



600 13TH ST., NW, SUITE 500  
WASHINGTON, DC 20005  
p | 202-753-5500  
f | 202-347-5147

16011 COLLEGE BLVD., SUITE 250  
LENEXA, KS 66219  
p | 913-262-1436  
f | 913-262-1575

[WWW.CHILDRENSHOSPITALS.ORG](http://WWW.CHILDRENSHOSPITALS.ORG)

November 13, 2023

The Honorable Melanie Fontes Ranier  
Director  
Office of Civil Rights  
U.S. Department of Health and Human Services  
200 Independence Avenue SW  
Washington, DC 20201  
Attention: 0945-AA15

**Re: Discrimination on the Basis of Disability in Health and Human Service Programs or Activities**

On behalf of more than 200 children's hospitals across the country, the Children's Hospital Association (CHA) appreciates the opportunity to provide comments on the Office of Civil Rights' Discrimination on the Basis of Disability proposed rule. The proposed updates to Section 504 are critical in ensuring that children with disabilities do not face any discrimination by any health and human service programs. Children's hospitals care for many children with disabilities, many of whom have special health needs and complex medical conditions. We believe that equitable access to health care and human services, regardless of disability, is critical in promoting positive health outcomes for all children. Therefore, we appreciate the opportunity to provide comments on this proposed rule.

Children's hospitals are dedicated to the health and well-being of our nation's children. We are regional centers for children's health, providing highly specialized pediatric care across large geographic areas. Although they account for less than 5% of hospitals in the United States, children's hospitals care for almost one-half of children admitted to hospitals. Children's hospitals provide highly specialized and complex care, especially to many children with physical and mental disabilities, special health care needs and complex health conditions.

Our comments focus on the importance of children with disabilities being placed in the most integrated setting when receiving long-term supports and services. This is important for these children to remain with their families as they receive healthcare services, allowing them to grow up as a part of their communities. Our more detailed comments are below.

**The Most Integrated Setting for Children with Disabilities (§ 84.76)**

We recognize the importance of ensuring that children with disabilities have access to the most integrated setting appropriate to their needs. Institutionalization should not be the first option for children and when able, children should be able to receive the long-term care and services they need within their homes to remain with their families and be a part of their communities. HCBS services for children with disabilities include private duty nursing, attendant care, assistive technology, non-medical transportation, case management services, habilitative services, etc.

Children covered under Medicaid are more likely to be low-income and have more complex disabilities, making access to HCBS services even more critical. Medicaid is the primary payer of HCBS in the United States and plays a significant role in providing these services to children with disabilities. The Early and Periodic Screening, Diagnostic

and Treatment (EPSDT) benefit under Medicaid requires medically necessary services to be covered for children with disabilities enrolled in Medicaid, including HCBS. States also implement waiver programs that provide coverage for services that are not otherwise available through the Medicaid program (including EPSDT). Waivers are an important lever for states to implement and expand access to HCBS for children with disabilities. Waivers and EPSDT are often used together to provide a comprehensive benefit for children with disabilities who would otherwise need the level of care provided in an institutional setting. This enables those children to remain in their homes and communities while receiving medically necessary services and supports.

However, to ensure that states are able to provide adequate HCBS through these pathways, investments must be made into the broader HCBS infrastructure. This is especially important to address in Medicaid since many children have both Medicaid and private insurance coverage, but only receive coverage for HCBS services through their Medicaid benefits. In private insurance, HCBS coverage is often times inadequate and unaffordable, or not covered at all.

Major issues exist in the HCBS infrastructure that place barriers to children with disabilities in accessing timely HCBS care. Long waiting lists prevent children and their families from receiving HCBS services when needed, increasing the risk of children with disabilities being institutionalized. Workforce issues such as payment adequacy and career development must be addressed for health care and personal care services, including private duty nursing. There is also a need for additional investments in information systems, with children's hospitals reporting that the highest quality and reliable providers in their states are the ones that invest in information systems.

A lack of accessible HCBS for children with disabilities has a direct impact on children's hospitals, who treat many of these children. An inadequate HCBS system reduces the ability for children's hospitals to be able to discharge children to integrated settings, such as referring them to community-based health care providers. This could potentially lead to children being institutionalized after their inpatient care, with no other options available.

The need for HCBS is more important now than ever, with the present youth mental health crisis causing the number of children with mental health challenges and disabilities to increase significantly. Children's hospitals' emergency departments (EDs) are overwhelmed by the number of children presenting with exacerbated mental health issues, many of whom may have a mental disability. A lack of HCBS services outside of these hospitals are affecting the number of children showing up to children's hospitals EDs, also causing these hospitals issues with where to direct these children after they are discharged.

The following investments should be made to strengthen access to HCBS for children with disabilities:

- Additional supports in the HCBS workforce to address widespread workforce shortages and improve recruitment and retention, especially for direct care workers. This is especially critical now as provider infrastructure has declined even more as a result of the COVID-19 pandemic.
- Increased investments in provider payment rates for HCBS services to support community-based providers. Federal funding provided by the American Rescue Plan Act (ARPA) has assisted states in raising rates temporarily, but with this funding expiring soon, states will need more sustainable supports to maintain increased rates.
- Infrastructure investments for state information systems, to improve incident reporting, case management, and health information facilitation.

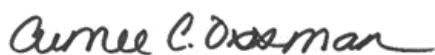
Placing children with disabilities in the most integrated setting is also important for children in the child welfare system, particularly those with intellectual and developmental disabilities. Congregate care should not be the first choice for placement of children with disabilities in the child welfare system, however, additional supports in the child welfare infrastructure are necessary to reduce institutionalization.

The youth mental health crisis has also exacerbated issues with children in the child welfare system seeking mental health care at children's hospitals. These hospitals continue to face challenges with where to direct children after discharge, with a lack of therapeutic community-based or family-based placements available. Major reforms and investments must be implemented to remedy this issue. Workforce and funding investments are needed to increase the amount of community-based therapeutic options available, as an alternative to institutional care. In addition, investments in respite care for parents, caregivers and other guardians in home placement settings are critical in keeping children with disabilities in home settings for longer.

With federal pandemic relief funding expiring soon, it is critical that sustainable solutions are implemented to bolster the infrastructure for both HCBS and the child welfare system for children with disabilities. Having additional accessible HCBS services for these children will promote their ability to be placed into the most integrated setting possible and improve their overall health outcomes. Similarly, children with disabilities in the child welfare system should not be unnecessarily segregated from their communities and should have the option to be able to return to or remain in family homes where they are more likely to have improved clinical and functional outcomes. This would also assist children's hospitals in their ability to comply with section 504's integration mandate, allowing them to discharge children to community-based providers and services when possible and therefore reduce unnecessary institutionalization.

We thank you for the opportunity to provide comments and look forward to continuing to work with you to improve access to care for children with disabilities. Please contact Milena Berhane at [milena.berhane@childrenshospitals.org](mailto:milena.berhane@childrenshospitals.org) or (202)753-5521 should you need more information.

Sincerely,



Aimee Ossman  
Vice President, Policy  
Children's Hospital Association