

Testimony HB1012
House Appropriations Human Services Division
1/27/2025

Chairman Representative Jon Nelson and Members of the House Appropriations Committee ;
Human Services Division,

Thank you for taking my testimony regarding Medicaid, 1915i and the DD waiver.

While we live across the border in Audubon, MN, our two adult children live in Fargo & West Fargo ND. My husband and I are guardians of both of them, adopted through ND foster care in Cass County, ND in 1998 and 2003.

When our children moved back over to ND, we were used to the system in MN, as our son had been on a DD waiver in MN. We were completely unprepared for the difficulty & roadblocks of the ND application system and its call center in ND. The SSP is cumbersome, impractical, incomplete, and all around hard to use. The system that you have now have instated where you contact a "call center" and someone wholly unfamiliar with your case tries to help you - instead of keeping it to your local human service zone, and having ONE case worker work your case, is ill-considered and is not working for those in need in ND, their families or the eligibility workers trying to help us.

We have been working with the ND portal/HHS system for about the past 16 months since we have a son on the DD Waiver and a daughter who is on the 1915i program and both are on Medicaid. We have expressed our frustration to their workers, and to Vicki Peterson from Family Voices of ND who is gathering information from everyone on their experience with the system. We have also expressed our frustration to eligibility workers and the acting head of 1915i, Mandy Dendy.

It would be too long to tell you all the details of what we've experienced so we will try to summarize just some of my experiences with the below bullet points.

- It took us a total of 6 months to be approved for medicaid for our intellectually disabled son - but a full 126 days to be approved for WWD Medicaid as nobody seemed to understand the type of Medicaid he qualified for (and there is nothing on the SSP that explains or gives a choice for WWD.) So we applied for the wrong type, he was denied, and then reapplied for WWD, (the call center was so unhelpful and didn't offer solutions during this time, nor were they aware of WWD or how it worked and never suggested it as an option for us). He went 3.5 months without any services in Fargo due to nobody understanding the issue. Finally after much work by myself & his DDPM, RSI in Minot had to step in and let us know he needed to apply for WWD, so we did and were finally approved.
- My son is Native American, and I just found out this week that if you are in an enrolled tribe (which he is) you do not have to pay the enrollment fee OR the monthly premium payments for WWD Medicaid. We've been paying WWD premiums since November of 2023. Even though we put his enrollment number on the initial application, they missed this and never told us it was even a policy. We just informed the call center

yesterday, who had to ask a supervisor if that is their policy, as the representative who answered did not know until she looked it up and called a supervisor. A supervisor called us yesterday and we are getting all his premiums reimbursed.

- We have made so many calls to the call center (way too many to document) and multiple times the phone representative did not know the answer to our question and we didn't learn for a while to ask for an "eligibility supervisor" or a "supervisor review." Nobody mentioned we could, and we would end the call feeling frustrated. Many times we would be on hold for an hour.
- It took 6+ months for a LIHEAP check to arrive for my daughter due to a series of errors on both my daughter's part (losing the check) and on the part of ND (not reissuing the check and not knowing what happened to the paperwork). Countless calls finally led me to Peggy in Economic assistance, who was tracking this on her end, but it took the call center **at least 2 months of repeated calls to them asking where the check was** for someone to tell me to contact economic assistance, and another 2 months for the check to finally arrive in our hands.
- The SSP application system has confusing questions, is difficult at best to fill out, doesn't leave room for "notes" or exceptions to the questions we are answering. We have no disabilities yet we greatly struggle with the SSP. I don't feel anyone with special needs or disabilities could fill out and manage the portal, I know my kids could not have navigated it. Each time a new letter comes in, you have to download it to your computer to even read it. The system is frustrating at best.
- We have gotten notices that both of our kids' medicaid will be closed due to a technical and/or human error (this just happened for both of them last week). This should NEVER happen. My daughter lost her services for a time period due to these errors in 2024 and could not get her medication, all due to a computer error. Had a caseworker been assigned to this, it would not have happened.
- As far as 1915i, it would be better to be structured more like the DD Waiver. Having a DDPM who oversees all our son's services, and isn't only billing when she sees him, is an excellent policy. I think 1915i was meant to be similar, but I've had so many more issues with 1915i than the DD waiver, as I documented to Mandy Dendy in a long email. My daughter went through 7 workers in 8 months (some left their job, some we fired, some terminated her) - each time we had to fill in a new worker on my daughter's status and we lost valuable time helping my daughter. The housing support coordinator allowed her to become homeless as he was absolutely no help in finding her housing (he would "meet" with her to talk about life, do ice breakers, have coffee - not look at apartments and tell her where the no-income, low-income housing was. I believe it had to do with billing, he can "bill" when he is with the client so he met her once a week to "bill" but did not help her find housing).
- The next housing support assigned to my daughter did not want to work with **me** as a guardian, so they terminated my daughter's case "effective immediately" (against policy - a 30 day notice is required) and this happened **while she was homeless, all due to me asking clarifying questions on email & correcting the housing coordinator when she the details of the apartment were wrong. The housing coordinator didn't**

