SUMMARY OF TESTIMONY
Presented to Congressional Constituent Representatives During the Governor's Council on Developmental Disabilities Meeting

April 2, 2025, 9:30 am-11:30 am
The Masonic Institute for The Developing Brain
2025 East River Parkway
Minneapolis, Minnesota 55414

The meeting was called to order at 9:30 am by Chair, Lee Shervheim, who facilitated the Town Hall Meeting. This summary was prepared as a supplement to the official minutes posted on the Council's website. The minutes includes a list of Council members and guests in attendance. The staff members from ICI who attended this meeting appear at the end of this document.

Each person who testified was asked to review and approve the statements contained in this summary.

Bonnie Jean Smith

Thank you for your time.
I live in north Minneapolis.
I'm the proud parent of four young adults, one daughter, the eldest and three sons who learn on the autism spectrum, and they're all completely different.

You look at me and can see I am a Black American, but you cannot look at me and see my father was a Navy Seabee attached to the U.S. Airforce. He and my mother raised my siblings and myself a village in Toul Rosiere, France.
"Conversation is the key to life".
My father taught us, "there is good, bad and ugly in every race, every profession, every institutional structure made by human beings".

Last year, I was privileged to work on a federal court project that included US District Court judges, magistrate judges, the US Attorney's Office, attorneys from the Federal Bar Association, and several advocates like me. I am presenting you with a folder that contains copies of the banners that we produced.

I had nightmares about presenting today because of the backwards direction that we are headed as a nation, backwards to George Orwell's *Animal Farm*, backwards to how the Nazis treated people with disabilities. If you look at the folder, you will see how many years we've been waiting for all these rights that everybody thinks they can take for granted.

The opening line to *A Tale of Two Cities* by Charles Dickens came to mind. "It was the best of times and the worst of times." But if we look at it, it is always the best of times and the worst of times. the question is, what are we going to do with the times?

Life is both threat and promise; opportunity with opposition; opposition with opportunities.
Evil is always present, trying to undermine good.

Understanding this, we can set our minds to see what we could do with the time that we have. Instead of waiting for better times and better conditions.
Be the Salt and the Light in this Darkness.

Katie McDermott
I live in St Paul and have three cats. I like to give a little story about me, because that's what I do, and then I'll go into my issues. I live in the area that’s within walking distance of many stores and restaurants. Walking around Como Lake brings me joy. I work at The Arc Minnesota as a self-advocacy associate, and I just celebrated my ten-year anniversary. As a person with an intellectual disability this is a very big milestone for me.

I have several concerns about issues that are impacting the disability community. I have a CDCS waiver. I can choose my own staff and where my money goes. I get to control what the services are, however, there is a 30% disparity in funding levels between a CDCS waiver and a traditional disability waiver. Legislation must change to equalize funding between the CDCS and the traditional waivers. I'm also worried about the cuts to Medicaid funding. I receive MAEPD medical assistance for appointments with health care. I worry that I won't have the same access to these supports. If there are cuts to Medicaid, I don't know how I would pay out of pocket for my medical expenses. My CDCS waiver helps me live the life in the community. I'm very worried that these supports would be taken away or limited.

Cutting Medicaid would also impact other folks with disabilities and my nieces and nephews, too. My nieces and nephews aren't on waivers, but they are on Medical Assistance. I don't know how my sister would pay for every time they need to go to the doctor. I have eight nieces and nephews, and so they are on Medicaid, and my niece just had an MRI for her knee injury.

I'm asking you to support the policies and protect the important services and funds that people with disabilities use every day. I really appreciate all the work you do. I'm calling on you to support the policies that help provide for disability and human rights.

Sumukha Terakanambi
I'm 26 years old. I'm from Lakeville, Minnesota. I'm the Vice Chair of the Public Policy Committee and a self-advocate. When I was four years old, I was diagnosed with Duchenne Muscular Dystrophy, a progressive neuromuscular disease. Because of the rapid muscle weakness, which is a primary characteristic of the disease, I require assistance with most physical tasks. I also use a power wheelchair for mobility. Like anyone else, I desire to work, contribute to my community and live a fulfilling life within the community.

Medicaid, or Medical Assistance, as it is known in Minnesota, has had a tremendously positive impact on my life by providing me with support, I need to have in my day-to-day life. Medicaid is a vital lifeline. It covers prescription drugs to maintain my health, personal care assistance, transportation to get to work and out in the community, durable medical equipment, modifications to make my home more accessible and assistive technology to support my employment. These services have given me greater independence and have significantly improved my quality of life.

When I was getting my master’s degree in public policy, Medicaid services ensured I could complete my degree and access various opportunities by paying for assistance on campus and transportation to get to campus, as well as my internships. Without these services, the burden would have fallen to my parents to help me throughout the day, which would have made things much harder since both my parents were employed.

I have been very disappointed and deeply concerned to see the federal budget resolutions, which call for significant cuts to Medicaid. These ongoing developments and the level of uncertainty have caused a lot of stress and anxiety for me and many others in the disability community.

