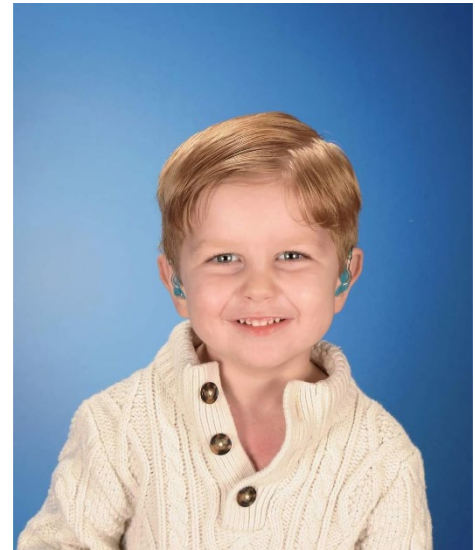


Senator John Hoffman,
Chair Senator Jim Abeler, Minority Leader
Members of the Human Services Committee
2111 Minnesota State Senate Building
Saint Paul, MN 55155
April 17th, 2024



Dear Chair Hoffman, Lead Abeler, and Members of the Senate Human Services Committee,

My name is Crystal Anderson and I've held many roles in the Human Services/Disabilities world including a direct support professional, Developmental Disabilities Social Worker, MnCHOICES Reassessor, CDCS Support Planner, and the most important role of all, a mother to the most adorable 3-year-old named Alexei, who has Cerebral Palsy and is also a part of the Deaf community.

As a family that receives CDCS waived services, I can tell you that this program is absolutely wonderful. It allows our family the flexibility to self-direct our services, hire caregivers that are known to our child and who we trust, use alternative therapies, sensory and adaptive equipment, and the list goes on and on. It truly is a wonderful option of the waivers.

Unfortunately, I can also tell you that as wonderful as this program is, it is also equally as broken. As a CDCS Support Planner, I have the privilege of helping families write their CDCS plans so they can take advantage of all the wonderful things I mentioned above. I also have the displeasure of receiving denials from Lead Agencies (counties) for items, services and equipment that have been previously approved in the person's plan, and that I've had approved in other counties prior. I see families that have made it all the way to receiving a waiver and the relief that they feel for getting that far (and it's a hard and tiring process) just to have them feel so defeated with denial after denial.

While I understand that Lead Agencies interpret the CDCS Manual created by DHS, this means that there are 87 different interpretations of what is considered approvable and non-approvable through CDCS. This is not only extremely frustrating for Support Planners in having to learn and retain what each of the 87 counties have interpreted, but for families as well. With the use of technology, families talk. Families connect and network and problem solve as a community, which is a great resource! But it also sets families up for disappointment and frustration when children with similar diagnoses and needs aren't afforded the same benefits/approvals, because they live in different counties. I have also had the same things denied in plans from the same county, but from different contracted agencies. The inconsistencies cause even more distrust with government services than already exists. It has become an "us versus them" mentality instead of what it should be: "What can we do to help this person as best we can?"

One example that I have of these inconsistencies is a denial that I recently received for Special Olympics. I have Special Olympics in dozens of plans that I write and have never been given a denial until this year, from a contracted case management agency, because it was “recreational.” This particular individual uses about 5% of her CDCS budget for several adaptive sports. She has done this for the last five years, without issue. Adaptive sports are her number one love, the thing that drives her, keeps her active, gives her peer connections, supports her mental health, and she even plays for an adaptive hockey team that is sponsored by the Minnesota Wild! This year, even after being requested to submit Alternative Treatment Forms signed by the participant’s primary care physician (even though adapted sports are not therapies; yet another county-to-county inconsistency), Special Olympics and Adaptive Hockey were denied. A direct neighboring county has this language, verbatim, in their interpreted version of the guidelines: “Examples when community activities may be allowed: Adapted activities, such as Special Olympics, Project Explore, Miracle League, etc.” Although participating in an adaptive sport may not seem like a big deal for some, it is to others. And when activities like this are approved for years and are suddenly denied because someone different is interpreting DHS’ guidelines differently than the person who reviewed the plan the year before them; we can do better. If that last part sounds confusing, it’s because it is.

Another example is the use of Personal Care Assistant (PCA) hours versus Support Staff hours. I have had counties deny Support Staff hours in a CDCS plan because they were “over the assessed PCA hours.” PCA is a completely separate program than a waiver (CDCS), and waived services cover more needs than PCA is able to. I’ve gotten this answer several times, and finally emailed DHS to inquire about it. I received a response from DHS about the difference in programs, and keep that email in my inbox, so I can forward it to counties when the imminent denials come again. I can’t imagine how many families have to lessen their support hours when they receive a denial, because they don’t have the energy to fight or appeal the decision. Some counties have even created worksheets that severely limit the number of hours that a parent can be paid for cares for their child. Even with the lifting of 40 hours per week for Paid Parents of Minors and Paid Spouse supports, some counties continue to deny the hours that are needed to support the participant. This both includes and excludes overtime for these positions. Some counties are still sticking to only approving hours up to the PCA assessed hours, what the Lead Agency/Case Manager thinks is “acceptable” for the Paid Parent/Spouse to work per week, etc. These revisions continue to get denied and families are having to jump through continuous hoops to be able to care for their loved ones. As a Paid Parent of a Minor, I can tell you that my CDCS budget will never fully support the hours that I actually work with my child and all of the additional cares that I attend to, due to his unique and additional needs. Parents and Spouses getting scrutinized and picked apart to identify every second of time they’re spending on cares is degrading and exacerbates the already difficult job that they have, and quite honestly these workers are so busy providing cares, they don’t have time for the red tape. I see so many families too defeated and tired to even go through the appeal process. And some families say they won’t appeal because they fear retaliation from the County.

Here are a few other notes to highlight the discrepancies between counties:

	Laundry Reimbursement	Internet	Snow removal/Chore
Ramsey	\$1000 max, \$10/load	\$20/mo; possibly more with justification	\$1900/year
Dakota	\$6/load, no max	\$40/mo	No max given
Washington	\$600 max, \$3.50/load	No max noted	No max given
Hennepin	No reimbursement	\$20/mo shared \$40/mo non-shared	\$1500/year
DesMoines Valley (Cottonwood and Jackson Counties)	No reimbursement	No reimbursement	\$1800/year; possibly more with justification
Anoka	\$250 max, .50/load	\$20 if shared	\$5000/household

I am asking that you support HF 4568/SF 4420 to contribute to the continuity of services and supports for families like mine, all across the state. With this improved legislation, all stakeholders will have a clearer understanding and definition of what can and cannot be approved, and take out the bias, judgment and grey areas that some workers may face while looking at CDCS supports and decision making for this life-changing program.

Respectfully,

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