want to "deal with the guardian" (and didn't feel she should have to). This agency is no longer providing housing supports, and has been reprimanded for the way they terminated our daughter.

- The workers in 1915i are not being taught how to work with the guardians. As stated above, one agency terminated my daughter because I was assisting them in finding an apartment for her, and I've also had a supervisor question my involvement in my daughter's life. I take great offence at this as we have been her guardians for 9 years and all the responsibilities fall back on the guardian, not a worker who meets with them 1 hour per week. She is also in jeopardy of losing 1915i right now for not engaging with the care coordinator, peer support or housing support. There should be a period of time the case is always open and the client can engage as needed.

As it's set up - 1915i can only **bill** when they see the client - but my daughter is completely overwhelmed with all the appointments she needs to keep in order to stay eligible for the services. A supervisor keeps telling us, we can't "Bill" when we talk to you - the guardians - so please back off. And yet, we are responsible for our daughters well-being, care and daily needs.

- When losing her Care Coordinator and her Housing Support all at once, she became homeless and I became her "main coordinator" for a period of at least 6 weeks and have been acting as co-coordinator for 13 months now. **Yes, this is my choice, but had I not been a safety net to keep the services afloat (paperwork, calls, etc.), she would have fallen through each and every crack of 1915i as care coordinators / housing supports came and went.** I was able to find her a HUD apartment, applied for ND Housing Stability, made sure her benefits were still coming, and have worked hundreds of hours in 2024 helping my daughter who has mental illness, addiction issues and brain injury.
- My daughter was just determined disabled by SS and is now on SSDI so we are changing over from Medicaid Expansion to Traditional Medicaid. Her case is very complicated as she also had ND Housing Stability, and SNAP. A case worker was needed to work her case and get her annual renewal application approved. **An amazing, wonderful case worker was assigned to her case who thoroughly helped me and has agreed to stay with me through my transition to traditional medicare. I don't understand why the clients in ND cannot be assigned a caseworker who understands each case and can "work it" when there are issues. The complexity of the information she gave me regarding what my daughter was eligible for in the upcoming months (and the paperwork needed to accomplish it) was mind-boggling and having this gal on my team has given me so much hope that it will be done correctly. Each client in ND needs someone like this.**

We respectfully make the following recommendations:

PLEASE get rid of the current SSP system, & go back to each person having their own case worker and a local one from their human service zone so we can find help in time of need and not a "new worker" after being on hold for 1 - 2 hours at a call center.

We know this is what North Dakotans need and what eligibility workers want.

Please revamp 1915i, it's full of concerns and is inefficient in really helping the people that need it most (those with mental illness and behavioral issues, which is already a difficult population to work with).

Please train your workers more thoroughly, and hire call center personnel we can understand and will get to the bottom of an issue for us, or will find a supervisor who can.

Please give those experienced long-term eligibility workers bonuses, raises and recognition as they are the ones who really care that it is done right for the client and who put in the hours to help even when it's out of their scope (I have run into a few of these angles).

Consider embedding a policy maker in the life of someone who is on the Medicaid program. Follow them, walk through their annual review with them, ask how they like their programs, and if the programs are working, if they can navigate the SSP, how well they are receiving services from their care coordinators, & their agencies. Send out surveys to clients and their guardians asking these questions.

Note: This email is intended to help ND improve their SSP and processes for people applying for help. There have also been some amazing people who have helped along the way, who have pointed us in the right direction, who have bent over backwards to assist us in the past 16 months, for which we are grateful. We also very much appreciate our adult children's current care team, they are excellent people.

Thank you.

Lori & Jeff Kenney
Parents/Guardians
13696 County Highway 11
Audubon, MN 56511
701-238-8046 Lori
701-361-9534 Jeff