November 13, 2023

RE: Discrimination on the Basis of Disability in Health and Human Service Programs or Activities Citation: 88 FR 63392; OCR–2023–0013; Doc. Number 2023-19149

To Whom it may Concern:

Thank you for the opportunity to provide important comments on the proposed rulemaking for Section 504 of the Rehabilitation Act of 1973. The Missouri Developmental Disabilities Council (MODDC) is comprised of self-advocates, family members and state department representatives that engage with the lived experiences of Missourians with disabilities and their families, and creates projects and initiatives for systems change. **The prohibition of discrimination and exclusion based on disability status is at the core of the work of MODDC.** Further, the efforts to update the rulemaking for Section 504 to align more clearly with Title II of the ADA will defragment our judicial system when it comes to delivering justice to individuals with disabilities.

The Council supports the proposed changes; both non-substantive clarifying edits and more substantive interpretations, in creating a more equitable experience for people with disabilities. The protections created in medical treatment, child welfare, web and mobile accessibility, accessible medical equipment and Home and Community Based Services (HCBS) are responsive to the lived experiences of people with disabilities in a way that will create meaningful change. Specifically, the definition of, "the most integrated setting" includes the level of detail necessary to accurately reflect the desire of Missourians to be maximally integrated into their communities and to enforce the Olmstead decision in all aspects of a person's life.

There are a few areas in the proposal where specific questions were asked that the Council would like to address:

Medical Treatment

The detailed clarifications that will prevent discrimination for people with disabilities in healthcare settings will provide better health outcomes for individuals with disabilities. As a state and society, we must acknowledge that people with disabilities have the right to be full, equal and valued members of their communities, free from abuse, neglect, and exploitation of all kinds, and the right to be treated with the dignity and respect afforded to all citizens.

In the public notice, Medical Treatment Question 4 stated, *"The Department seeks comment from all stakeholders on the risks and benefits of the proposed regulatory choices that the Department has put forth in this section."* While significant and impactful improvements are made in the clarifications of applying Section 504, there is still significant risk to individuals that are placed under over-restrictive and unnecessary guardianships. § 84.56(c)(2) provides the clarification that. "...the denial of treatment to an individual because of lack of consent to treatment cannot violate § 504." The Council urges the Department to consider how to distinguish medical cases and decisions that center the decision of the person with a disability, in this case the Ward, as much as possible. The risks of the absolute discretion and power of the Guardian in medical settings rendering useless that important protections of Section 504, is a slippery slope.

Child Welfare System

Adding the new § 84.60 to the section 504 regulation will dismantle disproportionate oppression and victimization of both adults and children with disabilities. The important distinction for parents and children with disabilities in the child welfare system are profound in dispelling discrimination and building into our judicial system a new culture of equity for people with disabilities.

In this section, research was cited that, "...intellectual functioning range often was considered and relied upon by the court in upholding the decision... the courts consistently considered parental IQ, rarely reviewed evaluation methods and results and frequently made statements that reflected a view of parental IQ as static, fixed and necessarily undermining of parenting capacity and ability to learn.[163]"

While this section creates protections limiting the circumstances when a parent's disability could be a basis for the denial of parental access to their child, it would be beneficial to specifically create stronger guidelines for the use of a Guardian Ad Litem in these cases. In Missouri, a judge can appoint a GAL in adult cases to act "the best interest of" the person. At that point, there is immediately another barrier in place, much like in the full guardianship system, that render the person or ward voiceless with little recourse to advocate for themselves effectively. Challenging the ease of the courts to implement GALs purely on the basis of disability will be a crucial piece of achieving the civil rights measures intended in these rules.

Thank you again for the impactful work create systems change for people with disabilities and their families. MODDC appreciates the opportunity to partner with HHS in their efforts to update a strengthen systems that will empower choice and equality for people with disabilities.

Sincerely,

Vicky Davidson

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Executive Director, MODDC