

Chairman Nelson and Members of the House Appropriations – Human Resources Division:

As you discuss HB 1012 and the Developmental Disabilities section, I'd like to provide insight and testimony to the impact this section of the bill has on the citizens of ND with disabilities.

My name is Annalise Duffy and I'm writing as a representative of GiGi's Playhouse Fargo, citizen of North Dakota, and parent to a child with Down syndrome. Please see her beautiful smile below.

I'm testifying in support of the Disabilities/developmental (IID/DD) 1915c Medicaid Waiver but want to express concern regarding the proposed budget for the DD waiver. The DD section is where provider increases lie for the services that we hold dearly in the disability community- Early Intervention, In-Home Supports, and Residential and day Supports for adults. Right now, there is a proposed 1.5/1.5% increase for the next biennium to fund the DD waiver. In comparison, there is a 4/3% increase for state employees.

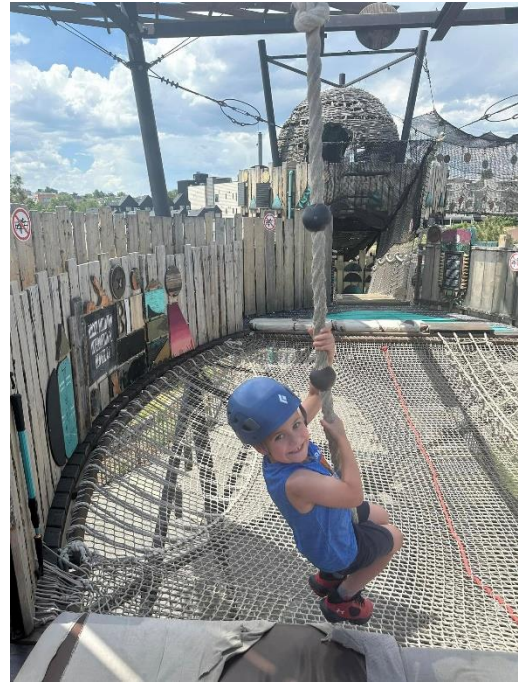
I don't want to go without saying how appreciative we are to have the DD waiver and the support that comes from it but feel the community that the waiver support is being discriminated against by having a smaller number of moneys allocated in comparison to the rest of the disability community ask.

One thing that is important to note is that our families who have individuals eligible for our Medicaid waivers depend on the service options within the waivers but also depend on having access to State Plan Medicaid for their loved ones. Quality waiver service and State Plan options are one of our advocacy priorities as individuals with Down syndrome and their families can achieve quality lives in their communities with the formal supports of the Medicaid waivers and State Plan Medicaid.

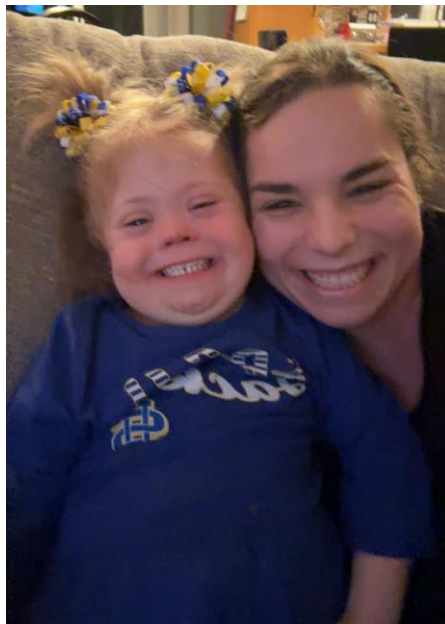
Below you will see some pictures of my daughter, Lakyn, who is 3.5 and how the waiver supports her along with what an inadequate amount of funding and increase could mean for individuals like her.



On the left is Lakyn holding her Early Intervention Diploma and on the right is a picture of her with Sidney, her Early Intervention provider. When Lakyn came home from the hospital after a 34 day NICU stay, Sidney was at our house helping support Lakyn and areas of development and growth within a few days. These visits continued every week during Lakyn's first year of life, and then every other week when she turned 2 until these pictures were taken. Sidney's services through Early Intervention helped Lakyn with crucial developmental milestones. From holding her head up, to sitting up, to walking, navigating concerns, and helping us navigate Lakyn's transition to Preschool, without support from the DD waiver, Lakyn's care and progress would have looked different.



Next you can see Lakyn on the left holding her Starbucks treat. This was when she was on a special adventure with our Respite and In-Home Support Staff, Allison. Words cannot express how thankful we are for our Support Staff. Without this support, I'm not sure we'd be able to give our son, Rony, who is 2.5 years older than Lakyn, the experience and one on one time he deserves. Whether it's taking him to sporting events, where the noise and people cause Lakyn extreme stress and discomfort, or being able to help coach his basketball team without worrying about Lakyn being safe or stuck in front of an iPad for "entertainment," Having support staff is crucial in ensuring our family can participate in "normal" activities while respecting the environmental needs/concerns that arise with taking Lakyn to unfamiliar or new places.



This is Lakyn and Allison. Allison has also been with us since Lakyn came home from the Hospital and as you can see, the two adore each other. (Yes, we're proud Jackrabbit Fans in the wonderful state of North Dakota.)

I hope that through this testimony, you are able to understand the importance of the continued support of the DD Waiver, and why equal funding is necessary. I ask that you please consider this request and vote to provide the same increase in funding, if not more, as other programs, (4%), so individuals with disabilities can continue to have support they need through Early Intervention and Quality Support Staff.

Thank you for your time and service,

Annalise Duffy

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