

Jawanda Mast

Testimony for the House Social Services Budget Committee

Thursday, January 30, 2025

Chair David Buehler and Members of the House Social Services Budget Committee,

Good afternoon. My name is Jawanda Mast, and I am a parent, advocate, and passionate supporter of positive reforms in the intellectual and developmental disabilities (I/DD) system. As the mother of an adult daughter with Down syndrome, I have spent over two decades advocating for policies that empower individuals with I/DD to live fulfilling, inclusive lives.

Today, I am here to address two critical points:

1. To ask the Legislature not to “slow down” the long-overdue reforms that are finally happening in Kansas’ I/DD system.
2. To urge this Budget Committee to remove the proviso placing a redundant \$20,000 cap on the Community Supports (CS) Waiver.

Do Not “Slow Down” I/DD Reforms

For more than a decade, parents like me, alongside advocates and experts, have pushed for transformative changes in the I/DD system. Some of these changes include:

- Eliminating the demeaning and outdated BASIS assessment,
- Fully implementing the Final Settings Rule to move Medicaid away from funding segregated environments and toward Competitive Integrated Employment (CIE), and
- Ensuring case management services are free from conflicts of interest.

Contrary to what some may claim, these changes are not happening “too fast.” In fact, they are long overdue. CMS issued the HCBS Settings Rule nearly **11 years ago**, signaling the need to move away from segregated, non-competitive environments like sheltered workshops. Kansas has been slow to act, and CMS has now placed the state on a corrective action plan. Failure to implement these changes could jeopardize all HCBS Waivers, including the new CS Waiver.

Even without federal mandates, these reforms are the right thing to do. They reflect the principles of dignity, inclusion, and opportunity that so many of us have fought to uphold for years. Slowing down these reforms would disregard the tireless efforts of parents, advocates, and individuals with I/DD who have been waiting far too long for meaningful progress.

I am among many who have advocated for many years to pass ABLÉ legislation as a means of empowering individuals with I/DD to live independent and inclusive lives. From helping Kansas implement ABLÉ accounts to advocating for competitive employment opportunities, my focus has always been on creating a system that uplifts and includes everyone. If you were here nine years ago, you may have heard my then sophomore in high school daughter Rachel’s ABLÉ Savings Act testimony where she talked about living her dreams, most memorably living in a pink house. We advocated for eight years to pass the federal ABLÉ Act because



we want Rachel and others with I/DD to live their dreams. One of the proudest moments in our life was when she opened the first Kansas ABLE Savings Account on January 26, 2017. ABLE has been one more step toward financial empowerment and her dreams of independent living.

But there is so much more.

The BASIS assessment must be eliminated. It is not evidence-based and does a disservice to Kansans with I/DD. My daughter Rachel is working today at the University of Kansas Hospital, but she has testified before legislative committees on several occasions. Rachel gave powerful video testimony before the IDD modernization committee that played an important role in changes, such as eliminating the outdated and disrespectful BASIS assessment and the creation of the CS Waiver. During one BASIS assessment, my daughter started sobbing when a man she didn't even know ask if she smeared feces on the wall. There are many very personal questions on the BASIS that a young woman with Down syndrome should not be discussing with someone she does not know. Now, if you bring up the BASIS, she gets a nervous look and begins talking to herself to relieve her anxiety.

I hope you will take the time to listen to her two-minute testimony at [Rachel Mast IDD Modernization Committee Testimony \(https://youtu.be/Xm3fPNCCMW8\)](https://youtu.be/Xm3fPNCCMW8). There were other similar testimonies. We need to move forward with evidence-based assessments that respect the dignity of individuals. I urge you to let these reforms proceed without interference. Slowing them down would not only be counterproductive but a disservice to families like mine who have spent years advocating for this progress.

Remove the Proviso Placing a Second \$20,000 Cap on the Community Supports Waiver

The Community Supports (CS) Waiver, set to launch in FY26, will be part of Managed Care in Kansas. As such, it already has a built-in financial cap through the per-member/per-month rate paid to Managed Care Organizations (MCOs). Adding a second \$20,000 cap in the budget proviso is unnecessary, counterproductive, and harmful.

This additional cap creates several problems:

1. **Discourages Enrollment:** Families may avoid signing up for the CS Waiver due to the added cap, leading more individuals to remain on the comprehensive I/DD Waiver, which is far more expensive for taxpayers.
2. **Creates Unintended Consequences:** Families may initially enroll in the CS Waiver but face devastating cuts to services if their needs exceed the \$20,000 cap in subsequent years. This will force many to move back to the comprehensive waiver, increasing costs.
3. **Caps on Caps:** The second cap is redundant and unnecessary, as the per-member/per-month rate already limits the state's financial liability.

For example, imagine a family whose loved one's care plan costs \$19,000 in the first year but increases to \$25,000 in the second year due to changing needs. The secondary cap would force a 20% reduction in their services, causing significant harm to the individual. Alternatively, the family might choose to move to the comprehensive waiver, which would cost the state significantly more. The \$20,000 cap in the proviso is not only redundant but will also harm individuals with I/DD and increase costs for Kansas taxpayers. I strongly urge you to remove it.

Case Management Conflicts

Concerns about conflicts of interest with case management have also been around for many years. If I understand correctly, CMS is also requiring this change, so having the Kansas legislature “slow down” this change will only cause more problems for Kansans with disabilities.

Conclusion

These are pivotal times for the I/DD system in Kansas. Let’s not jeopardize the progress that so many of us have worked tirelessly to achieve. I ask you to:

1. Allow the long-overdue reforms in the I/DD system to proceed without delay. Get rid of the BASIS as planned and agreed upon.
2. Remove the unnecessary secondary cap on the CS Waiver to prevent harm to individuals and avoid higher costs for taxpayers.
3. Move forward with the proposed conflict of interest changes required by CMS.

Individuals with disabilities, their family members, and others who love and support them are weary. We spend years advocating for changes and once approved we spend more years waiting for implementation. The time is now to forge ahead with these long-agreed-upon, required, and necessary improvements to our systems. We have waited long enough.

Thank you for your time and attention to these critical issues. I am happy to answer any questions at the appropriate time.

Submitted by,

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