

Washington Post Op-Ed
What Will Thomas Do When His Medicaid is Cut Off?
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A year ago, I moved from Murfreesboro, Tennessee to Alexandria, Virginia to accept a position as the Executive Director of a TASH, a national advocacy organization for people with disabilities. Moving meant leaving friends and family behind, but in my case it also means that now there are 636 miles between me and Thomas, a person for whom I've been the legal guardian for 23 years.

Thomas was born in 1973 after his mother had been exposed to the measles (Rubella) when she was pregnant. He has an intellectual disability and like Helen Keller, he is totally deaf and blind. His mother was 18 years old and unable to care for him so he entered Tennessee's foster care program at birth. When Thomas was 16, his foster father died and his foster mother couldn't care for him by herself. A year later, his Services for the Blind counselor found him tied to a bed in a nursing home in Memphis.

Thomas' Services for the Blind counselor arranged for him to be a residential student at the Tennessee School for the Blind. Thomas graduated from the School for the Blind when he was 21 years old. He started receiving adult services through Tennessee's Home and Community Based Services (HCBS) Medicaid Waiver program and I became his volunteer legal guardian. Over the past 23 years, Tennessee's Medicaid program has provided the resources for Thomas to live a life that I think his mother never thought would be possible.

Thomas lives in Nashville in a Habitat for Humanity house that a dedicated group of volunteers helped build five years ago. He has staff that is paid through the Medicaid program to help him. They have been trained to use sign language to help him through his daily responsibilities and to keep his possessions in the same place so he will be able to find them. He has a job stocking the snack baskets in the break rooms of three local businesses. He goes to the YMCA to work out every morning. He grows fresh vegetables in a garden in his backyard. On Sundays, he goes to church with the family of one of the staff members who has worked with him for over 13 years.

My job makes it possible for me to fly back to Tennessee every three to four months to check on him. Up until now, Thomas has continued to thrive in a stable program with dedicated staff that is paid to take care of him through Tennessee's HCBS Medicaid Waiver program. But the changes to Medicaid that are included in the American Health Care Act (AHCA) have me worrying what will Thomas do when his Medicaid is cut off?

The proposed changes to Medicaid in the AHCA could potentially pull over \$1.4 trillion dollars out of the program and cap the share that states receive from the Federal Government going forward. What many people don't realize is that 80% of

the people who receive Medicaid are children, the elderly and people like Thomas. In Tennessee, 60% of Thomas's HCBS Medicaid services are paid for by the Federal Government. Community services like Thomas receives are not a Federally mandated service but institutions like nursing homes are. If funding for Medicaid is cut or capped, institutions are likely to be the only option available for anyone who needs the kind of help Thomas receives.

Thomas doesn't know that his life is now in the hands of at least three Senators who need to vote NO to these devastating changes to the Medicaid program. Tennessee's Senator Alexander and Senator Corker could be two of those votes. I want them to know that Thomas and I are counting on them to look out for him and all the other Tennesseans who rely on Medicaid to lead lives that include having a job, living in your own home, going to church, and going to the gym. Otherwise, without Tennessee's HCBS Medicaid Waiver Program, I can only worry that, on one of my trips back to Tennessee, I will be the next person who ends up finding Thomas tied to a bed in yet another nursing home.