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July 20, 2023

Office of Fair Housing and Equal Opportunity
U.S. Department of Housing and Urban Development
7th Street SW
Washington, DC 20024

Re: Requests for Comments on Updates to HUD's Section 504 Regulations

Dear Office of Fair Housing and Equal Opportunity,

As the leading national organization representing individuals with spinal muscular atrophy (SMA), **Cure SMA is pleased to comment on why it is important for the U.S. Department of Housing and Urban Development (HUD) to update its Section 504 regulations.** In summary, individuals with SMA often feel discriminated against during the process of acquiring accessible housing, and this difficulty can lead to the institutionalization of individuals with SMA. Additionally, current housing accessibility requirements do not go far enough to ensure units and housing facilities are truly accessible to all.

SMA is a rare degenerative neuromuscular disease that robs individuals of their physical strength, greatly impacting their ability to walk, sit without support, transfer independently, and perform other essential functions of everyday life. Daily living tasks, including getting out of bed, bathing, cooking, and toileting, require adaptations or assistance. The ability to perform these tasks often depends on the accessibility of each individual's home environment and available equipment.

CURE SMA RESPONSE TO THE FOLLOWING HUD QUESTIONS:

- **Are there specific examples of discrimination that individuals with physical disabilities have experienced, or other challenges faced by such individuals, in securing affordable housing?**
- **To what extent are individuals with disabilities at serious risk of entering institutional settings or being unable to transition from institutional settings because they are unable to find affordable, accessible, and integrated housing opportunities in community-based settings?**

Most individuals with SMA depend on a wheelchair, scooter, or other mobility device. However, finding housing with accessible ramps, door openers, wider doorways, and other features that can accommodate these devices is extremely difficult. These difficulties often leave individuals with SMA to feel discriminated against during the process of acquiring housing. Cure SMA surveyed individuals on their housing experiences. **A mother of a child with SMA** shared *"When we were searching for a new home, the home builder refused to do any ADA modifications."*



This lack of accessible housing—along with barriers in accessing skilled caregivers—holds many individuals with disabilities back from living independent lives, requiring them to live with a parent long into adulthood or leaving them at risk of entering an institutional setting. One **SMA family member** shared *“While we have kept our daughter out of a nursing home, this is likely her near future.”*

A lack of affordable accessible housing forced **an adult with SMA from Rochester, NY** into an extended institutionalization situation when he was 15. *“I was told I would only have to be there for a month, I ended up living there for 5 years, 10 months, and 5 days”*. After years of waiting, he finally secured Section 8 housing. However, his apartment had significant barriers, including a bathroom that was too small to accommodate his power wheelchair and that lacked an accessible shower.

CURE SMA RESPONSE TO THE FOLLOWING HUD QUESTIONS:

- **What challenges do households face in finding available affordable and accessible housing in their respective communities?**
- **To what extent does the lack of accessible units and other facilities in assisted housing discourage applications from eligible persons with a disability?**
- **To what extent is the lack of accessibility a barrier to the participation in various HUD-assisted housing programs by persons with a disability?**

The search for accessible housing often leaves many individuals with SMA and their families feeling helpless. *“My niece and her son were in the shelter system because it was difficult to secure a wheelchair accessible apartment,”* said a **SMA family member**. Another **adult with SMA from Los Angeles, CA** shared *“When it comes to accessibility, housing is not fair or affordable. In order for me to find accessible housing, I’m paying about \$1000 more on average monthly in comparison to my friends because I have very limited options for accessibility and usually, they’re modern, more expensive buildings.”* Additionally, accessible units are often hard to find, as currently it is not required that each apartment complex or housing website indicate if a unit is accessible.

CURE SMA RESPONSE TO THE FOLLOWING HUD QUESTIONS:

- **What barriers do individuals with disabilities face in public and common use areas of housing and non-housing facilities?**
- **What accessibility features or advanced technology can help overcome these barriers?**
- **To what extent does the failure to maintain accessible features, including elevators and lifts, limit individuals with disabilities access to affordable housing?**



In Cure SMA's recent survey, individuals and families with SMA shared what adaptations would make their homes more functional beyond current design requirements. **An adult with SMA** shared *"A smart lock on the front door that allows me a way to unlock the door with a phone or scan card instead of a key, paired with an automatic door opener, would help me to enter their front door independently."* Other recommended accessibility features for housing units were hardwood or laminate flooring throughout the unit, no doorway transitions between rooms, a taller toilet, roll-in shower, lower kitchen cabinets and counters, and roll under kitchen prep station. The requirement for accessible housing needs to go beyond just the residential unit. Every feature at a residential complex should be accessible for people with SMA and other disabilities. Individuals with disabilities should have easy access to laundry facilities, with enough space around laundry units to navigate, and at least one washer and one dryer that is front loading and at a lowered height. Mailboxes for accessible units need to be at a lowered height, and any package room should be accessible and kept clean so individuals can access it. Many individuals with SMA shared that they frequently had difficulties finding accessible parking near their building's entrance, making it difficult for them to park an accessible van with a side ramp. Lastly, if a property has a pool, it should include an accessible pool lift for residents to access.

When a building fails to maintain accessible features, such as an elevator or lift, people with disabilities are left stranded. Elevator outages have left adults with SMA unable to leave the building to attend work, buy groceries, and participate in daily activities. **An adult with SMA** shared *"I was once stranded outside my apartment for 15 hours, and I am in constant fear of an elevator outage happening again."* Accessibility features are lifelines for people with disabilities, making it essential that these features are operational, and their maintenance and repair needs must be prioritized.

CURE SMA FINAL COMMENTS

Long after the implementation of Section 504 of the Rehabilitation Act, there remains an ongoing need for affordable, accessible, safe, and integrated housing opportunities for individuals with SMA and other disabilities. The 504 regulations have not been significantly updated since 1988¹, and now require significant changes to ensure that individuals with SMA and other disabilities can maintain their independence and participate in daily life.

Thank you for the opportunity to share the housing challenges of people with SMA and their recommendations for updating HUD's Section 504 regulations. For more information, please contact Maynard Friesz, Vice President for Policy and Advocacy at

¹ A Proposed Rule by the Housing and Urban Development Department, April 2023, <https://www.federalregister.gov/documents/2023/04/25/2023-08464/nondiscrimination-on-the-basis-of-disability-updates-to-huds-section-504-regulations>



Cure SMA, at maynard.friesz@curesma.org or 202-871-8004, or Sarah Bellish, Cure SMA Policy and Advocacy Manager, at sarah.bellish@curesma.org or 202-871-8005.

Sincerely,

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

Maynard Friesz
Vice President of Policy & Advocacy
Cure SMA

A handwritten signature in black ink that reads "Sarah Bellish".

Sarah Bellish
Manager, Policy & Advocacy
Cure SMA