



January 29, 2023

The Honorable Eric Holcomb
Governor
Indiana State House, Room 206
Indianapolis, IN 46204-2797

Dear Governor Holcomb:

On behalf of Indiana residents with spinal muscular atrophy (SMA) and their families, **Cure SMA respectfully asks that you personally intervene to ensure that individuals with SMA do not lose or face cuts in caregiving services through Indiana Medicaid.** Cure SMA is greatly concerned about the negative impact a current Indiana Medicaid proposal could have on the health, safety, and independence of Indiana children and adults with SMA.

As we shared in a [2023 letter](#), SMA is a neuromuscular disease that causes severe muscle weakness and motor function loss. SMA impacts approximately 1 in 11,000 births in the U.S., regardless of race or gender, and about 1 in every 50 Americans is a genetic carrier. In [Indiana](#), 135,711 residents are carriers of the SMA genetic mutation. If both parents are SMA carriers, every child they have together has a 25% chance of being diagnosed with SMA.

Thanks to your past leadership, Indiana has been a leader in supporting Indiana individuals with SMA and their families.

- In May of 2018, you [signed into law](#) legislation to add SMA to your state's newborn screening program. As you know, newborn screening is the most effective and efficient way for babies with SMA to access timely treatments and available supports. Even before the federal recommendation that states screen for SMA, the Indiana Department of Health started its SMA pilot and, in 2019, implemented a permanent program. This action alone has greatly improved the lives of Hoosiers with SMA.
- In addition, Indiana Medicaid has provided essential access to in-home caregiving for many children and adults with SMA. Due to the physical effects of SMA, many Indiana children and adults with SMA qualify for Indiana Medicaid caregiving services for assistance with activities of daily living, such as bathroom support, dressing, and wheelchair transfers to attend school, go to work, and participate in their community. Currently, family members, including parents and spouses, can serve as their loved one's paid caregiver. Given the shortage of direct care workers and the specialized care needs of individuals with SMA, paid family caregiving is a win-win-win for individuals with SMA, their family, and Indiana.

However, a proposal being considered by Indiana Medicaid jeopardizes your Administration's strong leadership around SMA issues by putting children and adults with SMA at risk of losing key in-home care. Indiana Medicaid is proposing to end paid family caregiving on July 1 within its Aged and Disabled Waiver program. While the intent is not to hurt families, this proposal, if operationalized, will disrupt care and limit the independence of individuals with SMA and their families.

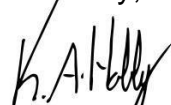


An **Indiana mother of a teenage son with SMA** said the Indiana Medicaid proposal to end paid family caregiving would absolutely impact his health, safety, and well-being. *“My son requires a lot of specialized care and knowledge of his specific diagnosis. If we were to lose attendant care, my son would be directly affected, and his quality of life would suffer.”* An almost **16-year-old Indiana boy with SMA** relies on his parents for the caregiving hours he has received since 2022 through Indiana Medicaid. *“I wouldn’t be able to do anything or have a life. I would be stuck alone in bed and rot away,”* he said. His mom said that if the state ends this program, *“it will take away my son’s ability to live as independently as possible and ignore HIS choice of caregivers.”* Under the Indiana Medicaid proposal, these families, and others across the state would lose their ability to care for their children. The only other options for these families would be to transfer to a [different program](#) that allows some form of paid family caregiving or to find a paid caregiver outside the home.


However, these Indiana Medicaid options are not workable for individuals with SMA and their families. The Indiana Medicaid proposal makes no guarantees that SMA families currently within the Aged and Disabled Waiver Program will qualify for or receive the same level of hours or compensation through the Structured Family Care Program. Finding a qualified paid caregiver outside the home is also problematic given the shortage of direct care workers across Indiana and the country. Cure SMA, in a 2024 national caregiving report, found that that 86% of individuals with SMA and their families struggled to find caregivers and 62% reported difficulty retaining paid caregivers due to the workforce shortage and low caregiver wages. This challenge will be exacerbated by Indiana Medicaid’s proposal to [pause a provider rate increase](#), which will further stagnate wages and benefits and worsen the direct care workforce challenges in your state.

Cure SMA asks you to intervene to either stop this Medicaid proposal or to build in caregiving hour and compensation guarantees for individuals with SMA and their paid family caregivers. Thank you for considering the views and needs of Cure SMA and the SMA community in the state. Please contact Maynard Friesz, Vice President for Policy and Advocacy at Cure SMA, at maynard.friesz@curesma.org or 202-871-8004, if you have any questions or need assistance in sharing information or update to residents with SMA in your state.

Sincerely,


Kenneth Hobby
President


Mary Schroth, M.D.
Chief Medical Director


Maynard Friesz
Vice President, Policy

Cc: The Honorable Suzanne Crouch, Lieutenant Governor, State of Indiana
Cc: Director Cora Steinmetz, Indiana Medicaid