



Make today a breakthrough.

June 16, 2023

Chiquita Brooks-LaSure
Administrator
Centers for Medicare and Medicaid Services (CMS)
7500 Security Blvd
Baltimore, MD 21244

Re: Comments to CMS HCBS Access Proposed Rule

Dear Administrator Brooks-LaSure:

As the leading national organization that represents individuals with a neuromuscular disease known as spinal muscular atrophy (SMA), Cure SMA appreciates the opportunity to comment on the Centers for Medicare and Medicaid Services (CMS) proposed rulesⁱ related to Medicaid. Cure SMA will focus its comments on the CMS Access Ruleⁱⁱ given many individuals with SMA and their families rely on Medicaid to access life-saving treatments, care, equipment, and home and community-based services (HCBS).

SMA is a degenerative disease that robs individuals of their physical strength, greatly impacting their muscles used for everyday activities such as breathing, eating, crawling, and walking. About 58 percent of children with SMA and 61 percent of adults with SMA receive their healthcare, including access to treatments, through Medicaid, according to Cure SMA's State of SMA report.ⁱⁱⁱ In addition, many individuals with SMA rely on Medicaid-funded in-home supports and personal care attendants (PCAs) to assist with daily activities, such as personal hygiene, wheelchair transfers, and food preparation and assistance. Medicaid home and community-based services touch "*almost every aspect of my daily routine,*" according to a **Medicaid beneficiary with SMA**. "*I would not be able to get out of bed each morning, shower, and get dressed to go earn a living at my full-time job.*"

Cure SMA supports the goals outlined in the Access Rule of "improving access to care, quality and health outcomes, and better addressing health equity."^{iv} Unfortunately, adults with SMA and families of children with SMA routinely face Medicaid access challenges, from a lack of caregiving hours and struggles finding caregivers to denials or delays in accessing treatment or durable medical equipment. Access challenges were exacerbated during the COVID-19 pandemic. Many individuals with SMA and their families went without in-home caregiving services for an extended period and some experienced treatment delays, especially during the early days of the pandemic. "*With appropriate care, which includes medical and nighttime assistance and support at school, my son can grow, thrive, attend school, and participate in many daily activities. Without the care he needs, he will languish...not from his disease, but from lack of support,*" said the **parent of a child with SMA**. An **older adult with SMA** shared a similar view, noting that "*The need for caregiving services will continue to grow as SMA treatments prolong lifespans and as Baby Boomers, such as myself, start to need*

assistance as we age.” Cure SMA agrees that the best way to strengthen Medicaid, improve quality, and address equity is through full access to treatments, care, equipment, and Medicaid funded in-home supports.

Cure SMA appreciates the comprehensiveness of the “Ensuring Access to Medicaid Services” proposal (Access Rule), as published in the May 3, 2023 Federal Register. However, we will concentrate our comments on the provisions related to promoting access to HCBS and improving HCBS quality.

PROMOTING ACCESS TO HCBS

Many adults with SMA and families of children with SMA struggle to find and retain PCAs and other direct care workers to assist with their activities of daily living. *“I struggle to keep caregivers long-term due to low pay and lack of healthcare and other benefits. At times, a lack of caregivers has limited my ability to work,”* said a **Louisiana adult with SMA** who noted that direct care workforce challenges *“compromise my safety, potentially leading to injury or emergency when not assisted in daily living tasks.”* A **Mississippi adult with SMA** said *“I’ve been shorthanded for months as I’ve been unable to fill all my caregiving shifts.”* A **Massachusetts adult with SMA** who manages his own caregiving needs through his state’s self-directed services program described how he received zero applicants for an open PCA position that, in the past, would have attracted about 20 applicants. *“Thanks to PCAs provided through my state, I have sustained my independence for years. Now I fear that institutional care is close. Please help.”*