Any cuts being considered, including per capita caps and work reporting requirements would hurt people with disabilities like me by leading to a loss of coverage, reduction in benefits and restrictions on eligibility. Losing access to this program would cause immense hardship for me and my family. It would be a huge financial burden that would have detrimental impacts on my mental and physical health. Members of Congress must understand that Medicaid is the only option for people with disabilities to receive coverage for home and community-based services. These services enable people with disabilities to live independently in their communities, instead of more institutional settings. As a member of the Council, I want to be able to spend my time and energy on improving our disability services system, not defending the very existence of disability services. We as a community, cannot afford to go backwards. Instead, we need to build on the progress that has been made so far.

We expect our leaders to provide the necessary support for people with disabilities to have meaningful lives. Let us work together to strengthen health care in Minnesota and across the country.

Jennifer Hall-Lande, PhD
I'm here representing Dr. Amy Hewitt and the Institute on Community Integration. I am a researcher in the field of autism and developmental disabilities, but more importantly, I am a family member and ally of people with disabilities who have benefited from services and supports and early intervention. ICI is a University Center for Excellence in Developmental Disabilities, and we are 40 years old. Our funding is a legacy of the Kennedy administration dating back to 1963. Of course, our funding right now is at risk.

I want you to know that for the past 40 years, ICI has been a leader, both nationally and in the state, promoting research, technical assistance and training that directly translate into improving the lives of people with disabilities, their families and communities across the lifespan. While our biggest contribution is how we've improved the lives of people with disabilities, I want you to know we also have a remarkable return on investment. Our core federal funding is about $600,000 but our operating budget is $30 million through leveraging philanthropic dollars, grants, contracts, and other federal funds. For every $1 of federal contribution $50 comes back to our state in jobs, programs, and policies that benefit communities.

We have approximately 145 staff and a lot of different projects at ICI. I'm going to profile a few today. I lead the Minnesota Autism Developmental Disabilities Monitoring (ADDM) project. That project monitors trends in prevalence and autism. It not only gives us a state number that is very valuable for policy and funding and understanding the services and supports, but it helps us understand key variables, such as age of identification. One thing we know about autism and more broadly, other developmental delays, is the earlier we identify a child, the better their life outcomes. We also know that the earlier we identify children with appropriate and effective interventions, we can save up to two thirds of the funding spent across a lifespan.

Next is the Minnesota LEND program and that stands for Leadership, Education in Neurodevelopmental Disabilities. Since 2009 we have trained over 300 LEND fellows who have taken leadership roles in research, administration, policy, and elected office and improved the disability workforce in our state.

We have the Telehealth Center which is doing innovative research on how we get services and supports to children earlier and to address our critical waiting lists. We have children sitting on waiting list for years when they could be getting valuable early intervention. Further, the telehealth center benefits Greater Minnesota and our rural communities that have less access to resources.

ICI also houses the federal RISP project or (Residential Information Systems) which has 40 years of data tracking about deinstitutionalization and how we can provide better support people living in their own communities. Our National Center for Educational Outcomes works to ensure that our schools and assessment systems are serving children and families with disabilities in an equitable way.

Finally, ICI has been a national leader in the field of direct support workforce, helping to professionalize that workforce, increase that workforce, reduce turnover, and advocate for sustainability for the past 40 years. This work is vital, and it is at risk. The cuts to the Department of Health and Human Services, NIH, CDC, and the elimination of the Administration for Community Living all are a threat to our ongoing work right now. This money has been appropriated and planned for, and that makes a difference in our community.

We ask that you advocate for increased, sustained funding. Thank you so much to all of you for being here and listening. We promise you the dollars come back to our state and nationally in multiple ways, so please continue to advocate for our funding.

Elizabeth Marsh

I live in Mora, Minnesota with my husband Andrew, and our two beautiful daughters, Allison, who is 15 and Madison, who is 13. Allison has a radiant smile and a love for fishing, watching Bluey and playing on her iPad. She loves her two golden retrievers. Allie also has developmental disabilities and complex medical conditions that require constant care and attention.

The proposed cuts to Medicaid are threatening the health care of millions of vulnerable Americans, including low-income individuals, children, the elderly and those with disabilities and complex medical conditions like my daughter. We were told at our five-month ultrasound that Allison had brain differences that would require delivery at Abbott Hospital and brain surgery at Children's Hospital when she was born.

The emotions during those early years were overwhelming. We faced countless surgeries; hospital stays and doctor appointments. There were missed days of work, mounting stress and a growing pile of medical bills. It wasn't until years later that we discovered additional services were available for Allison, like Medical Assistance and Medicaid waivers.

Allison is a remarkable young woman; she has had 11 brain surgeries and countless hospital stays. Through everything, though, she has been resilient, strong, kind, compassionate and a fierce fighter. She is in ninth grade, and she benefits from special education services and supports to help her learn alongside her peers in the mainstream classroom.

She also receives support through the Community Alternative Care or CAC waiver. Which is a Medicaid program designed to provide funding for home and community-based services to children and adults who are chronically ill or medically fragile and would otherwise require hospital level care.

The CAC waiver is crucial in ensuring that Allison can live where she is most comfortable, which is at home with our family, this support helps us create the best environment for her to thrive.

The waiver has allowed us to make home modifications for accessibility, purchase sensory items and adaptive equipment, hire direct support staff and many more things.

Living at home with her family, rather than in an institution or congregate care setting represents a significant savings for both the state and federal government. Living at home with family also ensures Allison's health and wellbeing.

