



Faces of Disability

My sister Denise was 50 years old when she suffered a major stroke in 2013. She was in the hospital and in-patient rehabilitation for five months. As a result of the stroke, she has right side paralysis, speech and cognitive deficits. Her mobility is limited due to neuropathy, continued paralysis and fatigue. Her brain injury has prevented her from returning to her job as an office manager, so we applied for Social Security Disability Insurance (SSDI), Medical Assistance (MA) and a Brain Injury Waiver (BIW).

Denise was awarded \$1,505/month SSDI with the primary intent to pay for basic living expenses before medical expenses. Since this income is above the federal poverty level, she is expected to pay \$775 for her medical bills and waiver services, before MA starts paying. This is known as her "spend-down" to qualify for Medical Assistance and Brain Injury Waiver services. The current spend-down standard leaves my sister with just \$730/month to live on, far BELOW the poverty level.



We are grateful for the MA and BIW services which allow her to continue living in her townhome in Farmington. These programs provide the Personal Care Assistants, home care nurses and other professionals needed for her to live in her home. But, the mortgage on her townhome alone is \$835/month. It makes no sense that Denise is expected to live deep in poverty, possibly losing her home, to access services that are intended to help her stay in her home.

Luckily for Denise, our Dad established a supplemental trust that is paying her spend-down for now, but the money in the trust will deplete very quickly. When her county financial worker was asked what would happen if she did not have

a trust, the answer was that she would need to go to a group home facility. The thought of anyone losing their home due to the spend-down breaks my heart.

The \$3,000 asset limit for people with disabilities is another problem. Denise became certified disabled in May 2014, but when she received SSDI in October 2014, it included retroactive payments, resulting in her receiving two lump sum payments totaling \$6,083. Since this exceeded the MA asset limit, we had to spend almost all of this money to maintain her eligibility for MA and the BIW. While we made some useful purchases, it makes no sense that we had to spend her SSDI income to stay within the asset limits.

Please reform our state Medical Assistance program by raising the income, asset and spend-down standards. Our state policy should not force my sister or anyone else with a disability to live in deep poverty to get the help they need. ~ Barbara J. Johnson, Eagan ~

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