Cure SMA is pleased that CMS recognizes how the direct care workforce shortage negatively impacts the independence and health of people with disabilities, including those living with SMA. *“Workforce shortages can prevent individuals from receiving needed services and, in turn, lead to poorer outcomes for people who need HCBS,”* CMS wrote in proposing its Access Rule recommendations.^v CMS also noted that workforce shortages can reduce the quality and cost-effectiveness of in-home services. To help address caregiver shortages, CMS is, among other things, proposing to require that *“at least 80 percent of all Medicaid payments”* be spent on direct care workers, including for homemaker services, home health aide services, and personal care services. CMS noted that the goal for setting a federal minimum standard was to stabilize the direct care workforce through enhanced salary competitiveness and to promote better service to individuals with SMA and other people with disabilities through more qualified employees, lower turnover, and a higher quality of care.

- **CURE SMA RESPONSE:** Cure SMA supports efforts to boost compensation of direct care workers who provide essential care and support to people with SMA and other Medicaid HCBS beneficiaries. One **adult with SMA** who, without the assistance of PCAs, would be unable to maintain her full-time job, said that her PCAs *“can make more money working in retail than they can taking care of me.”* Another **adult with SMA** said, *“I can’t tell you how upsetting it is to constantly be in the process of recruiting, hiring, and training new folks to assist me with my life, only to lose them a few months later to a job opportunity that pays more.”* A measurement tool, such as the proposed percentage

requirement, could stabilize the direct care workforce by ensuring most Medicaid HCBS funds are used for wages and benefits of workers who provide those critical caregiving services. *“PCAs are essential workers,”* said a **parent of a child with SMA**. *“They help keep the parents in the workforce, and give them a piece of mind while working, which can contribute to better health for all.”* Cure SMA defers to the operational expertise of CMS, states, and providers to develop and implement the most practical and meaningful measurement tool to address the direct care workforce challenges. CMS must carefully consider the impact any requirement will have on the availability of direct care workers and possible service disruptions, particularly for individuals who live in rural and underserved areas. *“I live in a rural place and am unable to access the caregiving services I need for dressing, medicine preparation, transportation, and grooming,”* said an **adult with SMA from Maine**.

IMPROVING QUALITY OF HCBS

Another key goal of the Access Rule proposal is to ensure high-quality Medicaid care and services that consistently meet the needs of beneficiaries, including children and adults with SMA. Current quality requirements *“vary across authorities and are often inadequate to provide the necessary information for ensuring that HCBS are provided in a high-quality manner that best protects the health and welfare of beneficiaries,”* as noted in the Access Rule’s preamble.^{vi} A **Texas adult with SMA** noted a *“dramatic decline”* in the quality (and quantity) of people applying for PCA positions. *“I’m afraid for my independence if this trend continues!”* In addition, individuals with SMA want to ensure that their own personal safety is not put at risk due to untrained workers or a lack of program oversight. Cure SMA appreciates that CMS is committed to increasing quality and consistency of care across the country through the Access Rule.

- **CURE SMA RESPONSE:** Cure SMA is pleased to provide comments on the quality measure provisions related to advisory committees, person-centered plan reviews, and incident management systems.

Advisory Committees: Cure SMA supports the Access Rule recommendation to create a new advisory committee made up entirely of Medicaid beneficiaries. The proposed Beneficiary Advisory Group (BAG) would provide an ongoing venue for individuals with SMA and others who receive Medicaid care and services to provide first-person experiences and constructive feedback to ensure Medicaid consistently meets the needs of the individuals and families the program serves. Cure SMA also supports the representation changes to the renamed Medicaid Advisory Committee (MAC), where at least 25 percent of the MAC must be Medicaid beneficiaries from the BAG. Increased representation on these state committees will ensure that state officials are hearing from people most impacted by Medicaid. Finally, Cure SMA supports the requirement that all BAG meetings and at least two MAC meetings per year are open to the public. Increased transparency will lead to a stronger Medicaid program in every state.