Every person, regardless of their abilities or disabilities, possesses inherent worth and dignity. Disabilities are a natural part of human diversity, and individuals with disabilities are not any less valuable to our society. Disability is something that's going to affect everyone at some point in their lives, whether it's illness, injury or age. It doesn't discriminate by race, ethnicity, sex, income or political party. Disability affects all families.

Medicaid is key to ensuring Allison lives her best life here in our home, and the proposed cuts to Medicaid, an introduction of lifetime Medicaid caps and work requirements would be devastating to not just Allison but our entire family and many others in similar situations. Cutting Medicaid will disrupt Allison's overall quality of life and will limit her access to health care that she relies on. It could lead to illness or even death.

Please continue to fight to keep Medicaid and related services for Allie and others and thank you for your time.

Heather Kainz

I am a parent advocate, and I live in northern St Louis County with my husband and our three children. My experience navigating Medicaid is one reason that I am pursuing a law degree and have become a passionate advocate for disability rights and equitable access to health care.

My youngest child was born 13 and a half years ago, and immediately faced medical challenges. He was later diagnosed with severe intellectual disabilities, profound autism, and complex physical disabilities. We live in rural northern Minnesota and lack access to the level of care he needs. We have spent thousands of hours driving between our home, Duluth, and the Twin Cities. He has needed surgeries, is reliant on a feeding tube, requires medical equipment, and has life threatening seizures.

Somewhere along the way, I was advised that my son would qualify for a Medicaid waiver, but I had no idea what that meant. I had never heard of a Medicaid waiver before, and despite having worked as a business analyst at a major health insurance company for a decade, virtually none of that experience transferred to navigating Medicaid. I tried my best to understand the paperwork I was completing, but when I asked the county caseworker questions, I received unhelpful, evasive, and patronizing responses.

When my son was two or three years old, we navigated the red tape to find out he had successfully received a CADI waiver. I still did not understand what the waiver was, nor did I know what the benefits were. This was not due to a lack of trying on my part; waivers were treated as some sacred secret by the county. The county treated us like we're doing something wrong. Comments were continuously made to us that this was taxpayer money, and the county worker acted as if we were taking money directly out of her own pocket. Just weeks after he was approved for a waiver, we received another letter stating that he was being terminated from the program because we had not yet accessed his waiver. I did not understand how to access the waiver or what we had done wrong, so I again sought help from his county worker and the supervisor.

Unfortunately, I learned then that St. Louis County is treated almost like two separate counties: north and south. The southern staff could not assist us because we lived in the northern part of the county, so we were advised to file an appeal. While that appeal was pending our family felt scared for our son's future as we began to understand what the waiver could provide him. It became clear that this was indeed a lifeline that had the potential to help us, to help him. After many discussions, my husband and I decided that a solution to the problem could be for us to relocate from the northern part of the county to the southern part.

After moving, I contacted the southern St Louis County team and informed them that we had relocated, that we had an appeal pending for the waiver termination and asked for their assistance. I also contacted the Minnesota Disability Law Center for help on the appeal. Southern St Louis County set up an assessment appointment with us and an attorney from MDLC attended. The assessor quickly determined that our son indeed qualified for a waiver and began working on having it reinstated - this time under the southern St Louis County team.

It has now been over 10 years that our son has had access to the CADI waiver, and the services he has been able to access have undoubtedly benefited his quality of life. Where our employer-sponsored insurance plan ran out, Medicaid filled in the gap. When he became too heavy to carry upstairs, the waiver provided home modifications, including a stair lift, allowing him to access his bedroom safely. The waiver has allowed us to make other accessibility modifications to our house to ensure that he is safe and that his caregivers do not get hurt while caring for him. The waiver has allowed him to access speech, occupational, and physical therapies once our private insurance benefits run out. The waiver permitted him to receive lifesaving care when he needed to be airlifted from Virginia to Minneapolis due to a seizure that would not respond to medications.

Medicaid is a lifeline for so many of our most vulnerable citizens. Without a robust program, people like my son cannot remain in the community, at home with their families, where they are safest and best cared for. Without Medicaid my son will face segregation and institutionalization. Medicaid must remain strong and available to those who need it most. Budgets should not be balanced on the backs of our most vulnerable, those who have been treated as second-class citizens for far too long.

Dupree Edwards
I live in Fridley, Minnesota, and I have an interesting story, because I grew up in the Medicaid and SSI systems. I was in the foster care system ever since I was two years old, and I aged out at 19. I got deeper in the system.

I was in high school, I went to Transition Plus at an early age 16, and I've been successful there. If Medicaid is cut, then my whole childhood and adulthood would go away. I am on a on a DD waiver. I became disabled when I was two. I ate a paint chip, and I got poisoned and it damaged the executive level of my brain. I was also born with a mental health disability. My mom was not doing well, couldn't take care of us and things like that.

Today, I work for the Institute on Community Integration. I serve on the Governor’s Council on Developmental Disabilities. I've been in struggling with my supports throughout my living situations, to learn what's the best to support me or what's helping me. I went to this house that I live in now that helped me understand what freedom is, understand how to make better decisions, better choices with my health and safety and things like that, you know, and if Medicaid is cut, then I don't know where I would go. I don't know where I live, I don't know if I have the support that I need. But right now, as I have as stronger, I would have the best support.

