MINNESOTA
COUNCIL ON DISABILITY

MCD 2022 Legislative Forum Transcript

Disclaimer: This transcript is based on a live script of the forum; therefore, there may be typos or omission of words. There might be language in this transcript that some could find offensive.

Opening Remarks

Executive Director David Dively

DAVID DIVELY: Welcome everyone! My name is David Dively and I'm humbled and honored to be the Executive Director here at the Minnesota Council on Disability. I want to take a moment to thank the staff, legislative leaders, state leaders, and community members who have all come together today to make today's event happen. Today's event features tremendous speakers and a very ambitious legislative agenda. This agenda will build our agency's capacity and the capacity of the community of people with disabilities that we represent and serve.

We are in a pivotal time in Minnesota. Covid is impacting Minnesotans with disabilities at a higher rate than the general population and it is reducing the ability to get the services and supports that people with disabilities need. Whether it's from staff shortages and congregate care settings or home-based services. At the same time Minnesota has a tremendous budget surplus that we can use to benefit the people who are in need the most.

So, what that means is that our elected officials and state leaders have a very critical role to play in our 2022 legislative session.

We're excited to be here today and I hope you are as well.

I'll now turn it over to our council chair Nikki Villavicencio. Thank you.

Chairperson Nikki Villavicencio

NIKKI VILLAVICENCIO: Good afternoon, Minnesota disability community! My name is Nikki Villavicencio. I use she/her pronouns, and I am the chair of the Minnesota Council on Disability. I have short brown hair. I'm wearing glasses. I'm wearing a green sweater. I have a blurred background today. And I'm thankful to be here with you.

I would first like to recognize all of the Council on Disability, the council members and our ex officio members. Thank you for your service and thank you for being here today.

Becoming chair during the pandemic has been quite the adventure, but the lesson learned is that society can learn a lot from seniors and people with disabilities.

Health care as a human right is more obvious than ever. That is why we must lean into our governor's message of unity to work on the issues of today and tomorrow.

I would like to introduce the governor and the Lieutenant Governor of Minnesota, Governor Tim Walz and Lieutenant Governor Peggy Flanagan. They will kick off our event and we look forward to hearing what they have to say about the role of state government to serve Minnesotans with disabilities and their commitments to an inclusive fair and equitable Minnesota for everyone, including people with disabilities.

Thank you, Governor, and thank you Lieutenant Governor for coming, and I will pass the microphone on to you.

Governor Tim Walz

GOVERNOR WALZ: Well, thank you Madam Chair and thank you for everything you've done, and good afternoon to everyone who is on here today.

I certainly know many of you wish we could meet in person, but it once again makes us think about where barriers are pre-Covid, where they'll be post-Covid and how do we make sure inclusion is a part of everything we do?

I am Governor Tim Walz. I'm a 57-year-old white male. I have green eyes, very little hair. I'm wearing a maroon shirt and my background is the Minnesota and American flag in front of a window with the desk of some of my personal memorabilia.

I want to thank the Council on Disability, David and all the work you've done being incredible partners and resource and advocates for us during a time of Covid to understand exactly the things David said.

The issues that we had pre-Covid were exacerbated by the Covid situation, making it much more difficult. The issues of systemic ableism simply were more pronounced during covid as well as stigmas that arose, but what I will tell you is the focus on making sure every Minnesotan was cared for and protected was the focus of the Council and the focus of - I know - everyone on this call, so I'm grateful for that.

We've said all along Lieutenant Governor, myself, and others state government needs to be an example. We need to be an employer of choice and we need to set what is expected of things to happen in society.

We know again David was absolutely correct. Unemployment is double amongst people with disabilities. That is simply morally unacceptable, but it's economically unacceptable. Employers are desperate to get folks into the workplace.

State government has a responsibility to make sure we're providing the necessary tools and the ability for everyone and the incredible amount of talent and skills that is represented in the community. We need to put that to use.

Minnesota, we know, is when everybody can participate and everybody is part of the economic social and community activities. Everybody does better with that.

And I can tell you there's legislators on here and many advocates on this call that made the Connect 700 program a reality. Last year, state government employed 8.5% of state government workforce were peoples with disabilities. And I say that statistic - and I will start by saying - that is unacceptable still. We can do better. I am I'm glad we're making progress, but I want to be very careful. We cannot rest on our laurels.

We cannot say look at we've done better than we did in the past because the point of where we started was so far behind that the ability to catch back up was paramount.

So, I want to thank those legislators. I want to thank those advocates. I want to thank the folks on here who continue to expect better from both state government and private sector. And hold those of us in positions of responsibility accountable to make sure that results do matter.

I know there's going to be recommendations and I will echo madam chair's point and David's point.

This year gives us an opportunity to invest back in Minnesota to make sure that those who were most impacted by the pandemic are the ones that we look to - that we lift up those opportunities and I will echo the chair's point. Health care is a basic human right, and the ability of all Minnesotans to be able to access quality health care at an affordable rate is absolutely paramount. And there is nothing stopping us from making that a reality in the current financial situation where we're in. So, we look forward to advocating with you.

I know you have legislators on here and the good news is there's few things that are more bipartisan than the care of making sure the community is served correctly. We have champions across the political spectrum who want to get this right, and I know that those pieces of legislation HF2017 and SF1570 are based on the input of the people and the advocates on this call. We share your desire to see those outcomes.

That piece of legislation will work through and it will be improved upon by the members who are on here. And it's our desire, the lieutenant governor and myself, to see that piece of legislation come to our desk in a time when the Covid pandemic, we hope, is at a point where we can gather and sign that legislation into law and see the results that we know it can bring.

So, I thank each and every one of you. I hear loud and clear the expectations that results are what matter. That we can need to continue to work together and at a time when our financial situation allows us to invest those resources necessary. There'll be a desire to make sure that they are going to the programs and the movements that folks on this call, quite honestly, have spent a lifetime advocating.

So, I'm certainly glad to be with you, and I –

One of my great pleasures is to have a partner who understands this as well as anyone, Lieutenant Governor Flanagan.

Lieutenant Governor Peggy Flanagan

LT. GOVERNOR FLANAGAN: Thank so much Governor. Give me some jazz hands for some applause here.

But "bozhoo" (hello) everybody! Thank you so much for this opportunity to be able to join you today virtually. I am Lieutenant Governor Peggy Flanagan. I use she/her pronouns. I have brown eyes, brown hair that I'm wearing in a low bun. I'm wearing hoop earrings and a white sweatshirt top and my background is a green, yellow, orange, red, and blue art piece that looks a little bit like a Trivial Pursuit playing item from the game.

So excited to be here with all of you, so thank you so much for having us today.

To madam chair, thank you so much for your just continued leadership and to David, thank you for everything that you do and the MCD team. Your continued work inspires me and so many Minnesotans, especially in this moment that we've talked about. Your work is more important now than ever before.

And as we enter into 2022, we will mark the 32nd anniversary of the Americans with Disabilities Act. And in order to make those lasting and effective changes, it is important to have Minnesotans with disabilities at policymaking tables and serving in leadership positions within state agencies. I'm not telling you anything that you don't know but when we center the lived experience of people with disabilities and make state government more accessible, we are helping to improve the lives of all Minnesotans, and having the Minnesota Council on Disability as part of our administration has been an incredibly important part of creating a more equitably supportive state, frankly, for everyone.

Which brings me to my next point which is how important the Minnesota Council on Disabilities has been to our state's COVID-19 response. We know that black, indigenous, and people of color along with people with disabilities are at greater risk for complications from COVID-19, and the intersection of those identities impact our ability to make sure that we're getting the kind of support that we need.

And we know that these communities, our communities face heightened difficulties when seeking regular care and services that they require when we are not in a pandemic.

So, I am so grateful for David for representing MCD on the community resiliency and recovery work group in 2020 and just his continued participation as an external advisor. David and the other external advisors' input to the development of our vaccine outreach plans, vaccine distribution plans were just critical to how the state was able to reach more Minnesotans with opportunities to receive the vaccine as it became available in 2021 and that work continues.

It helped with the creation of mobile vaccination clinics often stood up in partnership with community partners on the ground, and these mobile vaccine clinics were able to reach Minnesotans across the state, better meeting people where they are and had options, and over half we of the folks that we are able to reach with these services were Minnesotans with disabilities and that work would not have happened without MCD.

And in order to continue this work we need to make sure that we are hearing directly from people with lived experience. The governor mentioned it before, but it bears repeating that people with disabilities make up 20% of the total population, and while we are seeing an increase in the number of employees hired, we absolutely can do better.

And as the governor discussed as well, the Connect 700 is the only affirmative action program for people with disabilities in the state of Minnesota and our government. So, people with disabilities aren't involved in state government they are often overlooked in policy. Connect 700 can help ensure that people with disabilities are not only at the table but are also at the head of the table and that is our role and our goal. So, I agree that we must make state government a good place for all Minnesotans of all backgrounds, including those living with disabilities.

And as someone who is a first in this role, I know a little something about clearing a path and that is what our responsibility is.

