



Chair Chamberlain and Members of the Education Finance and Policy Committee:

Please meet Elianna Koch (Cook). She is 3.5 years old and is a very smart and talkative little girl. She makes us laugh every day. Our names are Peter and Ashley Koch and we are writing in support of Senate File 859 to allow our home care nurses to attend school with our daughter. We all live in Coon Rapids, MN. Due to COVID-19 and Elianna's medical condition, we elected to do distance learning last fall to keep her safe and healthy.

At 4 months old, Elianna stopped achieving milestone goals for infants her age. She was no longer able to lift up her head while doing tummy time like she was able to just weeks before. Elianna was admitted to Children's Hospital at 7 months old for RSV (a respiratory virus) and the doctors also performed a series of genetic tests. It was discovered that Elianna had the genetic disease, Spinal Muscular Atrophy (SMA), Type 1. SMA is a terrible disease that takes away the ability to walk, swallow and breathe. It is also the number 1 cause of death among children under the age of 2. Needless to say, we were devastated by this news and thought we were going to lose our little girl.

While in the hospital, Elianna had surgery to insert a G-tube into her stomach so she could receive nutrition and medications because she cannot swallow food effectively without aspirating. It was during this 3-week hospital stay that Elianna received her first spinal tap injection of Spinraza. Spinraza is the first SMA treatment approved by the FDA to fight off the effects of SMA on the body. It prevents the disease from progressing and helps people keep the muscle tone they already have. The results we have seen have been amazing. Elianna receives Spinraza every 4 months and she has been thriving ever since.

We are grateful to receive private duty home health care nursing for Elianna. For 10 hours a day and five days a week, Elianna receives exceptional care from her nurses. From physical therapy that helps strengthen her muscles to a daily routine of machines to keep her lungs her parents.

It was with this frame of mind with all of Elianna's medical interventions that we requested the Anoka-Hennepin School District to allow Elianna's nurse to attend 3-year old preschool with her. Elianna's pediatrician and neurologist also wrote letters to the district strongly encouraging that Elianna be allowed to attend school with her nurse. The district nurse denied our request because she said a trained paraprofessional could take care of all of Elianna's medical needs. She also stated that she didn't have to listen to doctors' orders. As parents, we were outraged at this decision. It took Elianna's nurses 2 months of consistent training to become fully comfortable with Elianna's machines and routines. The quality-of-care Elianna receives from her nurses would not be consistent with the care that she got from a paraprofessional at school.

At school, Elianna would need consistent monitoring and someone very familiar with her medical interventions and machines. She has several hospital-grade machines at home that would travel with her to school in case of a medical emergency. These include a cough assist to clear her lungs, a suction machine to keep her mouth clear of secretions and portable oxygen in case of a respiratory emergency. Since Elianna is also tube fed, she would need to have her G/J site monitored to keep that area clean and infection-free.

We have been very lucky that Elianna has maintained her good health. But her good health does not come without sacrifices. In sick times and healthy times, we fight to keep Elianna healthy. If we, as caregivers, take a day off from providing Elianna with exceptional care, she will get sick. We cannot afford to have Elianna spend another three weeks in the hospital due to care provided by a paraprofessional who isn't completely trained or comfortable with Elianna's medical interventions. Elianna has the right to a free and appropriate education with her peers. We shouldn't have to fight with the district on how to keep medically fragile children safe in school. We cannot send Elianna to school without the proper medical support of her nurses.

Thank you for taking the time to listen to our story. Elianna's health has always been our number 1 priority. We sincerely hope that Senate File 859 is passed successfully. As parents, we worry about many things that are beyond our control when it comes to our children. The health and safety of our children at school should not be one of them.

Peter and Ashley Koch

Currently Deacon James is a 5-year-old boy that has been hospitalized since Wednesday, February 10 for an acute side effect of an ADHD medication.

He is smart, he can count, knows his numbers, colors, shapes, and has the best imagination. He is also very medically complex. He is on continuous oxygen, has seizures, is fed via feeding tube 24 hours a day. He can eat and drink orally but easily chokes and needs very closely watched and responded to. He has mitochondrial dysfunction and his body quickly runs out of energy. He needs adults to watch him closely and help him regulate his body and help conserve his energy. He has dysautonomia, meaning his body doesn't regulate his temperature, heart rate, or respiratory rate well. He quickly becomes dysregulated and needs help in a matter of seconds. His temp will often drop to 95 degrees or lower and he needs immediate help. He has chronic pain and can at times be in excruciating pain and need medication to help him be comfortable again. His symptoms are often very subtle before he has an emergency. It takes months usually before a nurse is able to discern these signs and feel comfortable to help him on their own. He has nursing care 20 hours a day while at home.