And if we say, in Minnesota, we're all about Employment First, we're all about, you know, living our best lives to the fullest. Medicaid is also for children and families and moms. We cannot waste all the progress that helps people. And I know sometimes you can understand if people abuse the program, but that's a whole different story. Like she said, we don't want to go back to segregation. We don't want to go back into institutions. We don't want to go back of the things that we build up to now. And yes, there's still a lot of work to do. You know, there's always a lot of work to do, but cutting Medicaid will tear that progress down.

Jessica Heiser

I'm here today on behalf of Minnesota Disability Law Center and representing my director, Jen Purrington. I want to start by thanking the staff members who have taken the time to be here today and hear directly from our community. It means a lot to us when you show up. The Minnesota Disability Law Center is the federally designated protection and advocacy agency for the state. We provide free legal advice to all Minnesotans with a disability. There's no income eligibility, there is no citizenship eligibility. It's just free for all Minnesotans. We also have the statutory ability to monitor and investigate any facility that serves people with disabilities, so jails, schools, nursing facilities, healthcare centers. We can go in and monitor and investigate to ensure that people with disabilities are safe. We advise policymakers and legislators. We serve on 30 task forces around the state, and we consider collaboration and outreach a huge part of what we do for the state.

75% of our budget is federal funding, and the other 25% comes from the state and private donations. We are very dependent on federal grants from the US Department of Health and Human Services, Social Security Administration, and the US Department of Education, and so it is a very scary time for us right now. We have 24 staff members who work all around the state, with offices in the Twin Cities, Mankato, Duluth, and Crookston area. All our staff are all either attorneys or legal advocates. My area of focus is special education. I'm a former teacher, I'm a parent of a child with disability, and I've represented school administrators, so I've been through the special education system in many ways.

In our entire state, there are five private attorneys who take special education cases, so our work for free for families is essential. We are seeing a lot of fear and panic from families and school administrators that we work with, and they're worried that the protections for the children are going to be at best, watered down, and at worst, eliminated. We have seen the gutting of the Office for Civil Rights, the Texas v. Becerra lawsuit challenging Section 504, and moving special education under the Individuals with Disabilities in Education Act to the Department of Health and Human Services.

We have grave and legitimate fears that our clients are going to lose protections guaranteed under law. The other problem is with the rapid changes, there's a lot of widespread confusion and uncertainty. Even while these lawsuits play out in court, the changes are very real and palpable in our community.

We had a client come in last week because a young child (the only black boy in a kindergarten class in a small charter school) who was discriminated against. When he had behaviors one day, the teacher sent an email to all the teachers and all the parents in the classroom saying, this is the kid who acted out, and this is what his disability is. They sent him home for hours on most school days because the teacher was not trained to handle his disability. And that is exactly the kind of case that we would have referred to the Office for Civil Rights in the past, knowing that OCR would not only look at the potential discrimination occurring against this particular child but would also look at the school district as a whole to ensure that other children of color with disabilities weren't being subject to similar systemic behavior. Our regional OCR office is completely shuttered.

We're also deeply concerned about Medicaid funding. The House budget reconciliation proposal calling for $880 billion of funding cuts. There is zero way that that can be accomplished without hurting Medicaid recipients across the country and people with disabilities. As you've heard, people with disabilities rely on Medicaid to live in the community, stay in their homes, and not be institutionalized.

All the policy proposals being floated such as per capita caps, block grants, and work requirements are just funding cuts. If these proposed cuts go through, Minnesotans with disabilities are going to go without needed services. They're going to be institutionalized and likely suffer injury or death. I just want to emphasize to you all that people are losing sleep. I mean, this is a time of deep frustration and concern. We can always do better, but let's not do worse.

Jenny Arndt

I am from southern Minnesota, specifically Waseca County. I have several children of whom have various disabilities, including autism, intellectual disability, dyslexia, and ADHD. I am seeking help in navigating special education. I have struggled and fought with my school district for 13 years. Ultimately, I chose to leave my profession of over 20 years to dedicate myself fully to advocating for my children, ensuring they receive the education they need to thrive in our community.

We have been failed by our school district in the area of Child Find, resulting in my child losing five years of education. We were unaware that he was entitled to special education services while in day treatment.

We have encountered discrimination in our school district, leading to bullying from both peers and teachers. Some teachers and district officials have presumed incompetence regarding my child. Just because he has a disability does not mean he cannot learn. I refuse to be told to lower my expectations. We have also faced segregation; my child with ADHD and autism was excluded from a school trip due to behavioral issues.

Most recently, a special education teacher removed my son from her classroom and made him sit in the hallway because "he was too much."
In third grade, after a behavioral outburst, my child was locked in an unsanctioned seclusion room with padded walls, where he was held while screaming and banging on the door to be let out. I was not informed about this incident until three months later when the school mentioned it due to his increasing behavioral issues. As a result, he now suffers from PTSD and severe anxiety, leading to regression, denial of educational benefit. We have also been denied informed consent, assistive technology, parent participation, and due process rights.

I am asking for your help to shift the burden from families to schools. We spent thousands of dollars suing our school district with disposal money we do not have to enforce our rights.

Almost a year later the school district settled granting our requests just before we were supposed to go to court. Although we eventually got the necessary technology and my son is now learning, this situation was expensive, unnecessary and time consuming. Even the special education director acknowledged how foolish the whole process was.