So, I'm grateful for the work of the Advisory Task Force on State Employment and Retention of Employees with Disabilities as well. And creating an inclusive workspace workplace for all is –

Continues to be part of our strategic priorities of equity and inclusion.

And a few weeks back I was at a different table, a virtual table, with a group of students where they asked how they can continue to stay involved in ensuring social justice as part of the policy-making process. And that's why I'm super excited that we've got our legislators who are here as well, and I told them that there's opportunities and spaces if these spaces aren't accessible that they should work with their school administration to help create that space. And I'm here to tell you that that piece of advice also exists of course outside of school settings and that is why so many of you are here today. We have an important role in breaking down barriers and developing a more equitable Minnesota for everyone.

And I know that the last 21 months have been incredibly difficult. I just want to say that you know we are holding that many of us have experienced either have been impacted by Covid ourselves, have experienced the loss of a loved one and know that it has we are continuing through this process, and collectively are experiencing a lot of trauma.

And so, I just want to encourage you, as you continue to do this advocacy work and continue to simply live your lives, to be gentle with yourselves, with each other. And know that the work of the Council on Disability I think is the model of how we care for each other in this moment and how we do the work.

So, “gichi-miigwech" (big thanks) for all of the work that you have done and all of the work that we will be able to do together. Thank you so much for having the Governor and I today. We really, really appreciate it.

DAVID DIVELY: Thank you so much Governor Walz and Lieutenant Governor Flanagan for your words.

Well, I just wanted to briefly mention something that I think would be important to note is we want to show appreciation for the 5% increase for expedited funding under DHS' emergency powers to support services for people with disabilities in home and community-based services and congregate care settings.

And we're going to continue to advocate for that Olmstead civil rights goal like giving people a true choice of where they want to live in the community settings that they want to live in, and we will continue to advocate to ensure folks with disabilities have the funding and ability to live independently. And we hope that the governor's administration and then DHS positions will continue to support that goal.

And so, we appreciate that you saw that coming and we want to celebrate and recognize those efforts to increase the service providers that we desperately need. So, thank you!

All right, at this moment I'll pass it over to Trevor.

MCD Legislative Agenda

TREVOR TURNER: Hello everyone! My name is Trevor Turner and I want to thank you for coming to the Minnesota Council on Disability legislative forum.

I am the Public Policy Director for the Minnesota Council on Disability. I am a man of European-descent, dark blonde hair, and blue eyes. I use he/him pronouns, and I'm wearing a blue shirt with a striped tie and a blue jacket. My virtual background is an aerial shot of the Minnesota Capitol building.

Today, I'm going to be talking about the Minnesota Council on Disability legislative agenda, and you can find the full agenda on our public policy webpage at disability.state.mn.us. Again, that's disability.state.mn.us.

The Minnesota Council on Disability will be pursuing a new legislative agenda for the 2022 legislative session. This agenda was approved by our Council members unanimously last December under the theme of “Capacity Building.”

For MCD to fully execute its statutory mandates, our state agency must be adequately staffed and have the resources to represent and advocate for the over 1 million Minnesotans with disabilities.

The COVID-19 pandemic has had a dramatic impact on Minnesota’s disability communities. Minnesotans with disabilities experienced higher risks for severe disease and death relative to other Minnesotans. Our community is experiencing major disruptions in critical services, healthcare, education, employment, transportation, and more. For many in our state, the pandemic is a disruptive inconvenience but for Minnesotans with disabilities, the pandemic is drastically altering our livelihoods from which it will take years to recover.

As pandemic fatigue has set in across the state, Minnesotans with disabilities are experiencing a cavalier disregard for our lives from many of our fellow Minnesotans through a rebuke of COVID-19 mitigation measures meant to protect the lives of the most vulnerable. Despite the challenges, the Minnesota Council on Disability is working tirelessly to help our community weather the pandemic and ensure our state officials do not forget Minnesotans with disabilities.

Our staff has been deployed to the State Emergency Operation Center, is acting as disability advisors to our state agencies, are organizing coalitions to pass critical legislation, and are serving as unrelenting advocates for the disability communities in Minnesota.

The challenges and barriers Minnesotans with Disabilities face existed long before the COVID-19 pandemic, and those challenges and barriers were highlighted and exacerbated over the past two years. The pandemic has also shown how critical it is to have a fully prepared, well-staffed disability agency in times of crisis.

The Minnesota Council on Disability is one of the few representatives of over a million disabled Minnesotans in our state government. Our agency does a lot with very little. Still, our capacity is limited, and we are challenged to effectively execute the extensive mandates in our founding statutes. Therefore, the Minnesota Council on Disability will be advocating to expand our capacity so that we can serve Minnesotans with disabilities to the fullest extent that our community is guaranteed under Minnesota Statutes.

MCD represents and advocates for over 1 million Minnesotans with disabilities and each and every one of those Minnesotans has a story to tell and an issue to be solved. The diverse nature of the disability community means that our issues are vast and complex.

With new leadership beginning in 2020, we performed an audit of our founding statute and concluded that we would need dozens of employees to adequately carry out the statutory mandate. We have 8 employees and are unable to hire more with our current budget. Since 2004, MCD experienced several budget reductions which has limited or reduced our capacity and MCD budget has not kept up with costs of living and inflation over the past 30 years.

Minnesota's cabinet agencies often rely on MCD for our policy and technical expertise and with increased capacity, MCD could serve all of these agencies as well as provide services and support for the public. With current staffing levels, MCD often must choose between advising our state government or providing programming for the public, despite our statutory mandate to do both.

MCD is also the only independent state agency that represents all Minnesotans with disabilities in our state government and we ask that our elected officials support our agency so that we can support our community.

But even with an increased budget, we cannot do it alone. We need more people with disabilities servicing in our state government. In 2014 employees with disabilities only represented 3% of the state government workforce, despite 20% of Minnesotans having a disability. At this time Governor Mark Dayton issued Executive Order 14-14 which attempted to infuse the state Connect 700 affirmative action program for people with disabilities with more resources, accessibility, and enforcement authority. It also gave oversight powers to the Disability Agency Forum.

The Connect 700 program allows people with disabilities to choose an alternative hiring path from the traditional competitive hiring process by working in the position for 700 hours to demonstrate the competency and ability to do the job.

By 2019 disability representation among the state government's workforce rose from 3% to 7%, suggesting progress from Governor Dayton's executive order. However, due to limited data on disabilities, it is unclear how many of those employees with disabilities were new hires or the existing workforce aging into disability status. Another uncertainty about the success of the program came from the media reporting, and an internal study revealed that more than half of employees with disabilities resign from their positions within the first year. Many of those employees cited hostile work environment, discrimination, and inadequate workplace accommodations.

Governor Tim Walz issued Executive Order 19-15, which established a goal to raise disability representation in the state's workforce from 7% to 10% and ordered all state agencies to create plans on how they will hire more people with disabilities.

Provisions in the 2019 State Government Omnibus bill also created the State Employment and Retention of Employees with Disabilities Task Force, which was made up by different disability agencies, councils, and commissions. They were tasked with investigating the issue and providing recommendations in a report to the State Legislature by February 2021.

The Minnesota Office of Management and Budget also contracted an internal investigation led by the Wilder Foundation.

The Minnesota Council on Disability is leading efforts to increase disability representation in the Minnesota state government workforce. We believe that more disability representation in our state enterprise system, especially those in leadership positions, will lead to more informed decisions being made around state disability services and policies.

The Minnesota Council on Disability worked with several legislators to introduce SF1570 / HF 2017, which would codify the recommendations made by Advisory Task Force on State Employment and Retention of Employees with Disabilities by revising Minnesota Statutes. These bills would demonstrate the State of Minnesota’s commitment to the hiring, retention, and advancement of people with disabilities by modernizing outdated and potentially discriminatory language, creating more clarity and consistency on disability employment policy, training/educating hiring managers, providing support structure for employees with disabilities, and adding capacity for essential equity work.

Minnesotans often face difficult or even insurmountable barriers in both finding and maintaining employment, and the state of Minnesota is no exception.

The state also does not have adequate disability representation in its workforce and far too often policies that have a great impact on Minnesotans with disabilities are being decided by a small group of non-disabled policy makers. Minnesotans with disabilities need not only our voices to be heard, but a seat at the state governing table.

These are “Nothing About Us Without Us” bills which would require more consultation with people with disabilities and those who are disability employment experts. Increasing disability employment and retention among the state government workforce creates a pipeline of future leaders and policy makers in our state enterprise system. When Minnesotans with disabilities are making the decisions in our cabinet agencies, the disability community in our state will be better off.

And with that, it concludes my presentation and now we will have a chance to hear from our legislators through our panel. But first I would like to... we're going to hear from Speaker Hortman. Is she available?

House Speaker Melissa Hortman

SPEAKER HORTMAN: Yes, I'm here.

TREVOR TURNER: Hello and welcome, Speaker Hortman.

