

MCD 2022 Legislative Forum Testimonies

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Disclaimer: These testimonies are based on a live script of the forum; therefore, there may be typos or omission of words. There might be language in these testimonies that some could find offensive.

Joyce Lacey on Guardianship Laws

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 Covies 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

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

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 testify as Kim did follow up with anybody that's 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

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

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

Thank you for having me. My name is Damion Lievstad. I currently live 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 Clevern 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

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 tone 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

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 my 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

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

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.