

To Chairman Denver and members of the Senate Appropriation Human Resources Division addressing HB 1012,

I'm Mika Stokkeland, a passionate advocate from Bismarck, and as a proud parent of my son Jonny, who has Down syndrome, I'm driven by a personal commitment to create a more inclusive and supportive world, where individuals with intellectual and developmental disabilities have access to the care, resources, and opportunities they need to reach their full potential. That is why I am in support of House Bill 1012.

Unfortunately, the history of treatment for people with Down syndrome in the United States is marked by injustice, with many being relegated to inhumane institutions that denied them access to education and healthcare. However, progress has been made, particularly with the expansion of the Developmental Disabilities Assistance and Bill of Rights Act in 2000, which emphasizes capacity building, systemic change, and self-determination. This shift has enabled individuals with developmental disabilities and their families to play a crucial role in designing and accessing community services, supports, and assistance that promote independence, productivity, and integration.

There are over 400,000 people living with Down syndrome in the United States, and it is essential that we continue to move forward in providing them with the support, services, and inclusivity they deserve. We cannot afford to take a step back and revisit the dark days of institutionalization and neglect. As a parent and advocate, my voice is crucial in shaping the future for individuals with Down syndrome and other intellectual and developmental disabilities.

Medicaid, a vital joint federal and state program, plays a crucial role in helping families like mine cover medical expenses, significantly reducing the financial burden associated with medical bills and enabling us to prioritize our child's health. By providing access to medically necessary care without the worry of excessive costs, Medicaid improves overall health outcomes and allows us to focus on our child's well-being.

Moreover, Medicaid facilitates preventative care, enabling early detection and intervention for potential health issues. As health insurance premiums continue to rise - with the average family premium increasing by 7% in 2024 - Medicaid serves as a vital safety net for families like mine, who require additional care and services to support our child with Down syndrome.

The comprehensive range of health services covered by Medicaid, including specialty care, is particularly essential for individuals with intellectual disabilities. Specifically, Medicaid covers critical therapies such as Early Intervention, Physical, Speech, and Occupational therapy, which are instrumental in developing motor skills, communication, independence, and helping our children reach their full potential. We have seen firsthand the impacts these therapies have had on Jonny.

It is heartening to see that there have been significant advancements in recent years, a significant milestone in the journey towards protecting the rights of individuals

with disabilities was the expansion of the Developmental Disabilities Assistance and Bill of Rights Act in 2000. This landmark legislation marked a crucial shift in the approach to supporting individuals with disabilities, emphasizing the importance of ability building, systemic change, and self-determination. The Act's focus on capacity building recognizes that individuals with disabilities have the potential to grow, learn, and develop, and that they should be provided with the necessary resources and support to reach their full potential. By investing in capacity building, we can empower individuals with disabilities to take control of their lives, make informed decisions, and participate fully in their communities. The emphasis on systemic change acknowledges that the challenges faced by individuals with disabilities are often rooted in broader societal and institutional barriers. By working to address these systemic issues, we can create a more inclusive and supportive environment that enables individuals with disabilities to thrive.

Perhaps most importantly, the Act's emphasis on self-determination recognizes the fundamental right of individuals with disabilities to make their own choices and decisions about their lives. This means providing individuals with the autonomy, to pursue their dreams goals, and aspirations, and to live independently and with dignity. While there is still much work to be done, the expansion of the Developmental Disabilities Assistance and Bill of Rights Act in 2000 represents a significant step forward in the pursuit of equality and justice for individuals with disabilities. As we continue to build on this progress, we must remain committed to creating a world that values, includes, and empowers individuals with disabilities, and that recognizes their inherent worth and dignity.

The joy of welcoming a new baby, followed by the uncertainty and worry of COVID, and then the unexpected news of Jonny's Down syndrome diagnosis. It is like your whole world was turned upside down. Instantaneously I fell in love with Jonny's unique features like his almond eyes and the gap between his toes. That love only grew stronger as we navigated the challenges that followed.

