

Dear committee members,

As a group, organizations working on this bill reached out to the communities we serve and asked them to share the challenges they have faced and the barriers the system creates for them. This is a sampling of the feedback we received that we felt would be helpful for you in understanding why HF3896 is a necessary intervention at this time.

In addition to stories of access barriers we also received requests for assistance and advocacy and legal advice- for not just our state systems but also our federal disability systems. Our community exists in margins of red tape and paperwork, dependent on strangers deciding their life outcomes at every stage.

Please honor these stories and Minnesotans as we ask for your support to establish the accessibility task force and pilot programs. This task force will go a long way to ease the frustration and worry so many families and individuals are living with as they try to access necessary supports and services to care for loved ones and themselves.

The biggest disability challenges have been in providing comments on the word dense programs, applications etc related to disability services. Both case managers and supervisors also seem to want to say "no" every time we ask for anything needed because of my (also disabled and the actual recipient of services) son's specific disability.

Jane

Minneapolis

Hi I am an autistic adult who has tried two times to access waiver services and or PCA services. Early in the process I was told that nicollet county where I live does not participate in the consumer support grant program at all which could also be helpful to me. During my first attempt I did a full appeal of the decision with help from legal aid. However as recently as today in a discussion with my mental health case manager and my therapist I was told that waiver services are not appropriate for people who can physically perform activities like showering and that applying to go to grad school or getting a job would not be a reason that getting on a waiver would be appropriate. I know that I have gifts and abilities in contributing to my community and in supporting other disabled people through advocacy work but for me to engage in advocacy work I do need more support at home so that I can maintain my mental health and physical health. I also often feel disadvantaged or discriminated against for having access to mental health services before attempting to access waiver services because I had mental health diagnoses

before I had my autism diagnosis and because of that discrepancy I often get told that all of my symptoms and struggles are mental health issues only however we do know that autism is a developmental disability that affects people in a physical way as well. Additionally as a person diagnosed with autism as an adult I did not receive any of the important disability-related care and support that I needed as a child and it is very difficult for me to identify areas in which I can receive care and support now and because of this late diagnosis and early childhood neglect it is very hard for me to communicate areas of life in which I could receive support without hearing examples and stories from other autistic people with similar needs first.

Heidi Storm

Saint Peter, MN

The forms are hard to follow, they aren't accessible online, they give you such short turn around times (10 day) and often I don't even get it until day 8 or 9, the percentage for TEFRA is very high when there are so many expenses related to disabilities within the family, and trying to understand each different system for multiple family members is daunting, and then there are no staff available so I don't even get to access the support I'm paying for.

Anonymous

No ILS, no homemaker, no Mental Health case management after moving from a county where I had it for almost 20 years, asked if CSG was available since can't get any services I qualify for on my CADI waiver and was told the county doesn't even have it. Impossible to find mental health crisis resources that weren't over an hour away. No one to call with questions. No help.

Anonymous

Hello

My 11 year-old son has a dual diagnosis of ADHD and ASD. He is currently in 5th grade. He was diagnosed through U of MN when he was in kindergarten. After his initial diagnosis we explored services through Rice County.

We had the in-home visit with a social worker and my son was classified as disabled and eligible for services. We were assigned a county social worker and my son started to be invited to participate in respite activities, bowling, swimming, etc. Almost every time one of these opportunities came up we heard about it last minute. It would be the day before or maybe two days before the event. This made planning for him to participate hard. If we accepted the opportunity to go to the event it would cost us money because he was always signed up for after school care. So we had to decide between "wasting" money or sending him to a fun event.

We sat down with the social worker within the first year of our son being eligible for services and learned that we made too much money to access more services. If we chose to apply for MA or other insurance it was basically going to be all out of pocket expenses. This was not at all an option for our family financially. It was so frustrating and disappointing to learn that we make too much money to access county services/MA to help our son have more services. It is even more disappointing and shameful to be faced with the fact that you make too much money for support but not enough money to even consider accessing services that may help your child develop and flourish.

This experience with county services ended after about 2 years. The social worker for Rice County actually approached us about dropping the services. She felt that we were not getting much out of the minimal services we were eligible for and given the poor planning and scheduling we were not participating much. We agreed and so my son is no longer receiving any county support.

My wife and I both have college degrees and work full-time jobs. We do the best we can and our experience with county services was disappointing. We felt that to really have impactful services we would have to make no money or be unemployed. We are not "rich" but we get by. This middle ground is so frustrating because if we did not live within a good school district our son would not have made the progress he has. Northfield Public Schools is responsible for a huge part of the progress our son has made.

I would be happy to discuss this experience more if necessary.

Thank you
Chris
651-271-3687

Is anything truly accessible to disabled people? The system makes it extremely difficult to get any kind of help. If you don't have insurance or you have commercial insurance, ARMHS workers are impossible to afford. The cost of mobility devices and medical care are astronomical, even if a person has insurance. If you don't have the energy and resources to gather all the paperwork from your doctors (which the people who judge these cases ARE LEGALLY ALLOWED TO IGNORE) and hire a lawyer, you won't get Social Security assistance. It's

incredibly cruel to keep putting the burden of proof on disabled people! STOP GIVING ABLE BODIED PEOPLE THE AUTHORITY TO JUDGE WHETHER OR NOT DISABLED PEOPLE NEED ASSISTANCE!!!

Sarah

Minneapolis