This past year we were considering sending him to preschool. We had multiple IEP meetings and our biggest concern was keeping him medically safe at school. A nurse from the school came out and did an independent evaluation. She determined after 15 minutes that Deacon did not need nursing while at school. She also determined he did not even need a 1 on 1 paraprofessional. He would be fine with just the paraprofessionals in the class watching him. We were told it is district policy that home care nurses are not allowed to care for the child during school. She said that she would be in the building, but she was also responsible for 3 schools in our town. How was this nurse going to be able to respond to my son when she could be at another building across town? He could be dead by the time the paraprofessionals saw something wrong and called her.

He qualifies for hospital level of care nursing at home; however, the school says he needs none. We spoke with our pediatrician, who was appalled. She wrote him a letter requesting home bound services. He was to get 1 hour of schooling 2 times a week and His schooling must be done before or after school hours. He is missing out on valuable social and emotional skill building and being able to be around peers. With Covid now he has been able to participate in virtual preschool, but he is still struggling. He is not able to interact with peers. He is unable to go to school safely. He is not getting the same education that his peers are getting. He had a recent evaluation where he scored above his peers in problem solving. He is smart and he would excel at school if he were able to attend safely.

Jill Voerste

My name is Kristine Erickson and I am the parent of a child with medical complexities. My son, Bentley, is 9 years old, and is a student of Otter Lake Elementary School in the White Bear Lake School District.



Pre-Covid, my son attended school with his nurse. Bentley has a CAC (hospital level of

care) waiver. Bentley has Goldenhar syndrome, VACTERL Association, microtia (no left ear and deaf on left side), developmental delays, feeding tube dependent, chronic lung disease, hydrocephalus, chronic anemia, anxiety and PTSD related to 18+ surgeries/medical trauma, and a long list of medical diagnoses that do not define Bentley. He is love and he is loved.

I wanted to share our experience with the school and the district administration, as we are adamant that a nurse must accompany Bentley to school for his own safety and survival as he has already suffered at the hands of the school. The school district leaders have made it crystal clear they have no intention to guard the vulnerable population or accept concerns.

Bentley's condition is fragile and can change within 30 minutes. His nurses are trained and know the difference between his different coughs and how he acts. He cannot communicate his pain or discomfort. They learn to identify if his oxygen saturation is beginning to plummet and he needs to go to the hospital. Since he lives at home at a hospital level of care, it would seem like common sense that he would be under the constant observation of a nurse. As a mother and also a nurse of 22 years, continuity of care leads to better outcomes for the patient that piecemealed care. Our children are not a task, they're human beings.

As a mom and a nurse, I am passionate about ensuring all children with disabilities receiving the highest quality of care. Our school does not fund areas to promote accessibility or inclusion. When we, as parents, are sending our most fragile children to school and placing them in the vulnerable situations, having a their nurse is not only essential, it's crucial. The schools have made it crystal clear that they are not going to fund special education, they certainly do not have the bandwidth to support our children on a CAC or CADI waiver that are reliant upon the skills of a nurse. Our vulnerable children with cognitive or developmental delays do not always have the voice to self-advocate, they rely upon their nurses to assess and reassess their needs. Without their nurses, those needs go unmet. Unmet needs equates to suffering. This is more than a quality of life issue; this is a civil rights issue.

We would love equal rights for our children and can't even see that from where we sit. We are constantly reminded to be thankful for what we get as it will be taken away as fast as it's given. Our school superintendent has told me that I am no longer allowed to write the school board with my concerns and he will not look into any of my concerns. There is no handbook for raising a child with disabilities. If there was, I would probably have a chapter titled, "You Can't Make This Stuff Up Anymore," for all of the battles we face.

Every person is one catastrophic event away from living a life of disability. How do you want to live? There really is only one choice here. If this were your child, what would you do? Do the right thing.

Thanks in advance,

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To the Senators of the Minnesota Senate Education Finance and Policy Committee –

I am writing to you today in regard to your consideration of Senate File 859, sponsored by the PACER Center. My name is Meagan Lindquist and reside in North Branch, Minnesota within Chisago County, and am the mother of a seven-year-old daughter. The bill you are about to consider would directly impact my family and would have proven invaluable to us all during the 2018-2019 school year.

Marissa Joy Lindquist was born on June 24, 2013 at 26 weeks. She was two pounds twelve ounces and given a five percent chance to live. She spent three months in the NICU and was diagnosed with cerebral palsy, along with respiratory complications. She has had many health challenges over the years and currently is fed via her G-tube directly into her stomach, is non-verbal, and attends physical therapy, speech therapy, and occupational therapy. Based on her health issues, Marissa has had home care nursing since she was six months old. Despite her health challenges, she is a smart, funny, spunky little girl and will warm your heart when you meet her. Her determination and resilience have gotten her to where she is today.

Back in summer of 2018, Marissa had just turned five years old and we were exploring preschools to send Marissa to. We had heard that Chisago Lakes Primary School ("School") had a good special education program and contacted the school in July. We were told by the School that we would not be able to start the IEP, the Individual Education Plan, for Marissa until the end of August when the teachers were back from summer break. Once we started the IEP process at the end of August, it took until mid-October for Marissa to attend preschool at Chisago Lakes Primary School.

