

Senate Human Resources Division

HB 1012

Testimony by Mathew C. Schwarz

March 24, 2025

Good Morning!

Chairman Dever and Members of the Committee.

My name is Matt Schwarz. I am testifying in support of HB1012 as well as briefly provide general comments regarding Developmental Disability (DD) services our family has and continues to experience. I live in Bismarck (District 47) with my daughter Jessica (age 46). Some of you may have met or seen her recently for Disability Awareness Day here in the Great Hall. She was greeted for a few hours by various legislators and friends, including Governor Armstrong. A few of you may recognize me from prior sessions where I have been advocating several decades for my family. For example, recently, in preparing similar testimony in the House, I briefly reviewed some of my testimony from the mid '90s. Some of the same issues I discuss today were pointed out then but still haven't been appropriately addressed today.

My wife and both daughters were all diagnosed with Myotonic Muscular Dystrophy in 1978, a very multisystemic neuromuscular disease, after our second daughter was born. My oldest daughter, Stephanie, passed in 2004. My wife, Marcia, passed in 2016. Jessica continues to live with me in our home as we have our entire lives. We have gotten supports throughout the years, generally, from a program known as Family Support with DD Service Providers. My wife was a Registered Nurse (RN), but abandoned her career to care for our children after their diagnoses. I (we) recall vividly watching a child removed from ICU and taken to Grafton, as the Life Skills and Transition Center (LSTC) was referred to at that time. There was no way we were ready to accept that option with our daughter,

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even though it was commonly recommended by physicians in those days. I eventually retired early from my career as an electrical engineer in my mid fifties to provide care for my wife.

As I listened to the various presentations in the House and the Senate, I respect and appreciate the difficult work that legislators, staff, and Providers perform with the complexity of services in the DD world. However, I know, I speak not only for myself but other families. Wages are a big factor but there are other barriers, especially for individuals with intense medical needs. For example, caring for individuals with intense medical needs can quickly result in catastrophic results if appropriate care isn't provided. Not only is the work demanding but a higher level of skill is required. Additionally, families often face other serious problems. The different agencies that pass the buck back and forth results in denials, delays, waste of resources, and perhaps death! Families like ours have sacrificed a lot. But trying to navigate some of these additional barriers are particularly exasperating!

So, my testimony today is intended to give you a little insight into Jessica and our recent journey in that context.

Jessica had been on her ventilator 12 hours per day (while sleeping) and tethered to oxygen 24/7 for many years through a trach which she got at 10 years of age. Her cares are complex involving proper suctioning, changing dressings, monitoring oxygen saturations, etc. After many years of taking care of Jessica at night ourselves, and after Marcia needed more care of her own, which I provided by myself, we finally received Family Support for Jessica 24/7 with Direct Support Professionals (DSPs). We provided the necessary training for DSPs and because of evolving technology Jessica has continued to live in her(our) home with 24/7 supports.

Going on two years ago our DD Provider discharged Jessica from services after giving us a 30-day notice. Protection and Advocacy (P&A) and her Developmental Disability Program Manager (DDPM), attempted to intervene without success! From everything I can tell appropriate policies of both the Provider and the DD Division were not followed. In the evening at 10 pm some of Jessica's caregivers showed up at our home, knowing full well I wouldn't be able to care for Jessica on my own. They didn't ask who was going to pay them. Although, I ended up withdrawing \$10K per month from my retirement funds over the next several months. Various advice I had received indicated the State under **NDCC 25-01.2-02**, which was the result of the ARC lawsuit, was obligated to provide care for Jessica.

It states, **“All individuals with developmental disabilities have a RIGHT to appropriate treatment, services, and habilitation for those disabilities. Treatment, services, and habilitation for individuals with a developmental disability MUST be provided in the least restrictive appropriate setting.”** (my emphasis on the upper case).

I am not a lawyer, but my understanding is the ND Department of Health and Human Services (NDDHHS), and the DD Division in particular, are the agencies responsible for meeting this RIGHT. The State has accepted substantial federal funding and in return for taking these funds the state has promised to deliver the programs/services to the people that need them. With the RIGHT comes the corresponding RESPONSIBILITY for the State to provide the services described in NDCC-01.2-02.

As is obvious, I couldn't continue paying the caregivers privately out of my retirement funds. Eventually, I had to cave and enroll in the Self Directed Services (SDS) program which essentially made me, (a 75 year old Dad), responsible, not only for Jessica's cares, but also all the DD requirements typically required of a DD Provider, the Overall Service Plan, Data collection, etc. Obviously, this program

(SDS) was never designed for an individual with 24/7 needs on a ventilator. It was designed for families who needed some extra help and had caregivers they chose.

