

For people with intellectual
and developmental disabilities

Personal Stories Shared at June 18th Press Conference

James, Marianna and Amber's Story:

My brother, James, and my sister-in-law, Marianna, (who both had special needs) gave birth to Amber, my niece, in August 1992. They lived in a house across the street from my parents in Plymouth, MN, and my parents helped them with parenting and life activities.

When Amber started first grade, the school referred the family to social workers who assisted James and Marianna in raising Amber. In first grade, Amber was given diagnoses of Moderately Cognitively Challenged and ADHD. I became more involved to work with social workers, the school, and James and Amber. Eventually, Amber qualified for the Developmental Disabilities (DD) waiver program. As a result, she was able to get the assistance she needed. Amber had personal staff who helped her learn, grow, and experience new things.

In March 2004, life changed dramatically – Marianna, Amber's Mom, died from a sudden heart attack. Amber was only eight years old; no one in the house could read or write.

I became more involved and worked with staff and James to help provide the support and guidance Amber needed. It has truly been a community that has raised Amber! Without the waiver program – without the staff assisting Amber, she would not be who she is today. She would not have someone helping with homework nor someone teaching her life skills such as appropriate personal boundaries, how to be safe and how to make good decisions.

James, Amber's Dad, continues to be part of Amber's life. James and Amber moved here to Moorhead with me when I accepted a job in the area. We live in two side-by-side twin homes, which is working well. They have their space, yet I am close by and can assist and be involved daily.

With the waiver program, Amber has learned to make decisions and to accomplish things independently or with minimal support. With staff help, she has learned to do her own laundry, clean her bedroom and bathroom, and help around the house. She's even beginning to learn to cook! With the help of staff teaching, reinforcing, and repeating things, Amber has grown, learned and matured. She has started to take responsibility on her own.

Amber, now 18, walked through graduation with her class, but she will return to school with half of her day learning job skills and discovering her work interests. This is a critical time in determining her future. She needs continued support as she learns how to live independently, take care of herself and make life decisions.

Funding is essential for children and adults with special needs. Support services are critical to their ability to become independent citizens, care for themselves, to get and retain jobs. Amber and James would not be where they are today if not for the funding and support they have received.

Judy Holmen
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Nicole & Aaron's Story

I come to you today as the parent of 2 adults with Down syndrome. My 23-year-old daughter Nicole is a bubbly, social young woman who would like to run for the legislature someday! She graduated from Partners in Policymaking, a program run by the state's Developmental Disabilities Council, where she learned to advocate for herself and others.

She is fortunate to have a Developmental Disabilities (DD) Waiver, which provides funding for home and community-based services. These services help her develop life skills to increase her independence, life

skills to increase her independence, life skills, and involvement in the community. She is learning how to budget, shop, cook, and use the bus system. She is out in the community doing things like exercising at the Y and going to the library. She also received assistance in finding a job and has a job coach to help her learn how to do the job. She currently works at an agency in town that provides services for people with disabilities and Hornbachers, and she loves it! Although she still lives at home, her goal, and ours, is for her to live and work as independently as she can.

Part of the reason Nicole lives at home is because her 19-year-old brother, who has both Down syndrome and Pervasive Developmental Disorder (an Autism Spectrum disorder), doesn't have a waiver, and she is sometimes able to be home with him when their father and I are not at home. Aaron is a quiet, mischievous young man with inclination for electronic games & computers. He is still attending school, which helps the care situation for now. My husband & I have done a lot of team parenting over the years; usually one of us is at home while the other works. As you can imagine, this sometimes puts a strain on the family.

There are no DD waivers available at this time because the number receiving that waiver has been frozen & there is a waiting list of almost 2000 people. Aaron has more challenges and is not as independent as his sister, so he will always require more supervision and help with daily living skills. We are trying to find other support services for him, but with the recommended budget cuts in Minnesota, we worry that he will not receive the services he needs to stay safe and be a productive and fully integrated member of our community.

Donna Atherton
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Kay's Message:

Today we meet to voice our concerns for the devastating cuts to disabled Minnesotans that were proposed in the health and human services bill vetoed by the governor. These cuts will severely impact my seventeen-year-old son.

Even though my son has disabilities, our family has always strived to help him accomplish whatever he wanted. He will be a senior in high school this fall and plans to attend college after graduation. Although we have tried to prepare him for independent living, we now fear that he won't have the supports he needs to be successful.

The proposed budget cuts will effect programs that would promote my son's independent living. We have always told him that he could do anything his peers did, he just might have to take a different path to get there. My questions is: "Will his path be available, or will there be a Road Closed sign for him?"

I also worked for six years with adults with mental illness. When I left my job in January (because I needed to focus on my family), the mental health care field was already trying to adjust to earlier cuts. Personal Care Attendants (PCAs) had already received pay cuts. Services available to those with mental illness were severely limited. PCA hours were cut and eligibility for receiving PCA services was more difficult. What will happen to people if these services are eliminated? Not everyone has family to help, and people may be forced on the street. No one deserves that simply because of a disability.

I am speaking for those who can't speak for themselves. People with disabilities deserve the same human rights as you, your family, your neighbors. We all have strengths and needs. Doesn't everyone deserve an opportunity to achieve their goals?

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