratify the Declaration of the Rights of the Child (1959) has been proposed as one possible explanation for the neglect of protecting caregiving youth (Leu & Becker, 2017), the U.S. is generally unwilling to ratify international agreements out of concerns for state sovereignty (Hathaway, 2008). Nonetheless, the Declaration has proven an important guide for other countries and could be a useful framework for addressing caregiving youth rights and recognition. Kavanaugh, Kalipeni, and Stamatopoulos (2016) identify several relevant portions including Article 19 (the right to be protected from violence, abuse, neglect, and exploitation); Article 9 (interest in keeping children with their parents); Article 17 (the role media can play in raising awareness); Article 28 (the right to do well in school), and is vital to young carers whose schoolwork frequently suffers as a result of caregiving duties; Article 31 addresses rest and leisure, underscoring the right to have down time and rest from their caregiving lives; and Article 32 (the right of the child to be protected from economic exploitation).

Other models that aim to recognize caregiving youth and their rights, or the obligations and responsibilities of governments and agencies in meeting their needs, suggest opportunities at the local, state, regional, and federal levels. Notwithstanding the complexity of the legal landscape surrounding families and child welfare in the U.S., recent federal policies, legislative actions, and educational reforms suggest the possibility of solutions developing out of U.S. institutions.

Federal and State Policies

The Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregiving Act was signed into law in January 2018. RAISE was structured to bring more – and more diverse – voices to a national strategy for family caregiving. The Act includes three major elements: 1) the formation of the nation’s first Family Caregiving Advisory Council; 2) the development of a Report to Congress; and 3) the creation of the National Family Caregiving Strategy. The 2022 National Strategy to Support Family Caregivers includes both the definition and acknowledgment of caregivers under the age of 18, and proposes that as a special population, caregiving youth require special attention under the development of future policies (RAISE et. al. 2022). Public comments are currently under analysis and at the time of this writing, but President Biden’s Executive Order on Increasing Access to High-Quality care and Supporting Caregivers (April 18, 2023) includes “minor children” as possible

caregivers to those requiring additional medical support (Executive Order on Increasing Access to High-Quality Care and Supporting Caregivers, 2023).

The Helping Heroes Act was reintroduced in March 2023 as a bipartisan bill (S. 622, 118th Congress) aimed to support caregiving efforts in military and veteran families (Johnson et al., 2023). If signed into law, the bill would appropriate funding to create partnerships between various federal, state, and local agencies, as well as private organizations to provide services and supports for military and veteran families in which at least one member is disabled and receiving care (child or adult). The bill would also direct the VA to create a national Family Support Program, which would include providing family coordinators at VA medical centers to support veteran caregiving family needs. While language in the bill would require VA to collect data on the experiences of veteran caregiving families, this information is already being collected, as described above, but could be bolstered by the support this bill would provide through additional grant funding and research opportunities.

State Departments of Education and School Districts

One strategy for measuring how often students miss school for caregiving, and which youth experience this conflict most frequently, is to leverage existing school-based student surveys. All states are required by the Centers for Disease Control and Prevention (CDC) to collect information about students' health behaviors, daily experiences, and reasons for missing school, and the surveys are tailored by each state (Kann et al., 2000). However, most schools in the U.S. do not ask students whether they have responsibilities for taking care of other people, or the extent to which taking care of others may interfere with their academic endeavors (Armstrong-Carter et al., 2021).

A web-based analysis of state-administered school-based health and behavior surveys across the country reveals that only three states ask if students have missed school to take care of a family member or friend – California, Minnesota, and Rhode Island (Box 1). In 2019, Minnesota surveyed public school students in alternative schools and area learning centers. It was found that 10% of boys and 14% of girls reported having missed school to take care of a family member or friend in the last 30 days (Minnesota Department of Education, 2019). The same year, California found that up to 7% of students in grades 7, 9 and 11 had missed school to take care of a family member or friend in the last 30 days (California Department of Education, 2019). In Rhode Island in 2022, almost 14% of middle and high school students reported they had missed school to take care of someone else (Armstrong-Carter et al., 2023). These findings suggest that further research is needed to fully understand the scope of children's absenteeism for caregiving purposes, and which students are most likely to have this experience.