SPEAKER HORTMAN: Thank you! Good afternoon! I'm Melissa Hortman. I'm the speaker of the Minnesota House of Representatives. I'm a white female. I'm 51 with blonde hair and glasses. I'm wearing a blue shirt and a black jacket, and I have my background blurred.

It's great to be with you here today. I'm appreciative for the invitation, and I hope that you're all staying healthy and safe as we move through the omicron surge.

This forum is really important but even more important is all your activity in the legislative process. As Minnesotans, we care about each other, and we believe that all Minnesotans deserve the opportunity to be safe healthy and successful. We believe in equity, equality, and opportunity for all. Easy to say, hard to do. And that's something we strive for every day at the Minnesota legislature.

I know you have some really great legislative panelists after me and we're running a little behind time so I will be very brief.

I'm proud of the work that we did last year in the budget including ratifying the SEIU contract and raising wages for personal care assistants. Significant dollars were advocated were included for home and community-based services. We increased their rates for intermediate care facilities, developed a pilot program to assist parents with disabilities in childbearing tasks, Phase 2 of Waiver Reimagine, and much more.

We know that there is much more work to do and it's critical that we do not leave anyone behind during this pandemic. We are committed to supporting Minnesotans with disabilities their families and those in the disability services community.

Our projected budget surplus gives us an opportunity to make meaningful investments on addressing the challenges that people are facing every day and improving their lives, including the areas outlined in your legislative priorities like broadband access, affordable housing, affordable care, inclusive education, access to mental health services, and so much more. There will be some very stark choices about how we choose to invest the projected $7.7 billion surplus.

Some folks have come through the pandemic relatively unscathed. Some corporations are making more money than they ever have, and some workers have suffered only minor inconveniences by working from home.

As we work to invest the state's $7.7 billion budget surplus, DFLers in the Minnesota House of Representatives are going to be focused on Minnesotans who have had the toughest time coming through the pandemic and making sure that they have the resources they need to thrive as we move forward and hopefully move beyond this pandemic.

We have some outstanding leaders and champions in the legislature, and we are excited to work with you this session to try to make progress on many issues. Please continue to share your personal stories and experiences with us.

We all know that budgets are moral documents. It's not about numbers on a sheet of paper. It's about people's lives and what we can do to impact people's lives and hearing those personal stories and those personal experiences is really helpful to us as we try to make the best decisions at the state capitol to serve the people of Minnesota.

Thank you for inviting me to be here, for hosting this event, and for all you do to advocate for Minnesotans with disabilities.

Minnesota House Panel

TREVOR TURNER: Thank you, Speaker Hortman.

We appreciate you coming to speak to us and now we're going to bring up our legislative panel for the House.

We have Representative Schultz, Representative Reyer, and Representative Albright. Representative Hamilton was going to be on the panel as well, but unfortunately had a family emergency, so we will wish him and his family well and we'll continue with our panel.

So, we'll go ahead and get our panel spot-lighted up and then after that I will throw it over to... since Representative Schultz is first, I will throw it to her once everyone is spotlighted to introduce herself and what district are you representing and why did you agree to come here today.

Representative Jennifer Schultz

REPRESENTATIVE SCHULTZ: Well, thank you, Trevor. I just want to thank everyone for being with us today and sharing your stories that will come later.

I'm Jen Schultz. I'm a state legislator serving in my fourth term in district 7A, which is the east part of Duluth, and I'm a middle-aged white female with blonde hair. I go by she/her pronouns, and I my background is my home office with a picture winter window that overlooks Lost Creek and Duluth.

I chair Human Services Finance and Policy this session, and I was very excited to work hard with my colleagues in the House on the DFL side and my Senate counterparts on an incredible historic Health and Human Services bill. So, we're very proud of the work we accomplished last year; although, we know that there is a lot of unmet need, and so, I'm here today to learn about what your needs are that continue. I also want to be a strong advocate and champion for your community this year and into the future.

We do have a small budget surplus, and I definitely want to make sure that we invest where there are unmet needs. Some of my colleagues would like to see that returned in a tax cut. I know that we have bigger investments to make that will have a bigger impact on the lives of people of Minnesota, and I hope that my colleagues will join me in prioritizing those needs and invest, making those key investments that will help people who have been negatively impacted during covid and who have struggled even prior to Covid.

So, I'm proud of the increase in the wages for PCAs. I'm proud of the work we did on the DWS formula.

I'm very happy that we're able to invest the federal money from the Biden administration and home and community-based services. But I also realize there's a lot of work that we still need to do.

So, thank you for inviting me. Appreciate it.

TREVOR TURNER: Thank you Representative Schultz. Representative Albright.

Representative Tony Albright

REPRESENTATIVE ALBRIGHT: Thank you, Trevor. My name is Tony Albright. I represent Prior Lake and Jordan. I am a middle-aged white male. If you think about Santa Claus, that's basically my picture. White beard, white hair. My background is actually of the ice welling up on shore along the north shore of Minnesota.

I want to thank you and your staff for inviting me here today and for the conversation. I think it's probably one of the most important conversations that this legislature going forward into the next several months needs to have. And the reason that I say that is because of the isolation that we've all faced over the last several months with regard to an inability to share one another's difficulties with one another in a three-dimensional way.

Our legislature has been isolated from our constituents and isolated from those that come to the Capitol for a number of months for reasons that have been shared previously but that that needs to change. We deal best when we're in a three-dimensional arrangement where we can see the expression on people's faces, to see the expression and the faces of the people that are really in need of our services.

While it is true that with this state is experiencing a surplus currently, I would remind people that the disability landscape has changed as well. And I would dare say that investments as they have been called in a one-time fashion only really rectify maybe the symptom of a broader problem, and I would be my hope that this legislature really take a look at the true problem, and rather than make investments of a short-term variety that might be disappointing later when future funding is not there, to really look at the line items of the programs and the services provided to those that are in the shadows of life, if you will. That we provide meaningful services, supports and opportunities to those for the long term.

This is a visionary topic I hope we don't get lost in the numbers when we're talking about the future lives and careers of those that we serve through your organization.

So, thank you and I look forward to the conversation.

TREVOR TURNER: Thank you Representative Albright. Representative Reyer?

Representative Liz Reyer

REPRESENTATIVE REYER: Thank you so much. I'm Representative Liz Reyer. I represent Eagan, House district 51B. I use she/her pronouns. I'm a white woman in my 60s with short blonde hair, blue eyes, and black glasses. I'm in my home office with a blurred background, and I'm wearing a black jacket green sweater and a colorful green and red scarf.

First my thanks to the Minnesota Council on Disability for hosting this event today and especially for your advocacy for people with disabilities. I'm honored to be here today, and I wanted to attend in order to affirm my commitment to work on behalf of the disability community and to learn from all of you.

I ran for office out of a commitment to work for equity and to address structural and social disparities that limit opportunity for too many Minnesotans.

One of my earliest conversations while still a candidate was with Executive Director David Dively, and then as a representative I've had the honor of carrying legislation to support legal protections for workers with disabilities last session. We passed a bill that explicitly included interactive process as part of making reasonable accommodations within the Minnesota Human Rights Act.

I also chief author to bill HF2017, which we've heard about a couple of times today, to implement recommendations from the task force report, strategies for attracting and retaining state employees with disabilities.

Our state should lead and right now we fall short as an employer for people with disabilities. This harms all of us. Our state will benefit from proportional disability representation across our state system. This bill did not move forward last year, and this is the year we will get it heard and we will get it passed.

The Council has outlined a powerful legislative agenda, and I thank Trevor Turner for sharing that today. I'll just touch on a few other items from that agenda.

I fully support expansion of the Council's budget in order to be able to meet their statutory mandate, and even more importantly, to do the good work that is needed to support cabinet agencies and the public alike.

To improve true accessibility, I'm authoring legislation to require a percent of units in projects funded by housing infrastructure bonds to be truly accessible and a percent to be sensory accessible.

I'm carrying a bill to expand family hours for providing PCA services, and I will continue to be involved in discussions about the relocation of the Rare Disease Advisory Council to ensure that it is housed in the organization that will best enable it to achieve its goals.

Today, I offer you my commitment to be a steadfast partner to ensure that the rights and needs of disability communities are met, and I look forward to your input during today's session and beyond.

Thanks for having me!

Question

TREVOR TURNER: Thank you Representative Reyer and thank you for obviously for being our chief author for HF2017. You were very instrumental in ensuring that language got submitted last session which gives it a really good shot in this upcoming session.

So, we really appreciate that.

You all actually addressed a lot of the questions that I had for us today; so, for the sake of time, I think it'll stick with just one question. And that question is, "Do you believe, and would you support, that an expanded Minnesota Council on Disability with more resources that could serve our disability communities would be an effective use of our state funds to get a nice return on investment for an agency like ours?"

We're a very scrappy small agency with eight staff, but we do a lot, and I can imagine that we would do even more with a staff that was big enough to do our statutory mandate.

Would you support that? And I will start with Representative Schultz.

Representative Jennifer Schultz Response

REPRESENTATIVE SCHULTZ: Well, thank you for that question, Trevor.