Person-Centered Plan Annual Reviews: Cure SMA also supports the new requirements related to person-centered plans for Medicaid beneficiaries. The Access Rule proposes



that person-centered service plans be “*reviewed and revised, upon reassessment of functional need, at least every 12 months, when the individual’s circumstances or needs change significantly, or at the request of the individual.*”^{vii} The care and support needs of an individual with SMA may change during their lifetime, particularly during their transition to adulthood and other key points in their disease management. In addition, the proposed rule would require that states update a beneficiary’s service plan to reflect any changes uncovered during the assessment. These commonsense changes will, as CMS noted in its proposal, provide important safeguards for individuals with SMA and other Medicaid beneficiaries by ensuring their care and service needs reflect their changing needs.

Incident Management System Improvements: Cure SMA applauds CMS for trying to address abuse and neglect of Medicaid beneficiaries by mandating greater Medicaid HCBS oversight. Cure SMA supports the Access Rule recommendation to strengthen the incident management systems operated by states to ensure that critical incidents are reported and investigated. The Access Rule’s requirements related to electronic collection and tracking and a common definition of what is considered a critical incident will help improve the care and safety of individuals with SMA and other Medicaid beneficiaries and help prevent future incidents of abuse, harm, or neglect. Finally, we support the recommendation that these requirements be consistent across Medicaid HCBS, whether delivered through fee for service (FFS) or managed care delivery systems.

FINAL COMMENTS FROM THE SMA COMMUNITY

Cure SMA also urges CMS, whether through the Access Rule or other mechanisms, to require that all states pay family caregivers (i.e., a spouse, parent, or other legally responsible relative) who serve as a direct care worker for their loved one who receives Medicaid HCBS. While existing Medicaid authority allows states to pay family caregivers, several states still do not make this option widely available to HCBS beneficiaries in their programs. We were pleased that some states started or expanded paid family caregiving during the public health emergency (PHE) through Appendix K. States should be encouraged or required to maintain those flexibilities. Most individuals with SMA rely solely on direct care workers for their in-home care and assistance, which is why we support the direct care workforce and related provisions in the proposed Access Rule. However, we also believe that paid family caregiving should be a viable option in all states for those individuals with SMA and others who prefer to receive their approved in-home services from a family caregiver.

Thank you for your commitment to improving Medicaid access and for promoting high-quality care and services. We hope the views and comments from the SMA community will help to inform your team about how to better serve individuals with SMA and other people with disabilities who rely on Medicaid and Medicaid HCBS for their health, independence, and well-being. For more information, please contact Maynard Friesz, Vice President for Policy and Advocacy at Cure SMA, at maynard.friesz@curesma.org or 202-871-8004.

Sincerely,



A handwritten signature in black ink that reads "K. Hobby".

Kenneth Hobby
President
Cure SMA

A handwritten signature in black ink that reads "Maynard Friesz".

Maynard Friesz
Vice President of Policy & Advocacy
Cure SMA

ⁱ CMS Access and Managed Care Rules, Press Release Summary, 2023, <https://www.cms.gov/newsroom/fact-sheets/summary-cms-access-related-notices-proposed-rulemaking-ensuring-access-medicare-services-cms-2442-p>

ⁱⁱ CMS Access Rule, Federal Register, 2023; <https://www.federalregister.gov/public-inspection/2023-08959/medicaid-program-ensuring-access-to-medicare-services>

ⁱⁱⁱ Cure SMA 2023 State of SMA Report, 2023, <https://www.curesma.org/state-of-sma-report-2022/>

^{iv} CMS Access Rule, Federal Register, 2023 (Page 1); <https://www.federalregister.gov/public-inspection/2023-08959/medicaid-program-ensuring-access-to-medicare-services>

^v CMS Access Rule, Federal Register, 2023 (Page 23); <https://www.federalregister.gov/public-inspection/2023-08959/medicaid-program-ensuring-access-to-medicare-services>

^{vi} CMS Access Rule, Federal Register, 2023 (Page 5); <https://www.federalregister.gov/public-inspection/2023-08959/medicaid-program-ensuring-access-to-medicare-services>

^{vii} CMS Access Rule, Federal Register, 2023 (Page 13); <https://www.federalregister.gov/public-inspection/2023-08959/medicaid-program-ensuring-access-to-medicare-services>