Caregiving Youth in the United States: A Policy Perspective

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Sophia's family lives in a small apartment in West Palm Beach. She is 13 years old, has one younger sister who has autism, and a younger brother who has anger issues. Sophia's mother is overwhelmed with having two younger children with behavioral issues; she is experiencing depression. Mom's family lives in the Dominican Republic and Dad's family lives in Costa Rica. Dad is not living in the home as mom has asked him to leave due to adultery. Mom is seeking a divorce and leans a lot on Sophia for a listening ear. Sophia, like many other children in our community and beyond, serves as a caregiver to her family. This is one of countless examples of youth caregivers in the United States.

The National Alliance for Caregiving 2015 Report estimates that approximately 43.5 million adults in the United States have served in a caregiving role within the past year (1). While adults may be classically represented in this group, a population of caregiving youth exists in the United States; they are not included in this data. Caregiving youth are younger than 18 years old and provide significant assistance to relatives or household members who have a physical or mental illness, disability, frailties of aging, or substance misuse (2). Because children are often perceived as the receivers of caregiving, the term "caregiving youth" seems quite dichotomous, but the literature indicates that 1.3 to 1.4 million children between the age of 8 and 18 years serve as caregivers, as estimated in 2005 in the first national survey of youth caregivers in America (3). Twelve years have passed since this estimate was published; it is probable that this number has increased.

The AARP Public Policy Institute has calculated that the economic value of family caregivers in the US is $470 billion based on 2013 data, up from an estimated $450 billion in 2009 and $375 billion in 2007. An additional $8.5 billion dollars is the estimated value of youth caregivers in the United States, and this has not been updated with the most recent data (4). As evidenced by these numbers, caregiving by adults and youth is an invaluable service with tangible worth.

Most frequently, youth caregivers aid in the care of a grandparent or parent, and sometimes to a sibling with a health condition. Caregiving responsibilities include activities of daily living such as bathing, dressing, feeding, and toileting as well as instrumental activities of daily living such as meal preparation, shopping, household tasks, and even giving and managing medication. These caregiving tasks can come at a price, especially for children whose primary task is supposed to be education along with age appropriate play and recreation.

From increased risk of anxiety and depression to poorer function in school, studies indicate that youth caregivers do not always fare as well as their non-caregiving counterparts mentally and physically (5). This difference is magnified in minority and financially insecure households with caregiving youth. For example, studies in caregiving minority populations have shown decreased utilization of coping strategies and lower life satisfaction in comparison to Caucasian counterparts (6).

While most pediatric health care providers have interacted with caregiving youth while in practice, many have not had the awareness to identify them as "caregiving youth", in need of specific supportive services. Some may have even considered this concept as objectionable, labeling the family's circumstances as unacceptable for a child. However, pediatric health care providers must recognize that both societal determinants and personal motivations thrust children into this role. Necessity, love and a sense of obligation all contribute to this phenomenon. Rather than impugning families who rely on children as caregivers, it is the responsibility of health care providers to advocate for their support.

Multiple bills pertaining to the provision of support services for adult caregivers have been enacted to law on both the federal and state levels in recent years (7,8). While the US government recognizes adult caregivers, caregiving youth are ignored in this arena and excluded from these benefits. There is no policy in the US that either acknowledges or provides an avenue for respite or support for these children.

This starkly contrasts with other countries, such as the UK, Australia, and Ireland, where caregiving youth encompass about 2% to 4% of the total childhood population are legally recognized as caregivers (9). Such legislation is aligned with the spirit of The United Nations Convention on the Rights of the Child (UNCRC), passed by the UN in 1989 as a comprehensive safeguard for children's rights. The UNCRC provides a framework for the protection of political, economic, social, health, and cultural rights of children of all participating UN entities (10). While 195 countries have ratified the Convention on the Rights of the Child (CRC), only one UN country has not: the United States (11). With similar economic development to that of the US, the UK and Australia provide case studies for comparison.

The UK provides a brilliant model of a policy framework inclusive of caregiving youth. Largely since the Children's Act of 1989, "young carers" have been recognized in the eyes of the government (12). A national network of services exists for young carers, and they are recognized in various governmental policy and guidance documents (13). They are afforded the right to appropriate support services, involving formal assessment of their needs and ability to care for another person under the 2014 Children and Families Act and Care Act (14).

In Australia, stemming from policies that originated in the mid-1990s, the government has provided support to regional Carers Associations and Carers Groups to provide support services such as camps, mentoring programs, and counseling services, to name a few. Young carers in every region through age 25 years can rest assured that they will be provided support, as all Australian states have organizations and initiatives dedicated to this special population. Additionally, Through the Department of Families, Housing, Community Services, and Indigenous Affairs, Australia provides the Carer

Payment and Carer Allowance programs, which give monetary supplementation to adult and youth caregivers in the country (15).

While the Carer Payment provides pension-like income support for those providing constant care for another person, the Carer Allowance is a supplementary payment for those who provide daily care at home, and the payment most often utilized by youth caregivers. While young carers still encompass only a small portion of recipients of these financial support programs, utilization marks the need for support. Additionally, utilization among this group has steadily increased in the years since the policy's inception (16).

Despite examples of policy changes in other developed countries, legislators in the US have been slow to adopt any changes to benefit this group. Youth caregivers in the United States have no specific legal rights. Why is the United States lagging so far behind other countries on this important issue?

Chief among the advocates for caregiving youth is the American Association of Caregiving Youth® (AACY). The AACY is a private, nonprofit organization in Palm Beach County, Florida (www.aacy.org). It works among the domains of education, community, and healthcare. In 2006, AACY launched the Caregiving Youth Project, and partners with The School District of Palm Beach County to identify caregivers among middle and high school students and provide services in and out of school as well as at home. It fills an important gap in delivery of support services for this special population. AACY stands alone in the US, compared to the multitude of similar organizations in other parts of the world.

In countries previously mentioned, non-governmental organizations have advocated to move policy forward throughout their lands. In contrast, numerous young lives in the US lack support services and are at risk for school dropout. In the absence of policy infrastructure bolstering the efforts of AACY, and without further expansion, these young people will stay unrecognized and unsupported. An integrated system with components similar to those offered through the Caregiving Youth Project, should be established throughout the US.

In addition, much more can be done for youth caregivers on the local level. Pediatric health professionals should play an important role in providing support by identifying youth caregivers, recognizing their strengths, and understanding their unique role with its challenges including physical and emotional health risks. For example, in practice and in clinics, pediatric health professionals can raise awareness of issues facing caregiving youth among associates and staff as well as document family health situations and youth caregiving responsibilities. Additionally, resources that already exist, such as the AACY, can be utilized along with advocating on their behalf among legislators, religious and business leaders, and in educational and professional groups.

Since her enrollment in the Caregiving Youth Project, Sophia continues with Skills Building groups in school where she has learned she is no longer alone, has made new friends, and has even gone on a CYP fishing trip. She is managing her stress better and more willingly helps mom with her siblings. Sophia is being supported through her transition into high school. Mom now attends an autism support group and has gotten help through Legal Aid. She is also now enrolled in college. The future is beginning to look bright for what once seemed bleak.

Remember the faces of youth caregivers in everyday practice along with strong advocacy for reform on the policy level.

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