I absolutely support your request and all of your legislative priorities this session, and I'll be excited to work towards achieving those goals.

I've always been so impressed with our agencies' across-the-board ability to work for the people of Minnesota, given their very limited resources, especially now during the pandemic when so many of them are working non-stop, and they've been doing that for more than two years.

And I always brag about our state employees when I'm with other legislators from across other states. So, I'm impressed with what you're able to do with your limited resources and definitely would support increasing your budget, so you can hire more staff, so you can meet the needs of the people of Minnesota.

TREVOR TURNER: Thank you. Representative Albright.

Representative Tony Albright Response

REPRESENTATIVE ALBRIGHT: Trevor, that's a very intriguing question, and I served on State Government Finance for a couple of terms. I've also served on the Health Finance and the Health Policy committees for a number of terms, and one of the things that is often asked is, "Would you support an increase in the budget for any agency?" And while on the prima facie of that, it certainly sounds promising, and I want to make sure that I disclose I am in support of increasing funding where there is a budget and where there is a bona fide return that has merit, and with your question I would support an increase in your budget. But I would like to see the P&L, that profit and loss in terms of what you're going to do with it.

Too many times, and I don't want to be sounding like a curmudgeon, but too many times the requests come for the legislature that ask for additional money. Intention is one thing but the response and to identify how you're going to use that money is really, really important because, while emotion can certainly drive the moment, it really comes down to a cognitive and logical progression for your work, and so I would support the initiative but I look forward to the details.

TREVOR TURNER: Thank you Representative Albright, and I look forward to meeting with you, and I'm happy to meet with you and walk you through our budget request and assuage your concerns.

And now let's go to Representative Reyer.

Representative Liz Reyer Response

REPRESENTATIVE REYER: Thank you. Well, I've already tipped my hand in terms of my support for the budget increase, and it's based on both conversations with both Trevor and David as well as review. There's a very detailed outline on how the funds will be used and the benefits of driving the increase. So, from my analysis of the request, I think it's very well founded.

I would also argue that a budget for an entire agency that does so much important work that's still under $3 million is an excellent deal for the state. I think that we can't afford the risk of not making this investment and ensuring that we can be supporting our disability communities through policy, through action, through education, and through the types of more structural material, captioning and other types of technology that are required in our current technological times to make sure the needs of the community are met.

So, I am a strong endorser of this. Thank you.

TREVOR TURNER: Thank you, Representative Reyer. And I just want to point out that our budget actually was under 1 million dollars up until this last year when our COLA adjustment, our cost-of-living adjustment, just tipped us just over a million dollars. So… and our budget actually is –

Our request is still under $3 million dollars.

So, we would continue to do that, and we'd like to you know...this is an investment...A lot of people think it's really boring and to talk about budgets and state government, but this is for us planting seeds so that we can do more and more and more for other people in the disability community.

So many people come to me every day with issues from across the board from transportation, from health care, to human services, to education. And unfortunately, I'm only one person, and I wish I could clone myself and be a million people and help all these different people individually, but I can't.

But I'm looking forward to continuing trying my best to meet the needs of Minnesotans. But being able to have a staff that still under three million dollars would be able to do a lot, a lot more and help the people within Minnesota.

So, thank you. That's all the time we have today. So, I'd like to move on to the next panel, but I really, really appreciate every single one of you for being here.

And our next our next speaker is Majority Leader Miller. I want to make sure...Oh there he is, perfect.

Majority leader Miller, welcome to our legislative forum. I want to give you a chance to talk about the Senate side of things, and before we go into our Senate panel. So, welcome and how are you today?

Senate Majority Leader Jeremy Miller

MAJORITY LEADER MILLER: Good afternoon, Trevor. Thank you so much for having me. I hope everyone is having a great day. I came on a little bit late, but it sounded like people were describing themselves a little bit.

So, my name is Jeremy Miller I am a 38-year-old white male, brown hair, brown eyes and wearing a gray sweatshirt with a black vest today, and my background is two pictures in the background here at my office at the scrapyard. The first one is a picture of the golden horses on the Minnesota State Capitol and the other picture is a picture of the Statue of Liberty with an eagle.

Trevor, first I want to say thank you for all the good work that you do representing the disability community across the state of Minnesota.

This is my –

This will be my 12th year as a member of the Minnesota Senate, and during my time in the Senate I have worked very closely with the disability community here locally, as well as at the Capitol to try to get good things done for folks living with disabilities, including the staff.

I think it's incredibly important that not only do we support our disability community, but we also provide support to the folks who are caring for them.

As we look ahead to the 2022 legislative session, the state has a very, very large projected budget surplus of about $7.7 billion, and when the February forecast comes out in a month or so, it sounds like that surplus might even be higher. So, Senate Republicans will be working together with our Democrat colleagues in the Senate, as well as our colleagues in the House and the Governor to really try to figure out a way to make that money work for the people of Minnesota.

And when you have a surplus that large, we're simply collecting too much money from the taxpayers, so we're going to figure out some targeted ways to get that money back to Minnesotans, especially those Minnesotans who are struggling during this really challenging time of Covid and high inflation and other challenges that are facing people.

Trevor, I look forward to learning more about your priorities, and - as I do with any group or anyone who is trying to pass legislation at the Capitol - I would encourage you to bring the stakeholders together, bring legislators on both sides of the aisle together, and sit around a table or get on a Zoom and just try to figure out what the best path forward is. And those type of ways of trying to get things done generally lead to better outcomes than doing it other ways.

So, I know you have a lot of supporters on the call, and I'm gonna hang on here as long as I can until my next meeting to hear from the other panelists.

And again, Trevor, look forward to visiting with you and others to learn more about your priorities this session.

Minnesota Senate Panel

Question

TREVOR TURNER: Absolutely, thank you Majority Leader Miller. We really appreciate it, and I really appreciate all the work you've done for the Minnesota Council on Disability in the past and disability community in general. So, thanks again.

And we are now going to go to our Senate panel, which comprises Senator Abeler, Senator Bigham, Senator Hoffman, Senator Nelson, Senator Draheim.

We'll go ahead and get them spotlighted and we'll begin.

Okay, perfect! Everyone is here. You know, this particular time, I think I'm gonna have every one of you introduce yourselves. But instead of the question, "Why do you agree to be here today?," I would like to jump right into the question that we asked our last panel: "Would you support the expansion and capacity building of our budget so that we can serve the disability community even more than we already do?"

And then I'll start with the first person I have here is Senator Abeler.

Senator Jim Abeler Response

SENATOR ABELER: Well, thanks for having me. Can you hear me okay?

TREVOR: Yep!

SENTATOR ABELER: Okay good, technology! Oh thanks for doing the panel and thanks for all you guys do.

We just came off of hearing about the workforce and you know, maybe I'll get into that too, but just I can't get that off my mind. The workforce needs in the in the disability community group homes and people with special needs is grievous and the system is about to collapse.

And it just makes me -

If you watch the hearing, it was a very interesting hearing the first hour would be very meaningful to all your listeners, all the viewers here about what can be done.

We heard from some operators and some staff that they're 30% short, working 12 hours, sleeping in the basement, sending people home no respite. Half the people that were living in penalty are now… They couldn't get respite, so they're back in a group home, which is exactly the way we don't want to go. So, it's just a grievous thing.

And so, to your question about this expanding your function, specifically. I think somebody better coordinate this and I frankly don't know if it's you. I do not see coordination coming out of the administration. I see a bunch of well-intended people working in departments as a bunch of medieval castles, remembering Europe was a feudal empire and they had a castle and a castle and a bunch of well-intended things, and they are not coordinated and they're not collaborative.

And the individuals who need this service so greatly suffer.

If you were to expand, you'd have to be given some authority and so just another louder voice yelling at the castles doesn't do any good. If I thought I was gonna put someone in charge of more coordination, it would be you all because you actually live on the front lines.

We - Senator Hoffman and I and my committee - have been struggling with getting the agency to actually be interested in the needs of the individual, especially to the change as we've been going forward.

So, I'll leave it at that for now. Thank you.

DAVID DIVELY: Pardon me, Trevor. Thank you, Senator.

I wanted to just jump in and redirect the question a little bit, actually, to something a little bit consistent with what Senator Abeler was talking about,and a little bit broader as well, which is issues around employment for people with disabilities, economic success for people with disabilities. Whether that's support services, they need to be independent and living in the communities that they want to live into, you know, just as Senator Abeler was saying.

But also about if you are aware of our Employment and Retention of Employees with Disabilities Bill, improving how employees are protected, accommodated, and retained as part of the state workforce and maybe for this part we're just going to switch away from the Council on Disabilities capacity, specifically, and just talk about the disability community at large and their needs for independent living and employment opportunities.

TREVOR TURNER: Yeah, thank you, David. Obviously, I wish we had a lot more time to discuss a wide range of issues, but that is also the point, and there's so many different issues to talk about.

And I do want to thank Senator Abeler. He and Senator Hoffman were very instrumental in helping us get the Connect 700 and the Hiring and Retention of Employees with Disabilities language and submitted into the Senate, so we really, really appreciate that.