BOX 1

Rhode Island Department of Education

The Rhode Island Department of Education (RIDE) is leading the way for identifying and supporting caregiving students in public middle and high schools throughout the state. Rhode Island is the first state in the U.S. to include specifications for supporting caregiving youth in state-wide K-12 curriculum. The Rhode Island Department of Education surveyed public middle and high school students across the state about their experiences providing care to the family, in partnership with academic researchers and the American Association for Caregiving Youth. The support for part of a broader revision for RIDE's Readiness-Based Graduation Requirements (Secondary Regulations) that a) identifies caregiving youth, and b) specifies the "identification of additional supports and flexibilities, that are publicly posted and available upon request, to support the academic goals and learning needs of caregiving youth and students who work."

In formal partnership with the American Association of Caregiving Youth (AACY), the RIDE program will begin by educating school staff about the issues caregiving youth regularly experience. An urban demonstration project will include identification and support of students who are caregivers among schools with high non-completion rates. Each school will have a designated person to assist caregiving youth and support their well-being and success. Targeted school-based, state, and federal policies can enable caregiving students to achieve their developmental and academic potential and mitigate inequalities.

Source: https://ride.ri.gov/sites/g/files/xkgbur806/files/2023-05/Secondary_Regulations_Clean_Version_11-16-22.pdf

The Caregiving Youth Project

The first program in the U.S. to provide services for the youth caregiver population began as the Caregiving Youth Project (CYP) in the Fall of 2006 at a middle school. It works in a formal partnership with The School District of Palm Beach County. By the end of its 16th year, it regionally enrolled more than 2,350 students in 35 middle and high schools. Its participants are in 22 other schools which have yet to have a formal program. The CYP team provides services to students from grades six through twelve and has a newly formed alumni group.

Integrated CYP services strengthen students, families, schools, and communities. Caregiving Youth learn they are no longer alone, and their families feel cared about. Typically, student-caregivers begin with the CYP from 6th grade and continue through high school. The service area is throughout Palm Beach County which is about the size of Delaware.

Services (at no cost to the client/family) include:

- In school – eligibility screening, Skills Building groups, Lunch and Learn sessions based on top diagnoses of care receivers, individual support
- Home assessments – initial and follow up to strengthen the family and to determine what resources are needed including mentorship, technology, respite in the form of in-home care or cleaning, tutoring, special projects, and others
- Sponsored activities – overnight Camp Treasure, Zoom activities such as Jeopardy and other games, holiday parties, picnics, ice or roller skating, zoo, and others

Caregiving Youth elect to remain with the CYP into high school – and they do for an average of 5.46 years concluding with a nine-year average 98.1% high school graduation rate and more than 80% going on to post-secondary education or the military. Caregiving Youth report that the CYP has helped them with grades, confidence, skills, family life, communication and managing anger and stress.

Veteran and Military Families

As the veteran family community draws more attention to military-connected youth caregivers, programs are being adapted and created to provide support across multiple sectors. This includes the development of a national coalition headed by The Elizabeth Dole Foundation and Wounded Warrior Project, focused on military-connected youth caregivers and more than 1.5 million in new funding dedicated to this work (White House Press Release, 2021). The five programming collaborations include: (1) Cohen Veterans Network, with the support of Wounded Warrior Project, has expanded behavior and mental resources and therapy sessions for post-9/11 caregiver children and youth ages 6-18 to enable them with the tools and resources to thrive. (2) Our Military Kids, Combat Injured Program provides extracurricular activity grants for enrichment activities and tutoring for caregiving children and youth of post-9/11 combat-wounded service members. Each scholarship (fees associated with athletic, fine arts, STEM, and tutoring programs) is a maximum of \$300 to cover fees for one activity for a period of up to six months. Each child is eligible for up to five grants, provided the severely injured parent continues to receive treatment and the child is otherwise eligible. (3) National Military Family Association (NMFA), serves and supports military connected youth caregivers through both advocacy and its programming, including Operation Purple, which offers camps and retreats for military kids and their families. Powered in part by Wounded Warrior Project, NMFA's Operation Purple Camps have adapted curriculum for children ages 11-17 from families with a wounded, ill, or injured service member to specifically draw out conversations around the experience of youth caregivers and support them in identifying their needs, raising awareness for those needs, and asking for the support they need to thrive. (4) Military Child Education Coalition (MCES) Student 2 Student program in schools connects military youth to new military students in the