I am calling on you to empower our Department of Education to sanction districts that fail to implement the Individuals with Disabilities Education Act (IDEA) as it is written to provide a Free Appropriate Public Education (FAPE). It should not be my responsibility to prove that the district is failing; rather, it should be the district's obligation to demonstrate that they are providing the necessary resources to meet my child's needs.

Alan Morrison

Even before this administration our children were denied their diagnosis of their disability, and that led to a lot of incarceration, a lot of people who are low income and a lot of people in poverty. I have a traumatic brain injury.

I am told, you don't look disabled. I have been denied medical coverage for my household. Now, I've had to take out payday loans to get medication when my children needed it.

A lot of the young children with disabilities that you see on the streets doing crime were pushed out on the streets. These are children with disabilities. Once they age out of foster care, the school system, clinicians and doctors declare they are no longer disabled then they are pushed out into the streets then incarcerated and relabeled with a disability.

These are children. They need help.

We don't even have vocational training for junior high and high schools here and across the country. These people that are individual learners that can learn and are eager to work. I don't understand. I'm very fearful of what's going to happen next, especially to a lot of individuals, people of color, who have disabilities. I didn't have any access to medical coverage during COVID. I couldn't even get the medication to make my COVID easier. I had cancer and couldn't even get medical coverage. I was denied.

I was told I was a habitual user of the system. In 30 years of being a single parent, I've only had nine months of food and cash support from the system still no health care coverage of any kind. I'm still fighting for Medicaid. This is crazy. We have so many people, too many children and young adults we see on the street that we say they are “drug addicts”, or they are “this” or “that”.
Here we have a room full of law-abiding people but imagine if your opportunity was lost, taken away, vanished instantly with no warning.

As a person with a disability, we're lost without our cellphones.

Imagine these children being taken away from their families. They have a disability, they have no one to call and so they end up on the streets.

This is crazy, and it's going to get worse under this administration. That's why they’re building for-profit prisons, and all these disabled people will be institutionalized.
While we are staying silent, not raising our voices.

Joel Liestman
I am a resident of Maple Grove, the Director of Family Support for the Williams Syndrome Association, a Partners in Policymaking graduate, a member of the district 279 Special Education Advisory Council, an assistant coach for the Osseo/Maple Grove/Park Center Physically Impaired Adapted Soccer team, and, most importantly, the father of an amazing child with a rare genetic condition.

I know we have been asked to keep this civil, and I will do my best to do so, but do not mistake courtesy for acquiescence. Know that I have complete disdain for our Congressional leaders (including the ones you represent) who have surrendered the basic tenets of our political system — whether for profit, religious zealotry, or simply because they lack the imagination to realize how fragile democracy truly is. As I begin, I’m asked to make a very large assumption—one I do not like because, as former Senator Al Franken says, “When you ‘assume,’ you make an ass out of Uma Thurman.” To continue, I must accept the premise that you have a fundamental understanding of the consequences of cutting Medicare, Medicaid, and Social Security, as well as the devastating impact of abolishing the Department of Education on the Intellectual and Developmental Disability community. I must assume that each of you has been made aware that these programs ensure individuals with intellectual and developmental disabilities survive – and then thrive - by supporting their ability to participate in society, achieve personal goals, and live with dignity. If this is the first time you are hearing any of this, we've already lost. With that assumption made, I'll share my story.

My wife and I are very fortunate that our son is remarkably healthy, despite being born with a rare genetic condition (Williams syndrome) and arriving two months early. So far, he has not needed extensive medical or therapeutic interventions beyond what is available through our private insurance and our public school system. The greatest benefit he has received has come from the Department of Education's oversight of the IDEA. He has thrived because of a federal system that declares, "ALL students are entitled to a free and APPROPRIATE education," and ensures accommodations for those who learn differently than their neurotypical and physically typical peers.

As a student, he gets the chance to make friends, participate in the regular curriculum, and discover passions that spark his curiosity—just like any other child. As parents, we take comfort in knowing that there is a framework and a protocol ensuring that our son receives the educational opportunities he deserves, despite his disability. That is the absolute bare minimum that every family should expect. We're told the grand plan is to "turn education back over to the states" and that since Minnesota "values education," it shouldn't be a big deal. But as someone represented by State Senator Warren Limmer—who has demonstrated his derision for people with disabilities and other marginalized communities—I know we are only a few votes away from special education programs being gutted. That is the fear I have for my son. I hear it from families here in Minnesota and across the country in my job: "Will my child even be allowed in their school?"

Since this Presidential administration took office, I've received many calls and emails from families being told in IEP meetings some version of "We don't have to follow IEPs anymore, and we're pulling your child out of the classroom to avoid disturbing the real students." When schools do this, and as departments and agencies that were created to ensure that the law is followed and that equal access to education is provided continue to be dismantled, where are families supposed to turn? The Department of Health and Human Services? HHS does not have the capacity or infrastructure to handle education matters now, and as its workforce is slashed, it never will.
State Senator George Lang of Ohio has publicly lamented the cost of educating kids with disabilities, suggesting it is excessive compared to students from "a family with a loving mom and a loving dad who put education at a high level." This is the kind of rhetoric and mindset families are already up against. Federal conservative legislators might be savvy enough to not say such things in public, but their actions are shouting their disparagement for kids that learn differently.