Senator Hoffman, would you like to go next, and then you can just answer what David was referring to?

Senator John Hoffman Response

SENATOR HOFFMAN: Absolutely. You know, thanks for letting me be here, and thanks for the work that you and David and your group has been doing.

There are duties and powers of the MCD established in statutory authority, but it's mostly advising and assisting. You are the ones who are the go-to because not all agencies have people collectively in their own agencies that understand what reasonable accommodations are. What does it mean to have somebody that's in a human rights capacity? We know 1 in 5, so what brings me here, is 1 in 5 people in Minnesota live with a disability, right?

Who's the ones that are advising and assisting the departments and the agencies about what they should be doing in response and as such?

When that task force, which you guys headed up, became a viable and a real authentic report we absolutely –

We jacketed those into two bills, and thank you, Representative Reyer, for bringing that up earlier and also the Lieutenant Governor brought it up.

This is the year that we can help level the playing field to assure people with disabilities are absolutely working in employment in the state of Minnesota, right?

It was established under Governor Pawlenty, was enhanced under Governor Dayton. It was reauthorized under Governor Walz, and now let's make this a statutory place and as long as we're doing that as a statutory place, let's look at the broad authorities that you guys have under subdivision five and actually expand those, right? Because not everybody has working knowledge of what it means to have a reasonable accommodation. What does it mean to have a lived experience as a person with a disability within the state of Minnesota?

You all have that and so if there comes a time to expand on those priorities, absolutely count me in! So, thank you for having me here, and thank you for the work you're doing.

TREVOR TURNER: Thank you, Senator Hoffman. I really appreciate that. And let's go to Senator Draheim.

Senator Rich Draheim Response

SENATOR DRAHEIM: Thank you and Rich Draheim. I represent District 20, which is more of the Le Sueur County, part of Scott, and part of Rice counties. I'm a white male at 52, blue eyes, wearing a blue shirt and first off, I'd like to thank you for the invite.

A lot of the topics that you laid out are topics that I have worked on, and I think are vitally important.

You know the broadband, housing affordable care, employment, mental health, and then some of the comments that Senator Abeler and Senator Hoffman, who have pioneered a lot of this for decades, if you will.

The PCA problem is huge, and group homes are... in my area two are very, very much ready to go under and are barely hanging on.

But as far as the specifics on employment, I think we really took a bad turn the last year with employment, with Covid. I think we really need to examine what we're doing for the employment portion of your ask. I would be really interested to work on that piece specifically, and of course, the housing piece. But, once again, I'm here to learn and listen and I appreciate the invite. Thank you.

TREVOR TURNER: Thank you. Let's go to Senator Bigham.

Senator Karla Bigham Response

SENATOR BIGHAM: Thank you. And since Senator Abeler and Senator Hoffman didn't describe themselves, am I allowed to describe them on their be-?

No?

I am Karla Bigham, state Senator. I am a 42-year-old woman, short, round. Here I am in my office, and I have my Rosie the Riveter behind me along with my figurine of Ruth Bader Ginsburg, and I am wearing a black sweater over a white blouse.

Thank you. Thank you for having me on.

This is just super important when it comes to having a discussion with the panelists that have been on. I applaud each and every one of you, House and Senate, because this issue really has become front and center, as it should be.

And I'm gonna be honest, like, I don't know how much more I can add to it other than partnering with our counties on different things for us to make more efficient and more cost effective on some of the services. But I think Senator Abeler has the power to make those efficiencies. He's the chair, let's do a bill. Let's get it done to make things more efficient amongst the departments.

And I also want to point out because it hasn't been, broadband is so vitally important. So vitally important and we need to continue to make sure that the federal funds are going to expansion broadband for accessibility so that we can employ people with disabilities.

And I just feel that we are really able to build on some of the accomplishments from last year and important work that we did from last year.

I know it's been mentioned, but the PCA increases, other waiver rate increase, and all of the wonderful work that for years people on these two panels have been working on. But let's listen here and how we can do better that's really what we're here for, and I'm committed to that. So, I look forward to signing on to Senator Abeler's bill to make things more efficient. Let's get it done!

Thank you for having me. Thank you for being here. Thank you for telling stories and reminding us of the important work we have yet to do. Thank you so much.

TREVOR TURNER: Thank you, Senator Bigham. I really appreciate that, and then now let's go to Senator Nelson.

Senator Carla Nelson Response

SENATOR NELSON: Thank you so much, Trevor. Thank you so much for having me. I am Senator Carla Nelson. I'm here in my home office with a print of the Capitol behind me, of the Capitol dome. I am a middle-aged white female with dark curly hair and glasses, and I have on a maroon jacket today.

And it is a joy to be with you. I was able to join for the full meeting here, and I just -

And just a little background. My training is as a special education teacher, as a reading specialist. The disability community has been important in my life since I was a young teenager, actually, volunteering with the Warren County ARC while I was in college. I worked for the Polk County ARC. I went to college on a small scholarship from the Warren County ARC.

So, this community is incredibly important to me, and I think it is our moral duty really to make sure that we do all we can to help every Minnesotan live their best lives.

And I think we live in a wonderful time. Covid has stressed us greatly and it will continue to, I'm sure, for some time, but we also live in a time where we have miracles, modern miracles of medicine like vaccines, therapies, things that didn't even - when before Covid - even existed. We did not have any therapies or vaccines we do now and that's because of the innovative medical technology that we have.

We also have all the innovations that I think provide every Minnesotan with great workforce accommodations, and it's critical for our workforce that we make sure those accommodations are available for every Minnesotan.

So, I will continue to advocate for this community, it's near and dear to my heart.

I've been very involved in mental health, making sure we have necessary mental health access for all Minnesotans.

I have worked closely in the affordable housing community. These things are so important to all Minnesotans. They're especially important to Minnesotans who are in the disability community.

I was the author of the amendment that added home and community-based services to funding from the federal grants, and I'm so thankful Senator Abeler was able to carry that through to-

Through conference committee and signed into law.

I know the challenges remain. I do encourage people to reach out to me, sen.carla.nelson@senate.mn. I do want to hear from you about how we can make Minnesota more inclusive for all Minnesotans and make sure all Minnesotans have the ability, the tools to live their best lives.

TREVOR TURNER: Thank you, Senator Nelson.

I wish that we had more time to go more into detail into some of these things you all brought up, which I think just shows that there's so many different issues that we have to work with and address. And I think this also means that we need to do this more often.

And so, I hope to do more, you know, round tables and panelists so that we can talk about specific issues like transportation and the PCA shortage and all of that. And so, I think to the public here I want to make a commitment that we will engage more and do more of this instead of once a year, but more often so that we can hear all the voices and talk about all the different issues that we are trying to address and talk to through here so…

But thank you to the panelists. I really appreciate it. We're going to move on to our public comments section now.

So, in our public comment section.

Public Comment

Joyce Lacey on Guardianship Laws

JOYCE LACEY: My name is Joyce Lacey, and I'm here today to plead with you to call your legislators, and if legislators are on, I'm begging them to listen.

I'm here to plead with you to pass Senate File number 1462, and House File number 2093. Basically, what they do is they enforce the bill of rights for wards, that is people that have been put in guardianship and conservatorship throughout the state. It also lets people know that they cannot overdrug or unnecessarily drug their wards. I'm going to tell you a story of what happened to my mother, and I wasn't even aware there was a bill of rights because of what happened to her.

First of all, my mother had just returned from the national pageant. She was in a senior pageant and was crowned Miss Congeniality. She had a lot of spunk. If you remember the Golden Girls, she was so much like Sophia on the Golden Girls - tiny and petite but lots of energy.

So, we were helping with the Alzheimer's walk. It was September and her breathing got bad. She had congestive heart failure, and she was disabled but still going strong, like most of us are still doing. So, I ended up taking her to the E.R., and they wanted to keep her for observation. So, I agreed to keep her in the hospital.

Now, this is before Covids and so we all stayed in the hospital. The next day, a hospitalist doctor, a hospice nurse, social worker, and a chaplain of all people came, and they tried to convince me to put her DNR, dump her in a nursing home, and put her on hospice.

I said, “Absolutely not.”

I was the power of attorney and she wanted to live, and she was feisty and had so much to give to the community.

So, anyway, the doctor, hospitalist doctor - never seen her before in his life - he said, “Well, you're a very, very poor power of attorney. And by the way, are you the legal guardian?”

And I said, “No, she doesn't need a legal guardian. She's not incompetent.”

So, he left and he said he had wasted 27 minutes on me. Anyway, the next day they came back, they went over my head. They got an emergency guardianship conservatorship to do with her what they wanted to do. So, I said, first of all, they were giving her a shot.

She said, “No, no, I don't want to go into a nursing home.”

They gave her a shot and I said, “What are you doing?”

The nurse said, “We've been ordered by the guardian to make her comply with any and all means necessary.”