school. There are over 900 S2S teams worldwide at the elementary, middle, and high school levels. (5) Camp Corral, which offers camps and retreats for military kids and their families, also offers camps for youth, providing a fun, safe space for expression to meet "like" peers. Family camps allow families to be together and have fun and get support with and from other "like" families.

Additional activities include an American Red Cross pilot of resilience workshops targeting military-connected youth caregivers through in-person military-connected youth caregiver Resiliency Workshops for post-9/11 caregiver children ages 8 to 13 years. Curriculum development includes research and creation of a module tailored to military and veteran children in caregiving homes.

Sesame Workshop facilitates trainings and webinars on the use of their family caregiving materials to support providers in their work with caregiving families. It is also actively working to support the creation of new materials that would address the mental health well-being of youth caregivers, and help families navigate these ups and downs together.

Coalition to Salute America's Heroes, America's Little Helpers (ALH) launched a national program offering monthly virtual programming for military-connected youth caregivers ages 3-24, providing tools for youth and young adults to cope and thrive on their journey to adulthood. In addition to working towards lessening the feelings of isolation and breaking the stigma of being a child of a caregiving home through connecting with peers online, ALH provides access to resources through monthly email newsletters.

Curriculum and Clinical Training for Practitioners

From schools of nursing to hospital pediatrics, there are several emerging examples of curriculum development and clinical training for health professionals focused on recognizing and supporting caregiving youth.

Healthcare Providers

Health care settings can serve as a critical avenue of intervention. Medical professionals, including pediatricians and other pediatric health care providers, are uniquely positioned to identify and support caregiving youth. Medical providers make frequent contact with young people and their families and have access to health-related community resources and services that they connect children and families to. At present, not much is known about pediatric healthcare providers' knowledge and perceptions regarding caregiving youth.

To learn more about providers' understanding of caregiving youth within their practices, a survey was administered to 85 pediatric healthcare providers (e.g., pediatricians, nurses, physician assistants, etc.). Unpublished data from this survey indicates that the majority (58%) of healthcare providers were not aware of caregiving youth, and an additional 11% were unsure about their awareness of caregiving youth. Some of the barriers to identifying caregiving youth within healthcare settings include, lack of supportive resources, lack of a validated screening tool, insufficient appointment time, and provider attitudes (e.g., not an

important issue to ask about). Most pediatric healthcare providers in this study reported they would ask about this matter if it was brought up by patients, family, or staff, or if they had a relevant reason to ask.

Additionally, identification of this population may be limited by a child's willingness or ability to self-identify as a caregiver or ask for help. We understand from qualitative studies conducted globally with young caregivers that they may be reluctant to call attention to themselves and their caring responsibilities and circumstances can be complex and the child may not realize they are a caregiver, or their parent may mediate their recognition of this or ability to discuss with other adults (Bjorgvinsdottir & Halldorsdottir, 2014; Smyth et al., 2011). These complexities further warrant consideration of more effective methods of identification, such as questions on standardized patient intake forms and verbal screening of patients. Anecdotally, there is a fear by families that if others knew the extent to which children were helping support tasks not typically considered children's work, they would be removed by social services.

