



MEET THE NEEDS OF PEOPLE WITH SMA THROUGH PAID FAMILY CAREGIVERS

Utilize Medicaid authority to pay family caregivers of children and adults with SMA

DID YOU KNOW?

- Many with SMA rely on Medicaid caregiving services for assistance with daily living activities, such as getting dressed, eating, or bathing, with **75% of adults with SMA** reporting they need **41 or more hours of caregiving help**.
(Source: [Cure SMA survey](#))
- Family caregivers are family members who provide paid or unpaid assistance to a person with a chronic illness or disabling condition.
(Source: [Centers for Medicaid and Medicare Services](#))
- Children and adults with SMA have significant challenges in finding and retaining qualified caregivers such as personal care attendants (PCAs).
(Source: [Cure SMA](#))
- States have the legal authority within Medicaid waiver and self-directed care programs to pay relatives, including spouses and parents, for providing caregiving services to qualified Medicaid beneficiaries. (Source: [Centers for Medicaid and Medicare Services](#))
- Many states changed their Medicaid policies during the COVID-19 public health emergency to pay or increase pay to family caregivers of Medicaid beneficiaries to meet the caregiving demand and address the caregiving workforce shortage.
(Source: [U.S. Department of Health and Human Services](#))

WHY STATES SHOULD ACT

To help meet the caregiving needs of individuals with disabilities and address ongoing caregiving workforce challenges, [many states](#) have utilized existing authority within Medicaid to pay for family caregivers for certain waiver services. In these states, eligible family caregivers, including parents and spouses, are reimbursed for providing extraordinary personal assistance services identified in their loved one's service plan. Unfortunately, not all states use this Medicaid authority to pay family caregivers who can provide this essential service. With a caregiving workforce shortage, families have to make the hard choice between providing income from a job outside the home and providing assistance for their loved ones with SMA.

CURE SMA POSITION

To meet caregiving needs and address workforce shortages, Cure SMA urges all states to **pay family caregivers** who provide essential care, including assistance with activities of daily living, to their child or adult family member who qualifies to receive home and community care through Medicaid.

Allowing for the payment of family caregivers will help ensure that individuals with significant disabilities and older adults can access the home and community care they need to live independently in their homes and to **avoid or delay more costly institutional care**.

It has been an incredibly difficult journey to find caregivers. I have been shorthanded for months, unable to fill all my shifts.

~ Adult with SMA

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Cure SMA Advocacy | 800-886-1762 | advocacy@cureSMA.org | cureSMA.org

[Cure SMA](#) is a national organization that advocates for individuals with spinal muscular atrophy, a progressive neurodegenerative disease that robs people of physical strength, taking away their ability to walk, swallow, and breathe.