Before I know it, my son will turn 18. The supports he has now under IDEA will be gone. And if you do nothing, Medicaid, Medicare, and Social Security will be gone, too. The time for performative politics is over. Stop tweeting. Stop making TikToks. Stop going on panel shows and giving interviews looking for a great soundbite. Work. Get into the offices of your colleagues. Cry havoc in Committee Chambers. Shame those who stand in the way of the rights of ALL Americans.
Stop telling us you care. Show us.

Mike Nichols

I've been working with people with disabilities since I was 13 years old, developing programs, advocacy groups, and a theater group for kids with autism. In 2016 I became a parent of a child with a disability. My son, Lazlo, was born with cerebral palsy.

I want to start by saying, please protect Medicaid reimbursement rates for disability services. Minnesota gets a 50% Medicaid reimbursement rate. How would it feel to be able to get out of bed halfway? What if there are cuts to that rate? How would it feel to get out of bed 75% of the way? And that might seem like a kind of oversimplification, but when you look at the large scope of services, that's what we were looking at.

Lazlo attends an after-school program. I got a call one day saying they needed to provide him with a one-on-one support. He doesn't have a one-on-one support in his classroom, so I was a little confused. Why? They said Lazlo couldn't play the games in the gym with the other kids, so they gave him a box of fidgets to sit on the floor and play. So, he would sit on the floor and play with these fidgets, and then he needed one-to-one support, because he got lonely.

Why not adapt the activities in the gym so Lazlo can participate? That's interdependence. None of us are independent at playing any sport or anything else in life. Things are going better now. They adapted the games in the gym for him to play with the other kids. And he's enjoying that. The other kids saw this happening and started adapting things for him and engaging and interacting with him as one of their peers. And that's what happens on a community wide basis, when you include people with disabilities in the community.

Please protect Medicaid reimbursement rates for services from people with disabilities. With any cuts, agencies will collapse. Agencies that are doing hard work to integrate people into the community with disabilities will collapse. Caregivers aren't paid enough. Waiting lists are huge. Imagine the length of those waiting lists if any of those funds are cut. We need to move forward. We need to integrate people with disabilities in the community, and that takes support.

Jenny Santema

I live in Milaca, Minnesota, which is about an hour north from where you're at. We have a little more ice and snow, and I didn't want to drive in. I am a parent of an adult son who has autism, and he has low cognitive skills. My husband and I have full guardianship of him, and he lives at home with us. We receive CDCs, waivered services, and with those services, we had decided that he would attend a day program in our community, and in that day program, he works the whole time he's there. He receives some assistance because he lacks some of the skills to work outside in the community.

He's 29 now, so I don't know if he will ever be able to work outside without a job coach or some team of people that would be able to help him. He gets transportation to and from this program through the waivered services. Also, he attends this program for about 30 hours a week. I have PCA support before and after the program, and with all of that, if, if we didn't have those things, I wouldn't be working. I work as an early childhood special education teacher, so I am home for the summer months. But if these supports changed or were, God forbid, eliminated, I would have to stay home.

I have been one of his PCAs for the last 10 years. Out here, we cannot get many people to be PCAs, especially the consistency that my son needs. So those are limited services. We also, and I, I have chosen to have him live at home. The changes that we have in group homes out here that close or try and open and try and stay open, it is kind of a revolving door, which we didn't want to have him be a part of.

The thing that I am concerned about now is my husband and I are aging. We will in another 10 years, probably be receiving Medicare and Medicaid because we are getting older, and those supports for some of the families that I know are really they are really struggling with their own health care as they age and taking care of a child still at home who is maybe in their 40s or 50s. So those kinds of supports become extra important for people as they age, because there are no other ways for them to support their kids. So that is, briefly my story, but it's a little different perspective from these people who have younger kids, because I worry about the future, and I'm not going to be there at the end. What happens then?

Lisa Jemtrud

Hello! I'm from Savage, Minnesota, I'm a parent-advocate, the mom of two sons with disabilities. My youngest is 14, and he has autism and intellectual disability. He has a dream to work for the city in the public works department, because he loves snowplows and dump trucks, plus he loves to clean and organize. He also has a dream to have his own apartment someday and have a cat that can sleep on his feet at night. My oldest is 19 and has autism and developmental coordination disability and is a high school graduate. He is very smart and charming; he has dabbled in taking a college class and has been looking for part time jobs. He says, “Why won't anybody pick me?” He feels like he can't pick a job that he wants. He believes he is going to have to settle for whoever will take him.

Employment supports for people with disabilities is huge on my mind, both personally and professionally. I also happen to be Director of Employment Services for one of the largest disability providers in the state. I'm very concerned about Medicaid and waiver cuts, because the people we support are very dependent on Medicaid. Please know our wait lists are huge. They're suffocating. They're heart wrenching because people are isolated and waiting at home for someone to help them. The idea of needing to go backwards and serve FEWER people when the need is so great is so discouraging.

And the other part that that underscores for me and it's just so hard, even professionally too, to see this. We have people who want to work. We have people with skills. And if support goes away, we're really having a quite a big loss for our whole community.

