



## Debbi

### Eagan, Minnesota

Debbi's son, Josh, was born prematurely and had a serious brain hemorrhage upon his birth. This resulted in a multitude of complex medical complications, including developmental delay, cerebral palsy, respiratory complications (with ventilation use and tracheostomy), autonomic dysfunction, and he is non-ambulatory. Debbi and her family have been caring for Josh at home for more than 30 years.

Medicaid has enabled Debbi to keep Josh at home with the people who love him, understand him, and know how to care for his complex needs. Josh requires 24-hour awake assessments, treatments and other interventions, meaning someone needs to be with him at all times, and the family needs dedicated and consistent nurses who are trained experts in Josh's needs.

A home & community based services (HCBS) waiver allows for direct support professionals to assist Josh with all activities of daily living and many of his clinical interventions. The family relies on direct care workers to help provide Josh's care, a labor-intensive and complex undertaking they could not do alone. It would be impossible to care for Josh at home without these supports.

Consumer direction through Medicaid also provides a small stipend to support Debbi in caring for her son. At a time in her life when Debbi and her husband would consider downsizing, they must remain in their home that has been modified to meet the complex medical need of Josh. This consumer direction allows them flexibility to keep their home and a safe and secure place for Josh to live.

Josh's care is extremely intensive, physically, and mentally. Debbi has spent decades ensuring Josh gets what he needs to live, and most of this support has been made possible because of Medicaid. If Medicaid were cut, Josh would need to move into an institution, where he would be away from his family, the people who know him, love him, and understand his care needs.

**“If Medicaid is cut, people who are medically complex, have multiple disabilities, and are currently being cared for at home by their loved ones, will have to go into institutional settings where they are not at all equipped with the staff or knowledge to care for them. I know my Josh would die, quickly.”**

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*Higher hour caregivers (those providing care more than 21 hours a week) help with 5.6 instrumental activities of daily living on average.*