Which is they were giving her a shot of morphine to knock her out. I couldn't believe they could get by with that because she did not want to go in a nursing home, and the ones they were putting her in… We were in the Twin Cities because the Alzheimer's walk was at Target Field. The nursing home they were putting her in was 250 miles away, and I called and there was one closer, but they insisted she go to this nursing home.

So first off, we had an emergency. We had an ambulance bill of 215 miles, which you can imagine how much that cost. She gets to the nursing home and right away, after she's been drugged I don't know how many times, because she was feisty like Sophia. And they have a court reporter there waiting to interrogate her.

And I cannot believe that they could do that. That's entrapment.

Anyway, when she was at the nursing home, they refused to allow her to go out the door. They wouldn't allow her to use a commode or a toilet. She had to use a bedpan her entire stay. She was given day-old purchase rated food and drugged continuously.

And she didn't need the drugs, she didn't need objection, a could done, morphine, all these things. They're called chemical restraints, as you know, because people cannot use physical restraints anymore. They've started to use chemical restraints.

And this guardianship probate thing is done in a probate court, which is meant for property, so the person is made into a piece of property. Thus, it's kind of like slavery.

All my mother's money was taken from her, everything she owned including her person, and she didn't have any choice with anything. Whatever the guardian said, went. So that was it. Within three weeks, she had pneumonia, staph infections, UTI, bed sores. Never had any of that in sheer life.

So, what happened then was they had to take her to the hospital because she wasn't DNR, and she wasn't in hospice. So, they took her to the hospital. They took her to Fargo, and she ended up fighting all that with antibiotics.

On Monday they took her in. By Wednesday, she was sitting up. So happy she could sit on a commode to go to the bathroom and eat good food.

So, I found a place, a nursing home close by the hospital, Bethany. And they had a bed, and so I thought that's where she was going. But no, the next day came and she was being released. The guardian insisted she go 80 miles back to this other nursing home, which I late found out the guardian's company operated. Anyway, so she was force are the to go back there.

I was removed by security because I said they nearly killed her in three weeks. I would rather go to jail then have her go back there, but they forced her to go back, and she didn't want to go back.

Anyway, all her bills of rights were taken. Anyway, I called adult protection three times, got letters back from the county saying they decided not to investigate. I called the ombudsman. Ombudsman got a letter back going, no, no, they weren't going to investigate, either. So, she gets back to the nursing home. After she's fought all that and bite it, then the nursing home doctor puts her on hospice, and they drug her even more heavily.

Well, needless to say, she passed, and all this should have been avoided. My mother did not want to be DNR. She did not want to be on hospice. She didn't want those drugs. Then I later found out that hospice was given $11.5 billion from the Affordable Care Act to go basically from the…they used to be good. It was basically care, basically helping people that were terminally ill. Now, my mother wasn't terminally ill.

So, I want to make people aware of this because this could happen to any of us because, basically, it's a lot of money involved in this. They have a lot of lobbyists that are trying to go against us, but if we could get these bills - if you could write these down - House File 1462, House File 2093, and Senate File 1462. It's basically just to enforce the bill of rights.

And like I said, adult protection when they are in a guardianship, they wouldn't get involved. They wouldn't help my mother, even though pneumonia. You feel TI, bed sores, she was black and blue.

I got a police officer to come up and he said, "I wish I could help you. He said, "I can't get involved either because she's in a guardianship."

So, there was nothing anybody could do. But he said if she was a criminal or had, you know, a rap sheet or was in jail, she would have more rights because she could say, "I don't want those drugs. You can't give them to me."

And in a guardianship, they can truck you and drug you and drug you and you have no say. That's why this bill is so important to get passed. It can save lives. It can help these people to have their rights restored. Their human rights are taken away. It's not right. If people could call their legislators, that would be wonderful.

Thank you so very much. Really appreciate it.

Kim Pettman on Medical Care Access

KIM PETTMAN: My name is Kim Pettman, and I am kind of what you would call citizen advocate, and I like public policy. I happen to be a person who has multiple disabilities, primarily physical which also can cause chronic pain, which can also cause a little bit of other stuff.

Chronic pain can be a little depressing sometimes. A lot of people try to tell me, stay on point. The thing is, a lot of different things happened to me in the last year and a half and many different factors contributed to I'll call it an adventure.

Please, legislators and others, please contact me if you would like more information. I feel that I'm able to speak for myself, and I want you to think about the people in similar situations who are not being heard.

So, basically, the biggest problem I encountered was I did go to a hospital in Greater Minnesota during the pandemic when there was availability for me to go to ICU. I had septic shock and was in extremely big trouble for five days. Part of that had to do with a dental abscess that was not treated, partly -- well, mostly because of coverage issues and bariatric accessibility, which means although I had a good provider, three needed me to be in a certain type of chair that could recline so they refused to take out my teeth.

Different people were saying, you've got to get this taken out, including my mom, a former nurse, and others, but this dental abscess led to a great deal of infection. There were a lot of obstacles and I tried very hard --I'll skip that part of the story. It was a really big problem.

So, one of the main problems I run into is once that ICU period was over, and there were other infections going on, too, and I don't know if you can see but here's my arm, so I'll describe it. I have kind of a swollen arm. Because of lymphedema. When I was really sick, my arm poofed out to twice the size. And you see, lymphedema and infections don't go together well. It's just not a good thing.

So, when I was in the hospital and became what is called post-acute status, my body had gone through the ringer, and not everybody knows that people coming out of ICU or very serious conditions can be…they take a while to recover, sometimes months.

Unfortunately, kind of bouncing off a little bit of what Joyce said, hospital lawyers. The bottom line is in hospitals, the lawyers and the leaders often don't care about people with disabilities, and if you speak up, there's a lot of retaliation. So can you figure out a way to protect the people with disabilities and older people within these settings.

And also, I was stuck in hospitals for over a year because there wasn't a place for me to go. We need bariatric accessibility in long-term care.

So, thank you very much.

Kathie Leroy on the Right for People with Disabilities to Marry and Keep Disability Benefits

KATHIE LEROY: Thank you to all attendees and speakers for your participation today. I'll admit I'm kind of wading in to my very first meeting here on the inspiration of my son, Mike Leroy. I will go back a bit and contextualize where I'm at.

Mike Leroy, my 16-year-old, is also attending today so you may see him in his window with short blonde hair, a green hoody, gray pants and sneakers. He's using computer out a bit, so you may see the school room behind him, sitting in a blue power chair and has a head array.

I am really thankful to hear so many of the aspects of ongoing policy and priorities. I will admit to not knowing if I'm exactly in the right wheelhouse of speaking points for all of those but very interested in future opportunities to contribute and help increase advocacy amongst care-givers as well as individuals with disabilities.

My main goal today is to speak a little bit on Mike's behalf to share a story of how he's been able to personally learn more about legislative process and begin to find his advocacy voice, and so he has given me permission and asked me to kind of cover a few things. I'll back up a bit and say, you know, one of the things as a parent really looking to try and help him find his way and dream big and get the support he needs in order to get his education and pursue jobs. And he asked me the other day if we were rich.

So that was an interesting question. And he followed that up with, “How are you paying for my equipment, my medicine, my helpers?”

So, what that kind of cued for me or made me sit up and look at is, you know, we're on about an 18 month window here before he turns 18. That's a heck of a lot of stuff for me to download from my brain to his brain, and thankfully, we've been including him in the process. He's met with his doctors, he's made active medical decisions, chosen to get a brain stimulator put in. He is showing all the signs of being a really great advocate, and so we'll be continuing to explore that.

But it reminded me of a conversation that we had a year or two ago when he asked, you know, he was talking about how he also would love to maybe have kids some day and would he get married and how would all that work. Well, I explained to him that, actually, the way some of that works is really complicated, and he might need to think about if he's getting married or not based on the way that some of the programs are set up in the United States to make sure that people have social services support.

All of that kind of set-up is to share that Mike has been able to participate in the Minnesota youth and government process for the last couple years, and just this past weekend I got the unique experience of being a bit of a fly on the wall with 900 high school students, grade 8 through 10.

Well, I'm just going to play for you, then, the purpose of his bill. He had asked me to share it and I'm happy to testimony as Kim did follow up with anybody that' interested, but I'm going to just play a minute. This is how he presented his bill, but I'll just do the front part here.

[BEGIN AUDIO CLIP]

People who are disabled deserve the right to get married if they would like to do so. So social security, medical comp or other civil benefits. Situations vary by state, but across the United States access to financial and insurance support for people with disabilities is often determined based on whether or not they or their spouse has a job and according to that an income and assets. If the spouse works, then a person with disabilities receives less support. This is unfairly keeping people with disabilities from marrying Because it limits the health and financial support they will get.

[END AUDIO]

So, again, that's just an abridged version, but I think speaks to the importance of really broadening awareness among people of all ages. I was really encouraged by the receptiveness of his classmates and everyone's reaction, which, quite frankly, I mean, it's not super formal feedback, but he got so many comments afterwards from attendees. I can't believe this is a thing, that's so unfair. We really they would to change this.

So, in closing, I know it's not an item on the agenda right now, but I think as a national and local to Minnesota concern that I just wanted to make sure we have a little bit of awareness around it, as well. Thank you.