There are key training programs provided by the VA Fellowship through the Elizabeth Dole Center of Excellence for Veteran and Caregiver Research and the College of Nursing at the University of Utah. The Elizabeth Dole Center of Excellence for Veteran and Caregiving Research provides two-year fellowships through partnerships with universities at each of the VA Dole COE sites. The University of Utah College of Nursing is one of the national nursing programs working on curricula that include attention to family caregiving. They have dedicated staff and have initiated the Family Caregiving Collaborative (UU FCC) to bring scholars from across the university together to train students and develop research in family caregiving concepts including children and youth. The FCC funded the first pilot project in Utah to assess the needs of military and Veteran caregiving families in Utah (Kalvesmaki et al. 2023). And several nursing programs are working on curricula that include attention to family caregiving and caregiving youth, including Florida Atlantic University, Vanderbilt University, Regis College, and the University of Pittsburgh.

At the University of Miami Miller School of Medicine, more than a dozen dual-degree public health and medical students have conducted research and other projects related to caregiving youth, many of which have led to regional or national presentations and peer-reviewed publications. This group has worked to raise awareness of the population of caregiving youth in the healthcare community over the past decade. This has included presentations to individual physician practice groups, students and at hospital grand rounds in South Florida, presentations at the American Academy of Pediatrics and American Psychological Association, published articles in periodicals for Florida pediatricians, and an article published in Pediatrics in partnership with a former caregiving youth. Additionally, engaging medical students and other learners in the topic is an important strategy to help expand the alliance of those advocating for caregiving youth.

The University of Miami Miller School of Medicine academic projects have included a variety of topics, such as describing the responsibilities of a population of caregiving youth, exploring their role in medication management, understanding

pediatric healthcare providers perceptions, and exploring the emotional and other impacts of caregiving youth through one-on-one interviews. A local pediatric resident in training co-authored a resolution to the American Academy of Pediatrics centered on the promotion of research, advocating for the inclusion of recommendations for this population in the health promotion guidelines, as well as advocating for broader recognition of this population and their needs. Though this did not move beyond the resolution in terms of implementation of recommendations, future similar measures in pediatric, mental health, and adult care organizations would be of great value to continue to expand awareness of caregiving youth.

Also, on a small scale in comparison to the need, instructions to ask about caregiving are included in the history-taking guides for medical students rotating through pediatrics at the University of Miami's Miller School of Medicine. Future areas of research include the validation of standardized screening tools to identify caregiving youth and adding these tools to electronic medical record templates for both child and adult health systems in inpatient and outpatient settings and as related to discharge planning.

BOX 2

YCare Program

Given the complexity of care, and high numbers of care tasks associated with neurological disorders, assessing how youth know what to do, and who tells them how to do it is critical to not only youth well-being, but also the well-being of the person with the illness. Yet, few young caregivers have received specific training in care tasks. In a study of young caregivers in both ALS and Huntington's disease, 70% of youth never had any specific training or guidance, despite daily care for multiple care needs, including physically demanding care (Kavanaugh, Cho and Howard, 2019).

The YCare ("young caregiver training and skills education") is an evidence-based multidisciplinary care skills and support program developed for young caregivers, and health care providers who support family caregivers (Kavanaugh, Howard, and Banker-Horner, 2018; Kavanaugh, Cho, Banker-Horner, Barkhaus, 2020).

- **Modular:** Each module within YCare is created with the input of allied health care providers with expertise in the illness or disease. Iterative meetings with these professionals result in 3-4 modules, offered within a one-day setting. Each module lasts approximately 45 minutes, with debrief sessions for the youth in between.
- **Training:** The modules are taught by allied health professionals who received a ½ day training in the YCare model and young caregivers in the U.S. To date, over 80 allied health professionals have been trained in the model and conducted a YCare training, including Physical Therapists, Occupational Therapists, Speech-Language Pathologists, Social Workers, Respiratory Therapists, Assistive Device Specialists.

