

Senator Dever and members of the Human Services Committee,

My name is Scott Robinson and I am a parent of a young adult with Down syndrome. I am in full support of Senate Bill 1012.

We moved to North Dakota from Texas 18 months ago for the sake of our 26-year-old daughter Rebekah, who has Down syndrome. We came because the supports for the intellectually disabled are better here and because we have family here. Medicaid has proven invaluable for Rebekah's growth. Many Downs individuals are extremely outgoing. Rebekah is not; she's so shy she even avoids conversations with family. As soon as we arrived, the Medicaid FSS Respite Care program started paying for weekly visits from a companion, and that has helped Rebekah grow tremendously. She is so happy to have a friend. Parents have to accept you, but a friend doesn't. Even though her friend is paid to come, Rebekah calls her, her best friend. Having a friend shows Rebekah that she is acceptable, not handicapped, and that she can make friends. Since she started the program a year ago, we have seen Rebekah grow in self-confidence, in social skills (like making small talk), and in empathy for others. She now starts conversations with people, even new people, store clerks, etc. and sometimes has 5, 10, or 15- minute conversations with others – a huge leap from where she was only a year ago! Respite Care has been an empowering program for Rebekah, for which we are immensely grateful and which she would not have except for Medicaid.

Our biggest concern is what Rebekah will do when we pass from the scene (we're both over 65). She can never be fully independent, but she needs to be independent of us, or she'll have to go into an institution. Thanks to the Respite Care program she is growing socially, so we hope that one day she will be able to live in an apartment or group home independently of us. However, she will always need regular visits by a caregiver to support her living in society, which is why the Residential Care Program provided by Medicaid is so important. It empowers Rebekah to live as independently as she can. The alternative is more costly: Medicare would be paying for her to live in a nursing home.

I hope this shows you how much of a difference the Medicaid waiver has made and will make in Rebekah's life. There are many more North Dakotans who are not as high-functioning as Rebekah for whom Medicaid support is even more vital. As a group they don't have much political clout, they won't get much attention, but they have the same desires we all have, to live the most productive lives they can, and Medicaid is an irreplaceable part of that. Please continue full funding for Medicaid so it can continue to provide these services which mean independence to so many North Dakotans. (Please also consider adding a 3% increase for providers for both years of the biennium so we can continue to have qualified providers in our state.)

Thank you,

Scott Robinson