Why, you may ask, did it take over five weeks for Marissa to physically attend school at Chisago Lakes Primary School? Chisago Lakes Primary School refused to allow Marissa to attend school until her IEP was complete, which was found as a violation by the Minnesota Department of Education. Within her IEP, concerning the health services to be provided at school, there was a significant disagreement in the health services that the School was offering to provide versus the services we, as her family, believed was required for Marissa. The School stated that they were capable of providing her health services and did not want to have a home care nurse assigned to Marissa attend school with her. They initially stated that there would be confusion over supervision of the home care nurse as they would not be an employee of the school. They stated that it was the discretion of the school district nurse on the level of detail in Marissa's healthcare plan, which is separate from her IEP. The healthcare plan written by the district nurse was 1.5 pages, with one full paragraph explaining Marissa's medical history; in comparison, Marissa's care plan with her nursing agency is over ten pages.

As you can imagine, as Marissa's mother, I was not about to jeopardize her health over the School's perceived ability to provide her care. Over the course of numerous meetings, calls, and emails with the School and engaging our nursing agency to support the concern over the supervision of the home care nurse, and countless hours and energy put into the fight to have Marissa's assigned home care nurse attend school with her, it was finally agreeable to the School to have the home care nurse attend school with Marissa. They also listed in Marissa's IEP draft that Marissa should have a "licensed nurse" provide her care at school, admitting and acknowledging that the School was not equipped to provide the level of care that Marissa required while in school.

Marissa started attending preschool at Chisago Lakes Primary School by mid-October 2018 with her home care nurse. The School had also provided bussing services that allowed for both Marissa and her nurse to transport them to and from school. We were so thrilled to have come

to terms with the School, but unfortunately, that feeling did not last long. Marissa experienced a choking episode at school due to thick secretions, which can be typical for Marissa to experience, and her home care nurse immediately attended to Marissa with her treatment protocol; the School classified that this experience in the classroom as “traumatic”. In another issue, Marissa and her nurse were not allowed to use the “family bathroom” as it was for “other students” only. In another occasion, the School provided a room where Marissa’s bolus treatments for her feeding were to be completed, but under the condition that it was completed by a certain time as other students were supposed to use that room. We continued to experience pushback by the School concerning the home care nurse’s responsibilities and their supervision of the nurse while in attendance with Marissa. Additionally, the school district nurse’s healthcare plan continued to lack the detail necessary to provide appropriate and accurate care for Marissa.

By November 2018, I had engaged the PACER Center to support our effort to keep the home care nurse with Marissa while attending preschool. I had completed a total of seven authorizations to release medical information for Marissa as requested by the School. Yet, the School stated that they are obligated to “consider” doctor’s orders, but they rejected the doctor’s input. The School then downgraded Marissa’s level of service from “licensed nursing services” to “health related services” in her final IEP, without any notice to the family and reasoning as to why. Marissa’s pediatrician then provided clear orders stating that “it is essential to Marissa’s medical needs that nursing care and services be consistent between home and school, including transportation to and from school...” and further expanded on the focus on Marissa’s safety at school with a home care nurse. The School again rejected the pediatrician’s order for her home care nurse to attend.

The School finally decided to not allow for Marissa’s home care nurse to attend school with her. When the bus came the next day to pick up Marissa for school, it was the school district nurse that was on the bus to provide the care for Marissa. I asked the school district nurse how she was going to provide one-on-one care for Marissa while completing her daily responsibilities overseeing three schools in the district and her response was that it was still being worked out. I did not send Marissa to school that day or any day going forward to Chisago Lakes Primary School. The School later stated that “many of the tasks that Marissa’s home health nurse performs can easily be performed by a properly trained health aide.” While there are some of Marissa’s treatments that are trainable, “many” tasks are not all tasks for her treatments and ensured safety at school.

Marissa is now thriving in a local charter school, where her home care nurse attends school with her as this charter school recognized the benefit of the home care nurse and safety the home care nurse was able to provide Marissa during the school day. The teachers and staff at Chisago Lakes Primary School ultimately conveyed that they knew better than the family on Marissa’s complex medical history and level of care that was appropriate for Marissa. From the story that I shared with you today, my goal was to convey that I have been through the trials and challenges of working with a school district to ensure my child would remain healthy, safe, and cared for while at school. For Marissa and our other special children that require the need

for home care nurses, these children must have their assigned home care nurse attend school with them for the sake of their health and safety. School nurses and aides may have the medical training, but they do not have the knowledge and understanding of the patient, the student at school with complex medical needs.

I appreciate your time in listening to my story today. We have moved on from our terrible five-month experience with Chisago Lakes School District, but I hope that this story has provided you with an example to understand some of the challenges special needs families experience with schools and the goal to prevent this from happening to any special needs family going forward.

Meagan Lindquist