Under the **Settlement Agreement of 2020** that was signed by Governor Burgum in December, 2020, with the U.S. Department of Justice (DOJ), individuals like Jessica are included in the **Protected Class**. Nancy Nikolas Maier (who is in charge of carrying out the Settlement Agreement) and the DOJ attorneys have personally told me that Jessica is part of the Protected Class under the Settlement Agreement. But it appears anyone with Developmental Disabilities (DD) is referred to the DD Division by Aging Services, who, I am told does not agree. As a result, the DD population part of the Settlement Agreement have been ignored, which would be a violation of the Settlement Agreement.

It is important to note, families like us typically want appropriate supports at home while their children are young. However, as we age out, this isn't possible. My understanding is there are presently numerous families similar to my predicament. We have been caring for family members in our homes. But a life event can suddenly change all that.

For me that life event occurred last summer. Gratefully, fortunately, I survived! Last summer Jessica had been in the hospital ICU and was ready to be discharged. Beyond my control the hospital contacted various Nursing Homes to discharge her to but none of the local Nursing Homes accepted. We were frightened beyond belief where she may have eventually been sent. But there was no place for Jessica to go. Previously, individuals like this were funneled to the Life Skills and Transition Center. As you know, this is no longer allowed. Finally, her doctor concluded, as Jessica has experienced changes in her care needs, upon returning home, she now needed 24/7 nursing services.

The ICU doctor understood the laws regarding Home and Community Based Services (HCBS) well. She understood not only the medical benefits but the social

benefits of home, home routine, family, and friends and how that intertwines with health. We totally agree! Her letter written to ND Medicaid stated “First and foremost, we support and advocate for patients/clients to be maintained in the least restrictive environment as long as it is sustainable and beneficial to the patient/client. Secondary to sharing this statement, Jessica’s increased service needs would best be served by private duty nursing of 24 hours a day, 7 days a week.” Fortunately, Medical Services approved the doctor’s orders. However, every 60 days the Provider has to go through a strict protocol of submittals, which if not strictly followed would result in denial of services. The DOJ attorney told me they believe the process is overly burdensome. In Minnesota I understand, the similar standard is once per year.

Recently, we received a previously unannounced notice on January 2, 2025, from the nursing services Provider that Medical Services (a silo in the NDDHHS) had changed their policy on Private Duty Nursing. Their new policy was to limit the 24/7 services previously approved to what we understood to be a maximum of 8 hours per day (with some other provisions). They also indicated that parents and Guardians were responsible for the remainder of the cares requiring them in advance of signing Attestation SNF 197. This panicked not only our Provider, myself, but our nurses. Furthermore, the policy change was effective back to January 1, 2025. This clearly left Jessica’s nurses, some who had left other jobs to work for this Provider, not knowing if they had a job any more, had continued medical insurance, etc. After about a week the policy was again changed, January 8, 2025, (but still unclear to us) that things wouldn’t change for Jessica as of now. Language requiring parents and guardians providing services is still included. Guardians are trained to make decisions, not provide services! How do we know what unexpected changes might be implemented in the future again without appropriate notice, or appeal, from Medical Services regarding extremely life-threatening issues. Whatever happened to prior notice, public comment, etc.

Prior to Medical Services just changing policy with such important impact why not get input from families/clients that are dependent on these programs.

Two days after Jessica returned home, I endured my life changing event. Fortunately, the wonderful nurses and caregivers took over and Jessica recovered well.

As mentioned previously, had I not survived my life event, **Jessica had no place to go, a home with appropriate services**, beyond a short term. This has been and continues to be a crisis for families like us! **It is a primary issue in my testimony today!** Individuals with intense medical cares need appropriate homes located around the state. With evolved technology families/clients can receive appropriate services in a Home and Community Based Services (HCBS) environment. We have proved it works for 30+ years! As large malls' tenants are relocating to smaller strip malls, Specialty Clinics are performing services that used to be only performed in hospitals, large institutions are not needed to care for people including those with intense medical needs. When more specialized medical services are needed, they get those services, generally short term, at regional hospitals. **Hospitals (designed for short term) are where medical problems get fixed! Home (long term) is where you go to heal and live!** Smaller homes, four clients to a home, can and need to be built as soon as possible. Families/clients don't want to travel hundreds of miles to be with each other. Services in those homes should be unbundled just like regular families when they choose their doctor, dentist, physical therapist, etc. Families/clients should be able to choose their needed appropriate services like DD Provider, medical doctor, OT, PT, nursing services as needed, etc. If a client gets discharged from their Provider, **they should not also lose their home!** Individuals in the Protected Class of the Settlement Agreement include appropriate housing. These homes could be located around the state as needed and architecturally blended in with

local communities. Perhaps one in Bowman, a couple in Williston, Minot, Bismarck, Fargo and Grand Forks, as needed.