Mariam Egal on Special Education

MARIAM EGAL: Thank you so much and good afternoon, everybody. I don't want to name names, but all the distinguished legislators, I say good afternoon.

I'm here as Mariam Asman Egal, as a mother and I want to share with you my story that pertains to my son. If I can share the screen for a minute - I can send that another time. He's 24 years old adult autistic who has never been identified or diagnosed with autism or any other condition. And who happens to be my son, you know.

There is nothing I could do, we missed early intervention because of my denial. We have a history of autism in our family, actually two of my younger sisters have two autistic children. One of them is a young adult, mine is only 4 years old and the last sister, her son is maybe 12 years old or 11 years old.

My experience with autism was when my son was three years old, his doctor said, “Oh, wow, you know what? You need -- I want to refer him to speech therapy. He has delayed speech.”

And I did not like that, so I said, “Okay, let's make an appointment with a speech therapist.”

And I did. And on my way from, you know, his pediatrician, to my home, my mom calls me, and I tell her, I said, “Mom, you know, I'm taking my son to see a special therapist.”

And she said, “For what?”

I said, “For him to learn how to talk, he's behind with -- when compared to his peers.”

And sure enough, my mom said, “Oh, get out of here. You see how he has a big head? Your dad had a big head, and guess when he spoke, when he was five years old. And so forget about that shit and move on.”

So, I moved on. Because I really trust my home, and I don't want to spill over time but anyways, I have this young autistic adult male that I have raised on my own with no support.

But it gave me an incentive to work with families of children with autism, with families of children with special needs and make sure that they growth every intervention and that they dealt with the disability right there and then and embraced autism instead of being in denial because I was in denial.

My sister has -- who has the 30-year-old young autistic with severe autism in sin waited years back, “Oh, Mariam, I think he should be tested for autism.”

And I was like, “Just because you got autism in your family doesn't mean that my son, you know, is a retard. No, he's not. My son is okay. Forget about it.”

So, I was in denial so that cost us losing early intervention, but guess what? I educated myself about the autism. I started helping others so hide what I have to do for my own. I didn't want to say, “Oh, my, I have disability in my family.” No, I was like, “Hey, who has, you know, any challenge, the parents.”

I came to Minnesota solely for that and I have been here nine years just working with families of a different culture with the language barriers, with socioeconomic status barriers, with educational bearers, and with individuals, you know, that -- if helped earlier and with early intervention could [indiscernible] and integrate and live to their full potential.

So, I managed to do that and my work reflects I have shared -- I think with Trevor two links. I wanted you guys to see what my work has entailed and what was -- to me, what was an outcome, a positive outcome that came out of my work, the nine years that I was in denial about my own problems because my son was already a young adult, and he was in denial and he was in compliance.

And he was like, “No, I am not going to see anybody. I'm not crazy. You are crazy.”

But I can see he's smart, he is super. He has some challenge that I helped, and I adopted in helping him with his challenge. And he is super smart. He's like if he wants something to happen, if he wants to buy a house now and he has saved money and he has worked hard on his credit, it has to be on time.

But then fortunately –

So, I have those recommendations. I recommend that we partner with these community and so that we can get their feedback in a culturally and linguistically appropriate manner.

Thank you so much and I'm sorry if I went over time.

Jillian Nelson on Accessibility for Neurodivergent Minnesotans

JILLIAN NELSON: I wanted to bring forward three pieces of legislation. I'll introduce myself first, Jillian Nelson, the community resource and policy advocate for the Autism Society of Minnesota.

We are currently working on large package of bills. I want to highlight the overall package and then speak specifically about three pieces. We are working on expanding accessibility in the state of Minnesota. Minnesota has long been a leader in accessibility, but it is time that we recognize that individuals with invisible disabilities have unique accessibility limits that are not clearly outlined as in the Americans with Disabilities Act as that those with physical accessibility needs.

So, we're bringing forward a package that includes grants for public spaces, public courtroom bills, plain language bills that will all focus on expanding accessibility for all Minnesotans with all different types of disabilities.

One of those bills I'm going to speak to is our special education parent accessibility bill. Parents with disabilities face unsurmountable barriers in requesting accessibility accommodations through the IEP process. When this is brought to MDE or the Minnesota human rights commission, parents are often greeted with, well, with We need documentation that you followed the policy and procedure to request accommodations.

Unfortunately, at this time, there is actually no policy or procedure in how to request accommodations, as a participate in the IEP process. So, with the help of Representative Freiberg, we put together some policies and procedures on how parents can request accommodations in the IEP process, and we're hoping to move that bill forward with hearings in the House and the Senate and hopeful passage this coming session.

Under the encouragement of Senator John Hoffman, I have been working with Minnesota Disability Law Center, the Autism Senate Council, as well as a number of other organizations, to look at reforming rates for Medical Assistance for Employed People with Disabilities. These rates have not been adjusted in many, many years, and right now, they do provide a barrier for employed people with disabilities to access Medical Assistance, and in many cases, may actually be keeping people with disabilities out of the workforce for fear of losing their benefits or not being able to maintain employment with the high level of fees to access your services through this program. We're hoping that if we can reduce these fees, we can increase employment in the disability community, which can hopefully help with some of our greater workforce crisis by getting people with disabilities back into the workforce while still being able to maintain their benefits.

And then the last bill I want to speak with is one very, very close to my heart. I've been working directly with the Disability Law Center to draft language regarding a task force. I have many people here, every story we've heard links back to the inaccessibility of our disability county and state services. And a person living in Minnesota with a disability knows that accessing Medicaid, accessing a waiver, accessing anything that relates to your disability through the county and state services is One of the less accessible systems that exist in this world.

I'm a firm believer that disability services should in fact be the most accessible system we have in any government system. So, Disability Law Center and I are moving forward with legislation that will propose a task force be assembled to look at the accessibility of all state and county disability services, as well as launch a number of different pilot programs to test out different solutions for accessibility so that we can move forward in making legislative changes and departmental changes to make sure that things like waivers, things like Medicaid, things like the Smart process, things like the MnChoice process are the most accessible systems so that the payment with disability that need services are able to get services.

With that I feel like I covered a whole lot of information. But that's what I wanted to share. If anyone has any questions or information or if any representatives or senators listening to want to join us on this work, feel free to reach out to us at the Autism Society of Minnesota. We are happy to work together to make the most accessible Minnesota possible.

Damion Lievstad on Homecare Workers

DAMION LIEVSTAD: Thank you for having me. My name is Damion Lievstad. I currently liver in Plymouth out with my parents. I was born with a neurological disorder called Spinal Muscular Atrophy, and I've been in a wheelchair since I was ten years old.

Subsequently, I've been using home care services since I moved to Minneapolis in 1992. Well, not just in Minnesota but nation-wide. The shortage has a tremendous impact on those of us who rely on home care services, as it inhibits our ability to experience the sense of security or stability in our lives that most people take for granted.

Due to our inability to hire and retain quality home care workers, we know our health safety and needs will not be consistently met. Without this basic expectation, it's difficult to know what next week, next month or certainly what the next year will look like. It makes it impossible to plan for a paid job, planning event with family and friends, or get involved in our communities.

After all, simply surviving becomes our primary task. While I've been blessed with [indiscernible] family…The time, energy and challenges are finding workers-for me and thousands of other people with disability can be really vulnerable, burdensome and a time with little hope.

Yet, I am confident if we work together on services together, as people rely on services, people providing services, people coordinating service and with our family and friends, the future can be amazing for all of us.

To do so, however, we must be willing to talk openly and listen intelligently to people who use and rely on these services.

The workers in the profession in order to increase our -- in order to increase workers coming into the workforce. I believe there are several things the state can do. One is to create a college tuition credit program. This credit program for those who want to go to college could get a tuition reimbursement by working in home care. This would not only bring people into the home care field, it would also provide equity for other people who cannot afford college or a means to do so. Currently, Representative Clevorn of District 44A has HF 338, which is a bill to set up a program for that.

Another program would be a student loan payback program. After graduation, majority of students who were home care workers during college move on and find odds full-time jobs. Without the life-sustaining support that I require.

Similar to the college version, this would create, encourage students to continue to work in home care industry and provide care to elderly and disabled Minnesotans while -- making college more affordable to those who otherwise could not attend.

Another thing they could do is create a tiered-wage system for PCAs. Most PCAs start out making the same wage as someone who's worked five, ten or 15 years as a caregiver. We need a tiered system that will pay PCAs more that have worked longer and developed more skills.

Health care will allow home care workers the ability to -- health care like MnCare for someone working in home care, even part time, to be able to get affordable insurance. Currently due to low wages, many home care workers have two to three care jobs which then puts them over the income limit to qualify for subsidized health care.

Currently if you have over ten hours your PCA is paid 7.5% more. But we need to make a tiered system so that our clients with greater needs can receive more competitive waivers and change the system so that high needs clients have the ability to attract and retain quality home care workers.

Thank you.

