



**Robert G. (Bob) Bethell Joint Committee on Home and Community
Based Services and KanCare Oversight**

October 3rd, 2023

Madam Chair and Members of the Committee:

On behalf of the Kansas Council on Developmental Disabilities (KCDD), thank you for the opportunity to provide testimony to the Joint Committee. KCDD's mission is to empower individuals with intellectual and developmental disabilities (I/DD) and their families to lead systems change, build capacity, and advocate for inclusive, integrated, accessible communities where everyone belongs and thrives throughout our state. KCDD is made up of self-advocates, family members, state agencies, and other partners from around Kansas.

The Council applauds the leadership of this Committee and appreciates KDADS ongoing efforts to engage stakeholders and improve the I/DD service system in Kansas.

Kansans with I/DD, Kansas families, and our state's caregivers are faced with an ongoing crisis the disability community has never faced - the state's longest I/DD waitlist and waittime, a disability workforce in crisis and inequitable funding of supports and services for those who choose to self-direct their services.

In the state of Kansas, approximately 5,100 people with I/DD are waiting for life sustaining services such as in-home care, day-service programs, and specialized medical care. The average wait time on the Kansas Waiver Waitlist is 10 years; and even after waiting for more than a decade, an individual with I/DD still may not be able to find a Direct Support Professional (DSP) to facilitate the in-home care due to staffing shortages and lack of rate parity amongst those who choose self-direct services and provider agencies. In rural areas and underserved populations in Kansas, these issues are exacerbated.

In order to better serve Kansans with I/DD, their families, and our state's caregivers, we must find a solution for the ongoing crisis related directly to our Kansas' Waiver, Workforce & Wages all while offering self-advocates, families and caregivers more choice and self-direction.

Specifically, our testimony will focus on the following:

1. Eliminating the I/DD Waitlist in Kansas

As we mentioned above, the Kansas I/DD Waitlist has reached an all time high. These numbers continue to grow and directly impact our entire I/DD system, Kansas families, and most importantly, Kansans with I/DD. KCDD believes we need a clear, proactive direction and strategy to reduce growth, allocate the necessary resources to fund a reasonable amount of slots per year, and ensure KDADS has the resources it needs to better serve and support our I/DD population throughout Kansas.

The Council's top priority is to fund, staff and eliminate the I/DD Waitlist. ***We are requesting that***

¹<https://ici-s.umn.edu/files/QpgFykE-Rj/2020-ny-sds-self-direction-report?preferredLocale=en-US>

Governor Kelly, KDADS leadership, and our Kansas Legislature allocate funding for new waiver slots to reduce the waiting list by 20% in 2024. It has been ten years, under the Brownback Administration, since we have seen a significant increase in funding for slots and Kansans with I/DD cannot afford to wait any longer for services. We increasingly see a number of individuals with I/DD who are not entering the service delivery system via the waiting list, but rather through the crisis exception process. KCDD believes it is vitally important that key stakeholders work together to increase funding for additional waiver slots in order to give people with disabilities and their families the services they need and deserve.

In addition to increasing waiver slots, we encourage the implementation of the Community Supports Waiver as soon as possible. This new waiver, in combination with increased spots on the existing waiver, is needed to begin the process of reducing the burden on individuals and their families who have endured a decade-long wait time for services.

2. The Kansas Disability Workforce Needs

We must also address the workforce, talent pipeline and career pathway for individuals who dedicate their lives to serving, supporting, and caregiving for our population. In January of 2023, the Kansas University Research Center conducted a study on how the pandemic affected Medicaid-funded Home and Community-Based Services.

“They found worker shortages, low wages and increased employer responsibility placed on consumers contributed to unmet care needs, stress and negative health outcomes.”

To address this need, we must start with increasing and enhancing the rates that will attract, retain, and create a better career path for all professionals and providers, as well as entities supporting our community. KCDD will continue to advance and advocate for new, innovative solutions that modernize our disability workforce in Kansas. For example, amending our waiver to allow for paid-family caregivers. We commend KDADS leadership for already initiating steps to adopt this change for Kansans with IDD, family members and caregivers.

3. Moving Toward Self-Direction & Choice

The direct care workforce crisis impacts all providers across Kansas both large and small; this crisis, however, impacts Kansans with disabilities and their families who choose to self-direct their services the most. Kansans with I/DD who wish to self-direct their services often utilize one on one supports and services; while provider settings typically take place in a group setting (e.g. 3:1 staffing ratios). Providing supports with a higher reimbursement rate and higher staffing ratios means that providers can offer workers a higher base pay (with benefits) than a person self-directing their supports, severely cutting into the limited available pool of direct care professionals.

Evidence demonstrates that self-direction provides more choice and greater control for individuals with disabilities and their closest supporters such as family members and caregivers. KCDD looks forward to working toward a future support system in Kansas that offers new and better incentives, self-direction and choice for individuals with I/DD (and their families) in Kansas.

Additionally, we look forward to building upon the 2022 I/DD Modernization Committee's recommendation to provide the option for families to utilize Individualized Budget Authority to

² <https://stateofthestates.org/wp-content/uploads/documents/Kansas.pdf>

³ <https://stateofthestates.org/wp-content/uploads/documents/UnitedStates.pdf>

self-direct their supports and services in Kansas. ***The cornerstone of both self-direction and Individualized Budget Authority is to maximize an individual's opportunities to live independently in the most integrated community-based setting of his or her choice.***

Our KCDD Action & Investment for Kansas

Our Council is also taking significant steps to ensure Kansas not only addresses the key components mentioned above, but also enhances public-private partnerships to improve the quality of life, health outcomes and ensure every individual with I/DD has better access to supports and services throughout every corner of our state.

Next month, KCDD will be launching a new effort to prepare for the future public health and healthcare challenges of our community in order to vastly improve the health, supports and the wellbeing of people with disabilities in Kansas. This ground-breaking endeavor will be supported by a diverse set of stakeholders, self-advocates, families, caregivers as well as healthcare professionals, researchers and providers aimed at developing a new blueprint and approach to improving health outcomes and ensure our healthcare systems in Kansas better serve and care for our I/DD population throughout our urban, suburban and rural communities. Our KCDD leadership looks forward to keeping this important joint committee apprised of our critical work ahead.

KCDD is seeking to address public health challenges to improve supports and wellbeing of people with IDD through a new Health Equity and Outcomes coalition set to launch on November 8th, 2023. This coalition invites stakeholders, self-advocates, providers, and researchers to convene to develop a new approach to:

- a. Increase the quality of life and life expectancy of all Kansans with I/DD
- b. Improve medical care access, expertise and training across all healthcare professionals and speciality areas
- c. Address access issues as well as supports, services and disability-related benefits across Kansas' rural, urban and suburban communities
- d. Address disparities in health and healthcare delivery across our state for the entire IDD population
- e. Enhance the workforce and establish a formal career ladder in Kansas for professionals, direct support providers (DSP), healthcare providers, etc. who support and work with the IDD community

Thank you, again, for your ongoing leadership addressing the needs of Kansans with I/DD. The Council looks forward to working with members of this committee as we continue to make progress for Kansans with I/DD.

Sincerely,

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² <https://stateofthestates.org/wp-content/uploads/documents/Kansas.pdf>

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