

EXECUTIVE SUMMARY

Report on Caregiving Youth in the U.S.: Progress and Opportunity

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.