Lisa Juliar on Covid Policies and Disability

LISA JULIAR: Hi, thank you. Thank you for having me and allowing me to share just a small part of my story.

For the last 20 years, I have been an advocate for inclusion both in education and in health care. For the last decade, I've worked as a patient and family engagement specialist, working towards safety in all settings of health care.

I would just like to share a bit of my story because for the last two years, my son has essentially been excluded from society. And I would like to just share it and hopefully there will be some changes coming in the future.

As we know, there was distance learning, my son has a chromosome disorder and is nonverbal. He was not educated for a full year because he is not able to learn in a virtual setting. He is not able to talk because he has some low muscle town in his face and so he drools. That means that he is not able to safely wear a mask without feeling like he is drowning.

In the last year, he has been denied urgent care when he slammed his finger in the car door and was pleading and had been in pain because he couldn't wear a mask. He was not allowed to come to speech therapy because he was not able to safely wear a mask. He has shunned from restaurants. He has been kicked out of movie theaters. He has been disrespected. He has been made fun of. I have been accused of not caring for our community and told to keep him home until the pandemic has passed.

I understand that this is not the mainstream narrative that everybody clings to, but this is important as a person with a disability. I have never in my wildest dreams imagined that he would be so discriminated against, shunned, and excluded from society as he has in the past two years.

He has not seen his social worker for two years. He has not been able to access vocational rehab. He is 20 years old, he has very limited time. He has decreased his reading exponentially. He is depressed. He has not seen his friends.

This is a tragedy. and it is not meant – it is not okay to –

And now, and now we are going to put more mandates out there and exclude him further.

I want to say to any legislators, any leaders that if you are not paying attention to people that cannot safely adhere to these mandates, you are part of the problem.

Owes a gentle, kind soul who loves people. He also relies on facial expressions to communicate, so at times, I have taken my mask off to communicate with him. He touches my face, he brings himself closer to me. I am his only connection sometimes to society. And I've been yelled at because my mask is below my nose.

I am shaking right now, I am sad but there is no reason that we should come to this as a society. He is not a leper who should be shunned and not allowed to participate in all the things that you all participate in, that everybody around him participates in. This is a tragedy that needs to be looked at.

Thank you very much for your time.

Karen Larson on Direct Support Professional Crisis

KAREN LARSON: Thank you very much. I'm sitting her crying. I would my agenda, everything all ready to go, and Lisa you blew me out of the water, Lisa, thank you very much. You guys got to understand, when you hurt a child, you better watch out because mom is coming full force.

My son is 34 years old, and we've had to fight every fight between education, between medical issues, between just getting the services we need. It's really important.

I was so proud and happy to hear, that you all want to hear stories, right? Well, hearing them and making action on it are two different things. We need you to hear. We need you to listen, we need you to understand. You don't walk in our shoes. You don't know what it's like to get doors slammed in your face and if you do, thank you, but most folks don't know that because they don't walk this road we walk. They don't know how hard it is.

We have -- I've been fighting for 34 years, and things just are getting worse now, you know. We thought we were -- Minnesota was doing really good I thought I would never hear this in the State of Minnesota again.

The main reason I raised my hand is up until the point I raised may hand, we didn't talk about the direct support professional crisis we have; and thank you, Damion, for covering that issue. Thank you for everybody else for covering that issue.

You know, people are sitting in their chairs all night and not getting to bed because they don't have staff to put them to bed and they don't have staff to get them out of bed. People are not going to work because there's nobody there to support them at work. You can't put people to work if you don't have the supports there for them to work, period.

You have to watch where the funding is going. You funded PCA. Awesome, PCA, awesome, thank you very much. But there are other support workers like DPSed out there that did not get a raise, did not get the funding they need.

And I want to talk about a provider aspect. I'm not a provider. I don't work for a provider but I'm telling you right now there's doors closing everywhere in Minnesota. There's group homes shutting down houses and moving people to a strange neighborhood. Pack up your house now, you have to move to Minneapolis because there's no house here for you. Changing the person's whole atmosphere, environment. They know where the local grocery store was, and now they don't because they moved to Minneapolis, and they know nothing about that community.

Now folks are stuck at home, no job, no communication, no community involvement, no socialization. Talking about shunning, because that's where we're headed and it's happening every day, an employer that's been around forever and ever said if I lose one more DSP, I'll have to shut my doors and they've been around forever and it's happening every day. This is not a crisis anymore, you guys, we're moving into emergency care needed now. We need to do something. And if you need more information, the University of Minnesota ICI has tons. You want stats to support the stuff that I'm talking about passionately, Amy's got the stats. We just need to pass legislation so folks get what they need, and shunning folks is not happening.

We've worked really hard in Minnesota to hold that up and make a wonderful Minnesota for everybody. Let's don't go backwards. Let's make it better. Let's be number one again. Thank you.

Roger Day on ADA Violations

ROGER DAY: First off, I want to congratulate and thank everybody who's helped create this event and everybody who's participating in it to make it what it is. This is really a fantastic thing, if there's anything that I really want to drive home is that more of all of this good work will be great, and so my message is, I like the progress and the passion that I see, and I want to compliment everyone on following their passions.

In my early 30s, I was disabled by Minnesota's government in general and its judiciary in particular, and so I have PTSD from governmental and judicial abuses, and so I've got a bit of a unique disability. My disability only really shows up when I deal with government to try to overcome the abuses, and I developed a government phobia, frankly. And so, it makes it very hard to take political action to try to address the cause of my disability which is political activity.

Really hateful political activity on the part of certain individuals in positions of power. I'll leave it at that, but I suffer from a number of legal challenges, and I have turned to the Minnesota Disability Law Center over the years for help with those challenges, and the Minnesota Disability Law Center just doesn't have the resources to be of enough help to me. I've gotten a little bit of help from the Disability Law Center, but it hasn't been nearly enough, and I've had to go into state and Federal court on my own and the State of Minnesota who I've been trying to bring to justice has let its lawyers put up differences, such as sovereign immunity from the ADA.

And so, I've tried to sue the State of Minnesota for ADA violations, and the State of Minnesota has tried to get out of them, and I think that's atrocious. That the state of Minnesota allows the state Attorney General to make arguments that the state should get out of ADA violation litigation.

So, it's a mess. I think the legislature should look very hard at what the Attorney General's office does, and I think the Disability Law Center could be a big help with that. So, the one thing the legislature could do is provide a lot more funding and direction for the Disability Law Center and can also look directly at what Minnesota does within disability litigation. Because Minnesota does not play fair and state and Federal judges actually go along with the dishonesty of the Attorney General's office.

And so, we've got a serious problem with judicial corruption and with a state Attorney General's office that is not working for the people but is actually working against the people.

So, again, keep up the good work. This is a really great community, and I think we've got a lot of work ahead of us. The pandemic has created new challenges, and I see people rising to those challenges, and it's really wonderful. So, let's keep meeting and keep working.

Thank you.

Pat Lang on Parenting a Child with a Disability

PAT LANG: My name is Pat Lang. I am the parent of a very, very medically fragile child. I am also the coordinator for the health information center at the PACER Center, so I've been –

I've had the privilege of working with Senator Hoffman and Senator Abeler who so graciously help us fight the fights. My concern now is my daughter is -- and I thank you, Damon, who gave great, great ideas about how to help the workforce shortage.

My daughter requires 24/7 nursing care. It's not a shift at night. She gets treatment, she's completely dependent on machines. She's on a vent, on a feeding tube. She has a should not, ice diabetic. Many, many things. She can't move on her own and she requires home care nursing.

All of that has been justified by the services that she's supposed to receive. But there is a home care nursing shortage. The home care nursing shortage is horrendous, and there are ways to think out of the box to pay these women and men that work in this industry. There are things like Damon mentioned, education reimbursement, gas cards. There are ways that you could have a tiered payment depending.

My child, you can't sleep as I mentioned. She gets over 68 immediate passes a night. She really could be in a hospital.

When I have -- I've gone 72 hours without sleep because I'm working as well as -- so I can pay taxes, and I am doing the medical care of a nurse when I don't have a home care nurse.

It is something that needs to be addressed. They need to have access to insurance, as well, so that they not only can do the job they want to do in the homes like mine, but they get a fair pay.

They work harder because they're alone, and they should have the health care benefits and be able to get those and have a good wage.

One of the things that also happens, and we did have a bill in front of the legislature is -- legislation and that is once we get a home care nurse, the school sometimes -- now my daughter is past that, but I fight for that where the school says, “Oh, no. We don't want your home care nurse to come to school with your child.”

Well, wait a minute. When that home care nurse can't go to school with that child, that the State says needs her, that the doctors say needs her, that nurse is going to go find employment somewhere else and there we go.

That family loses a nurse again. We can't continue, too, in this state, to be like this.

Yes, I know there is a shortage everywhere but let's get together with the great minds we have, the dedication of all of you and figure out -- figure out out-of-the-box ways to get the staff that we had so that we can be a better family unit, be a better state, and take care of our kids that are the most vulnerable.

I thank you all for what you've done and what you're doing. Please, please hear me and let's do something.