

House Human Resources Division

Testimony by Mathew C. Schwarz

February 5, 2025

Good Morning!

Chairman Nelson and Members of the Committee.

My name is Matt Schwarz. I am here to briefly provide general comments regarding 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 the other day for Disability Awareness Day here at the Legislature. She was greeted for a few hours by various legislators and friends, including Governor Armstrong. A few of you have recognized me from prior sessions where I have been advocating for decades for my family. For example, yesterday, in preparing for today, I briefly reviewed some of my testimony from the mid '90s. Many of the same issues were addressed in those days.

My wife and both daughters were all diagnosed with Myotonic Muscular Dystrophy in 1978, a very multisystemic neuromuscular disease. 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 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, 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 yesterday, I respect and appreciate the difficult work that staff and legislators perform with the complexity of services in the DD world. However, I know, I speak not only for myself but other families. It makes my head spin!

So, my testimony today is intended to give you a little insight into Jessica and our recent journey in the context of what was presented yesterday.

Jessica has 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, 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 DSP's. We provided the necessary training for DSP's and because of evolving technology Jessica has lived in her home with 24/7 supports.

Going on two years ago our DD Provider discharged Jessica from services after giving us a 30-day notice. P&A and her 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 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, (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 with the U.S. Department of Justice (DOJ), individuals like Jessica are included in the Protected Class. Nancy Nikolas Maier and the DOJ 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 are ignored.

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. 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 for 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.

Recently, we received notice on January 2, 2025, from the nursing services Provider that 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 NDDHHS regarding extremely life-threatening issues. Whatever happened to prior notice, public comment, etc. Prior to NDDHHS 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. 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 (HCBS) environment. As large malls tenants are relocating to 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. Smaller homes, like 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 choose their doctor. 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!

There are many other details that would take too long to describe in my testimony. However, we continue, as do other families, 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 often taking months, including appeals, hearings, etc.

An example is our medical supplier, 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 many other families/clients whose needs are great but different than ours at the present time. Your challenges are great but they cannot have been unanticipated. For families/clients like Jessica that have intensive medical needs, appropriate services in the services in the least restrictive environment include a minority. However, the red lights have been blinking for DHHS and the DD Division for many years.

In closing, I liked what the Chaplain at the State of the State Address by Governor Armstrong said in his prayer. I'm paraphrasing but the message was taking care of the most vulnerable should be a priority!

Thank you for your time and attention.

Mathew C. Schwarz 701- 471- 3197 (Cell)