Cuts have a cost, and I've been focusing on that a lot lately, because in this case, it couldn't be truer. Cuts that look good on the spreadsheet aren't cuts. There's no money saved with these types of proposed cuts. I'm not an economist, I'm not a mathematician, but I can see it plainly, there are going to be tons of ramifications that cost money. If we have reduced services, there's less independence. We will have fewer people working in the workforce. There'll be losses of earned income, and these are people who would pay taxes, who would be spending money in the marketplace. Also, I believe parents and parents and caregivers could be affected - if they are providing care, they won't be able to do their jobs. They'll have to be at home, providing supports that could have been made in other ways. So, there's a financial loss there, too.

There is quite likely to be an additional strain on medical systems, health care, mental health - and those things aren't free.

hear quite a bit about special education. I agree with the other statements that special education programs have worked very well for us. Moving special education under another umbrella - (which will for sure result in less focus and less expertise - IS A CUT). These are investments not cuts.

Lastly, how can we help? How can I help? What would be helpful to keep shining a light on these discussion topics. We're here to tell our stories, collaborate and share!

Lee Shervheim

I have been married for 34 years. I'm the dad of seven kids, four boys and three girls. The reason I'm here today is because my three daughters have Down syndrome. Anne was born in 2004, and we became aware of an organization that helps families adopt children from Ukraine. We adopted two daughters with Down syndrome and my daughters are now 20 and 21 years old.

Our family has been the recipient of so many services such as early childhood, IDEA (50 IEPs), support to go to school events, the ADA making our communities accessible, ABLE accounts, SSI, and Medicaid services for healthcare services, and the waiver. The waiver provides health, safety, independence, and integration through assistive technology, PCA support, independent living skills, and therapies.

As my daughters move into adulthood, we now are looking at employment. Last summer, my daughters decided to create a summer bucket list. They had an active summer, and they were able to do everything they wanted to do. Any cut in federal funds will impact their lives.

COMMENTS FROM PUBLIC

Jillian Nelson

I'm the policy director for the Autism Society of Minnesota. I'm a former council member, and I'm also an autistic adult, and I receive a CADI waiver. I am standing here today because my staff showed up, because my PCA was available to get me out of bed, make sure that I ate my food, gave me my medication, and that is why I am the policy director at the Autism Society of Minnesota.

I look around this room and I see people from all walks of life with all types of disabilities. I see family members. I see allies. Do you know who I do not see in this room today? I do not see a single millionaire or a single billionaire, and right now, we are talking about cutting $880 billion from a system of that affects 99% of America to protect the tax benefits for 1% of America. The 1% will never worry about whether they can afford support to get out of bed if they become disabled. Billionaires will never worry about whether they're going to be able to get to their job in the morning. Because to be honest, if I had a billion dollars and I lost my job, it wouldn't be the end of the world.
These are people that will never worry about whether they have access to the medical equipment they need, to the care they need for chronic pain, and we are willing to grow their bank accounts on the backs of people whose lives are literally at risk over this $880 billion.

I spent a lot of time yesterday listening to US Senator Cory Booker, and I would like to say that number one, I would like to see Minnesota do the same. You are all on the hill. You all have the same capability of making a stand, of taking a large initiative to do better for Minnesota, we come from a long line of belief in doing better. I believe Paul Wellstone said, "When we all do better, we all do better." It's time for Minnesota representatives, Congress people, senators, that you do better for us. Minnesota has long been what the rest of the country looks to for disability standards. I am heartbroken daily as I watch the rest of the country fight to protect Medicaid, and to see Minnesota standing by so silent. We have the most to lose, and that still says a lot, because we're still a long way away from a disabled utopia. We still struggle, we still go without, we still must fight for basic human rights and dignities as people with disabilities, and we're the best. If we let this happen, we're going backwards decades. We can't afford to go back decades just to line the pockets of a few people who already couldn't count all their money if they quit their jobs just to count their dollars,

Tom Pearson

Governor Walz had the wonderful declaration of “One Minnesota”. It's a promise of diversity, equity and inclusion, and if anybody is left behind, then we have more work to do. DEI has now become pejorative, and it is being wiped clean. This is inhumane. The real problem is that it is creating an impression in the minds of the general public that DEI is a bad thing. I would like to see our political leaders stand up and push back against that. Stand up for DEI.

Sarah Hall, PhD

I am a researcher here at ICI. I had a mentor early in my life, and the most important word she said was “listen.” My brother Charlie has multiple disabilities, and I became his guardian, not to speak for him, but to help him speak for himself and to help him make choices. He needs his Medicaid funding.

He lives in a group home. He goes to a day program and does volunteering. I thought very briefly about moving my brother from Nebraska to Minnesota because the services are better. But I can't do that because he's been living in the same group home with his friend, Russell, for 30 years. Those connections are so important. I am never going to move him away from Russell. I must follow up with the residential services often because they aren't always taking care of my brother well. We need quality staff. They need to be paid well. They need quality training for my brother's health and his safety.

I send him money for things because it matters. It's the relationships and the community participation that matters in his life. I have been advocating for him to go to church. And it's been half a year. We're getting there.

Our work is so important at ICI because I see the impact on my family and as a sibling and a guardian, and someone who supports people with disabilities.