The hospital stays and the NICU experience was incredibly stressful, with all the tests, monitoring, and uncertainty about our son's health. And then, on top of all that, the financial burden of the medical bills. \$45,000 is a staggering amount, and one can only imagine how daunting it would have been without the assistance of Medicaid.

The importance of programs like Medicaid provides critical support to families like mine. Without it, many families would be forced to choose between their child's health and financial stability. It is unacceptable that anyone should have to make that choice, and it's clear that we need to continue advocating for accessible and affordable healthcare for all.

As we navigated the uncharted territory of our son's diagnosis, we were fortunate to meet some truly exceptional individuals who would become instrumental in our lives. One of my most influential mentors offered me sage advice that day: "Advocate for your

son's voice, immediately." At the time, I did not fully understand the significance of those words, but I would soon come to understand the importance of being a strong advocate for my child.

It was during this period that I was connected with a dedicated social worker and a talented therapy team. They had a deep understanding of my son's needs and helped me get acquainted with the resources available to us. Our journey as advocates and supporters of our son's unique needs truly began. With their guidance and expertise, we started to navigate the complex world of services and resources available to us, and we were empowered to become the best possible advocates for our son.

The journey of ensuring my child receives proper care has been an emotional rollercoaster, filled with uncertainty and worry about their well-being and rights. The constant unknown has taken a significant toll on my mental health. However, thanks to Medicaid, I have found a sense of relief and security.

Finding suitable childcare for an infant is challenging enough, but when you add special needs to the equation, it becomes even more daunting. I compiled a list of over 25 local licensed and private daycares, only to be met with disappointment as none of them could provide the necessary care. I felt defeated and unsure of what to do, as my husband and I both have careers that we could not abandon. Without family support to rely on, we were at a loss.

But then, Medicaid stepped in and changed everything. Through their assistance, we've been able to assemble a wonderful team of caregivers who not only provide the required care but also love and accept our child for who they are. They have become an integral part of our lives, offering emotional support and a sense of belonging. They are more than just caregivers - they're like family. They help with transportation to therapy sessions, providing a sense of stability and normalcy in our lives.

Medicaid has been a game-changer for us, allowing us to balance our careers while knowing our child is receiving the care and attention they need. The peace of mind that comes with knowing our child's rights are protected and their needs are being met is invaluable.

As parents, we're consumed by fear and uncertainty about the future, worrying that we may be forced to make an impossible choice between our careers and caring for our child. The prospect of having to abandon our professional lives to ensure our child's needs are met is a daunting and unsettling one. This is why it is essential that we prioritize and protect the rights of individuals with disabilities.

We must recognize that every individual, regardless of their abilities, deserves equal access to opportunities, resources, and support. It is our collective responsibility to create a society that's inclusive, supportive, and empowering for people with disabilities. By doing so, we can alleviate the fears and anxieties that many parents like

us face, and instead, provide a foundation for our children to thrive and reach their full potential.

Protecting the rights of individuals with disabilities is not only a moral imperative, but it is also crucial for ensuring that families like ours can maintain a sense of balance and normalcy in our lives. By providing access to necessary resources, services, and support, we can prevent the unnecessary disruption of careers, relationships, and overall well-being. It is time for us to come together and make a commitment to prioritize the rights and needs of individuals with disabilities, and to create a world that is more just, equitable, and inclusive for all.

It was my pleasure to assist you and provide a platform to discuss the important issues surrounding the care and rights of individuals with disabilities. I am grateful for the opportunity to help amplify my voice and concerns. I want to acknowledge the emotional labor and dedication that goes into advocating for the needs of loved ones with disabilities. It's not an easy journey, and it takes courage and resilience in sharing our story.

Thank you again for allowing me to share my story, and I fully support continued advocacy and pursuit of a more inclusive and supportive world.

Mika Stokkeland, Mother to a Perfect Child