

Testimony

SB2012

Senate Appropriations

Human Service Division

Chairman Senator Dever and Members of the Senate Appropriations Human Service Division

My name is Vicki Peterson and I am providing testimony today as a parent of a young adult, my son who is soon to be 21 years old. He is diagnosed with autism and intellectual disability and chronic health conditions. He is currently receiving services on the ND Developmental Disability Medicaid Waiver. He was in Early Intervention and at age 3 had continued services on the waiver and he has received school services as well.

Aaron has what is labeled severe intellectual disability. He is mostly nonverbal but does have some communication with assistive technology devices or with those who know him best and know how to communicate with him. He has grown so much in his life already, at one point he was completely nonverbal and struggling in so many areas including his physical health, but the programs he was able to access and the support agencies and schools have been there for Aaron and for myself.

Services Aaron has currently included respite and in-home supports. We utilize self-directed and have since self-directed became available. This has worked well for Aaron as we have had great staff that has spent much time with Aaron so they know how to communicate with him, know his likes and dislikes, have gained his trust and mine, are able to help with in-home supports as I am a single mother and have no other means of help in my home and for that break. Using the option of self-directed supports has been the best option for Aaron, as changes that happen often with staff, the training time it takes to continuously train staff from agencies and just the pure lack of workforce has made the self-directed fit very well into Aaron's person-centered plan. He needs the 1:1 support for his communication needs and direction and supervision.

In the overview you have received from Tina Bay, as Director of Developmental Disabilities, she explained the services currently in the DD waiver that are self-directed. Day Supports is not one of them. Aaron is finishing his education in Life Education now this year at age 21, he currently is on an IEP and has had the opportunity for Life Education. He has been able to hold certain jobs with the support of a full-time para in his school years. We were hoping to keep a job at the Food Coop but that was ended when the store closed. Looking at the options for day supports I have been told 1:1 support may not happen as that is not how their program works, they are in small groups. I have no issues with the groups as long as it would be something that Aaron enjoys and understands. He typically cannot understand what people want him to do without 1:1 attention and trained. He does not like to be in larger groups, he struggles with all types of communication. He also loves to shop for groceries, he is good at stocking items, can cook with the support of recipe and aid support, loves baseball games, bowling, videos (keep in mind children's videos) loves to travel to the ocean. I want Aaron to have a quality of life that he enjoys, not what a program dictates according to what they feel Aaron likes and can do. I have had respite staff that could and wants

to continue with Aaron but the day supports where he could utilize them must be done with an agency and not self-directed so his supports he has now have to be outside of those hours.

No secrets about the lack of workforce, so what holds the policy back by saying Self-Directed could not be used as Day Supports? Again it would be a choice and it certainly would not be for everyone. I ask the question of why should he not be supported by someone who knows my son as well as I do, wants to continue to support Aaron including community activities for ones he will like, enjoy and participate in and not ones he is dragged to because another person being supported likes those. I would not be asking for any more hours than I already have qualified for the in-home supports and respite. He currently uses those hours outside of school which is perfect, but school will be ending and so now the daytime is open for him.

Throughout this testimony I talk about a possible policy change but it would be connected to Medicaid dollars so Appropriations is the best fit to ask you to consider Self-Directed Supports to include Day Supports offered in the Developmental Disabilities Waiver.

Thank you for your time.

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