We, as other families, continue to experience excessive denials for equipment and supplies, which we never experienced while I had private insurance. Even with doctors' letters indicating medical necessity, the process is overly cumbersome with denials, often taking months, including appeals, hearings, etc.

An example our medical supplier is Sanford Equip. They have indicated they perform services to families in Minnesota and ND. But they have much greater difficulty getting approval for families/clients supplies and equipment in ND than Minnesota. I have asked and they have agreed to meet with legislators to discuss their experiences.

There are numerous other families/clients whose needs are great as well, although different than ours, at the present time. However, again, this is a crisis that has repeatedly been brought to NDDHHS attention for many years! I have notes including documentation from the DD Division obtained during a meeting we had in 2020 with Tina Bay and Protection & Advocacy (P&A) indicating there were about 80 individuals with similar needs to Jessica. I have recently been told this number has decreased! What has happened to those people? I know some have passed as I recently learned. These individuals, **also have a right to life, with appropriate supports!**

For your information the following demonstrates our continued challenges we are presently facing with Medical Services. Jessica has been referred to the Mayo Clinic in Rochester, Mn for specialized surgery. Multiple doctors confirmed there is no other doctor in ND that has the proper experience to perform the complex surgery which is a common procedure at Mayo. Initially, as has been typical, Medical Services denied the procedure. I had to appeal their decision. Upon further intervention by Jessica's doctor, they finally approved the procedure.

However, transporting Jessica who is on oxygen, a ventilator, including heated humidification, is a complicated undertaking. I have plenty of prior experience transporting my family members to Mayo over the years. We know transporting her ourselves is much less expensive than using ground or air ambulance because it would involve multiple trips. This time nurses need to accompany our trip. Medical Services has denied payment of things like overtime, temporary licensing of nurses since Minnesota is not a compact state for nurses, insisting on they making their own lodging reservations, etc. Not only is this a problem because they are completely unfamiliar with the needs of such an undertaking, but the recommendations will not work the way they insist upon. We started this process in December, 2024, and still haven't got the issues resolved as of today, on how to appropriately transport Jessica for her medical appointment on April 15, 2025. It takes a long lead time to get reservations for lodging near the Mayo Clinic. I am very familiar with the landscape, lodging, parking, leave alone the necessary layout of rooms for multiple individuals in the same building, for both safety and moving around, with Jessica and all her equipment while she attends her appointments. Necessary considerations are refrigeration for her medications, location of outlets in her room, underground tunnels, etc. so one doesn't have to go out on the street carrying ventilator, oxygen tanks, suction machines, ambu bags, etc. So, it doesn't work to have lodging 4 miles from the Clinic as is being suggested by Medical Services! As of today, as I stated earlier, I continue working with the bureaucratic controls, multiple denials, delays, and appeals of getting my daughter the medically necessary services she needs.

Previously, testimony was provided on how appropriate Person-Centered cares can have unexpected positive results for individuals with intensive medical needs. Like the ICU doctor understood, **appropriate cares make all the difference!** Benefits of being close to home, home routine, family, and friends and how that intertwines with healing and health are increasingly recognized as critical. Skilled caregivers combined with modern medical care have resulted in unbelievable,

sometimes referred to as miraculous results. Jessica's primary physician for over 20+ years, recently stated she is in the best condition Jessica has ever been as long as she has known our family. One of our caregivers is actually considering doing a Masters Degree thesis on her experience from when she started working with Jessica to date.

In summary, as I have led you through our journey with the services provided to our family, the need for homes for individuals with intense medical needs (those 26-80?) is critical. **Those of us aging out are running out of time! We insist our adult children get the appropriate home and care they deserve. We want this transition to occur before we are gone so we can help them adjust to what could be another frightening experience for them!** The red lights have been blinking for NDDHHS and the DD Division for many years. **Something needs to be done, now!**

I sincerely thank you for listening to my extensive testimony to help you better understand the issues facing families like us.

In closing, I liked what the Chaplain at the State of the State Address by Governor Armstrong said in his prayer. As I recall his primary petition was taking care of the most vulnerable as a priority!

Thank you for your time and attention.

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