Chet Tschetter

I am a direct support professional, and I support Nathan, a family member of my friend. He is an autistic man. He is not a person who can live in a group home. He lives in an apartment attached to my friend's home, and that's the best situation for him. He needs support, and he is fortunate enough to get the Consumer Directed Community Support (CDCS) waiver so that family members can be paid to help support him, as well as myself and two other DSPs.

I talk with Nathan multiple times a week, and he is scared about what will happen if funding is cut. That's a very real fear for him and for his family. That's a hard thing for someone who is already living with autism and has lots of anxieties. We beg of you, the Senators and the Congressional members, to really stand up for and support Medicaid. Don't be afraid to stand up and make some noise in Washington.

Mark Olson

I work on the direct support work that we do here at ICI, and I've been doing that since the 1980s. We have seen progress, but that progress is going to go away now. You've heard a lot of great stories today. Here is another Wellstone quote, “You got to pick a fight to win one.” It is time for us to hear from the US Representatives and US Senators from Minnesota about how important these services are to the people of Minnesota. And you need to stand up and pick that fight.

Medicaid, Medicare, Social Security and all these pieces are being attacked and they are important to people's lives, not only those of us that work in the field, but most importantly, to those that we support.

Lee Shervheim
I just want to thank every single one of you for sharing your stories today. It is impossible for me to imagine someone sitting here and listening to you all and not feeling how important this is and how scary and confusing this time is for everyone.

Taylor Mills (Congresswoman Morrison)
Congresswoman Morrison is just getting her feet on the ground, but we are going to do everything we can to stand up for you, to raise your voices, to elevate your stories. I took some notes, but I'm going to ask a couple of you some questions afterwards. But thank you, thank you again. Your story matters. The work that you're doing matters, and we're going to do everything we can to thank you.

Michelle Manivel (Congresswoman Morrison)
I want to thank you all for coming out and sharing your stories too. I want to really encourage you. I would love to talk with each of you. Please reach out to us anytime. We really appreciate the offer for a tour. I would love to come visit people.

Charlie Hammond (Congresswoman McCollum)
I just want to reiterate the Congresswoman's support for all these programs and her commitment to continue fighting. I also want to thank you all for your stories and I am going to be doing some followup.

Sarah Sandgren (US Senator Smith)
Thanks for your advocacy and for your time and for the work that you do every day, day in and day out. Without your stories, without your pushing, without your efforts, we don't have the backup that we need. I think Senator Smith is dedicated to both picking and winning the fight. Please stay in touch with our office. Please continue to share with us the ways that you want to see us step up. We are working to do everything that we can on all these fronts. We are trying our best. The fight is needed and appreciated.

Allie Glass (US Senator Klobuchar)
My Senator enjoys stories and uses them, and that drives the work that we do. So, situations like this, where we get to hear directly from individuals is crucial to the work that we do, because we're bringing this to the floor, to committee meetings, to things like that, to really be able to show the people of Minnesota, but also people of the country, of the impacts that these proposed cuts will have. What I love about these opportunities is it gives us a time and a space to start the conversation. We ask that you call and tell us your fears, your concerns, and your hopes for the future. We welcome all that information because that drives what we do and how we do our job. Because at the end of the day, we work for the people of Minnesota, and so it's crucial that we hear these stories.

Gammachis Kobbu (US Senator Klobuchar)

A lot of people like you come to our office for help. They are not being heard and not being listened to, for the smallest things.

My mom and my dad are immigrants who came to the US and who literally had no English. They had to figure out everything with little or no help. My brother has disabilities and is a college graduate. So many other people are doing the same things, and it shouldn't have to be like that. Like Allie said, we are hearing you. We are doing everything that we can possibly do to listen to you and do what it is that is right. For individual cases, you are welcome to contact me directly.

Lee Shervheim
Thank you all very much. When we began the meeting, our objective was to listen, and I think we've done a really good job of that. It also involves remembering those things that are important and understanding the passion that's behind the voice and the emotion that's behind all of this.

Many people probably watched at least part of what US Senator Cory Booker did over the last couple days. He said during his 25th hour and fifth minute of speaking, I don't know how to solve this, but I do know who has the power, the people of the United States of America. The power of the people is always greater than the people in power.

That's just such a poignant way to say it. This is such a good way for us to end here, because at the end of the day, we're all citizens, we're parents, we're spouses, we're friends, and we need to figure it out and do what's right and do what's best. Thank you all very much.

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Matt Roberts
Chris Rogers
Megan Sanders
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Janet Stewart
Krista Stokes

Jennifer Sommerness
Chet Tschetter
Emma Worthley

<u>OTHER GUESTS</u>
John Cundy
John Daly
Kurt Meyer
Jillian Nelson

Additional Comment (unattributed):

Medicaid cannot be taken away. It is going to be dehumanizing to a big part of our community. Social security benefits should be prioritized and not renegotiated.
We are a diverse group of people. Disability is diversity. We need each other to be able to thrive. We all have inalienable rights as human beings. Let us just treat everybody as a person. We plead with our representatives to step up the game. You are already doing a lot but step up the game. Reach out to people who can support you. Not all of us can go to Washington, but we have enough voices on the ground to give you the materials you need to do the work that you do. I also want to speak to the fact that I have a triple disability. I am Black. woman. and immigrant. I know what it means to have different abilities and need different services. I plead with you: Immigrants are human beings created in God's image as well.

Respectfully submitted,

Colleen Wieck
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