- Youth participants: Youth attendees go through the YCare program in peer groups, addressing the need to create social support for young caregivers, offering an opportunity to feel not only supported but able to discuss the illness and care tasks in a normative way with peers who “get it.” Groups are kept small, in order to provide one on one interaction with the trainers, but also to allow for focused peer engagement.

Over 140 youth have attended the YCare program. While YCare was originally created for the ALS community, it is currently being adapted to:

- Alzheimer’s and related dementia care (ADRD)
- Cancer care
- Care for siblings with illness or disability
- Military connected youth

Policy and Program Recommendations

The authors recommend three high-level areas for developing more inclusive policies and comprehensive programs for caregiving youth. For policymakers and practitioners expanding services and support for caregiving youth, several key insights emerge from the review of the literature.

1. **Including young people as caregivers.** Overall, young people under the age of 18 should be included as part of future policy and recognition of family caregiving. This includes caregiving legislation and programming that addresses aging and intergenerational care. For instance, policies supporting grandparents raising grandchildren should incorporate support for the child when/if the grandparent requires care. Within the allocation of aging network resources, there should be provision to prioritize the resource waiting list when caregiving youth are the providers of care.
2. **Increasing coordination between national, state, and local agencies and organizations to identify opportunities for action and advocacy.** For states with a Family Caregiving Task Force, guidance should be provided for integrating the needs and concerns of caregiving youth into evaluations and recommendations. Support for organizations and practitioners who are navigating state and federal systems that intersect with issues of care and young people will help accelerate successful interventions.
3. **Supporting existing expertise and sharing best practices through researcher-practitioner partnerships.** A more comprehensive and coordinated effort should build upon the success of existing networks and encourage greater participation by those working in adjacent or overlapping areas of research and practice. Partnerships help ensure that support and

programming efforts are guided by evidence. Partnerships also help extend the base of evidence, enhancing and informing the development of new programming and policies for caregiving youth.

Concluding Recommendations

This report describes the research, practices, and policies that are accelerating recognition and support of caregiving youth in the U.S. Progress relies on a dedicated, collaborative network of scholars who are training of researchers and experts; non-profit leaders who are advancing innovations; and government and education agencies and actors who have embraced novel researcher-practitioner collaborations to build evidence-based interventions.

Each section of this report makes targeted recommendations. We thus conclude by identifying three key actions that require national-level leadership and endorsement. Securing and accelerating existing progress will require a concerted and coordinated investment by the federal government to improve research, practice, and policy on behalf of caregiving youth and their families.

1. **Form a National Task Force on Caregiving Youth.** The distinctiveness of service provision relevant to caregiving youth as compared to adult caregivers demands a more focused and dedicated approach than is available under current structures. The formation of an expert task force would ensure that President Biden’s April 18, 2023, Executive Order on Increasing Access to High-Quality Care and Supporting Caregivers, which included explicit reference to “minor children” who are caregivers. A National Task Force on Caregiving Youth would provide strategic leadership to ensure that any additional federal action will advance, rather than reinvent, existing successes.
2. **Conduct a national-level prevalence study, followed by strategic investments in high-impact areas that are likely to have rapid and scalable impacts on health, education, and labor policies.** Federal research agencies, including but not limited to the National Science Foundation, National Institutes of Health, and the Institute of Education Sciences, could designate funding mechanisms or incorporate research on caregiving youth. Such a move would enhance access to the resources that will be necessary for rapid growth of empirical evidence related to caregiving impacts, experiences, and interventions.
3. **Support access to resources and adapt existing supports for caregiving youth that are proven successful in the U.S. context and internationally.** The current geographic patchwork of support for caregiving youth means that

some young people are recognized as caregivers, while the vast majority remain unrecognized, unsupported, and misunderstood in their schools and communities. States, local governments, schools, non-profit and community-based organizations, and healthcare providers require resources and expertise to evaluate and enact policies for support. Existing best practices should be sustained and circulated as models for adoption and adaptation, with direct support from experts.

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