

Testimony
Amy Clawson , Parent of Tim Clawson, who has Cerebral Palsy
House Finance - Health and Human Services Subcommittee
March 14, 2017

Dear Chairman Romanchuk, members of the HHS Subcommittee, thank you for the opportunity to provide testimony on the Developmental Disabilities budget proposal, especially the Waiver Increases to support Complex Care.

My name is Amy Clawson; I live in Walton Hills, Ohio with my husband, Paul, and my young adult child, Tim. Tim is 20 years old and has spastic Cerebral Palsy and depends on caregivers for all aspects of his life. Tim has been lucky to have had an IO Waiver to support most of his needs.

I am writing today to ask for your support with the proposed budget Waiver increase to cover Complex Care for individuals like my son. We are concerned about individuals who are dependent in all areas of daily living require a workforce that is stable and well-trained to meet their everyday needs and to maximize their quality of life. The proposed Executive Budget incentivizes providers to serve these complex individuals.

My son cannot walk, is not mobile, he cannot roll from his back to stomach, he cannot pull up on his own, he needs total support with bowels and bladder care, he needs full support with bathing, showering, dressing, undressing, and feeding. Despite using multiple medications, Tim cannot control the spasticity of his own body. He is 6 feet tall and is extremely high tone. He becomes very upset when he cannot control his body. It is heartbreaking when this happens. Only the most caring people know how to handle this.

Tim is a very spirited soul. Tim laughs at jokes, looks at what he wants and needs, he reads ESPN's updates on tv and watches football with passion; he can use his communication device to give you football statistics and to tell you where he wants to go for activities. He can verbally approximate the words "I love you" and ask for a hug. For all of this, he brings great joy to our lives and the lives of those around him. We are extremely grateful for his IO Waiver that allows him to live where and how he wants to. He is an amazing young man. I worry that without a commensurate pay for his complexities, and as we age, we may no longer be able to give him the freedoms and quality of life he is used to having. The Complex Care rate increase would be very beneficial to Tim.

Currently, with a lower pay rate, my son's providers are extremely hard to find and keep. The qualified providers usually have a higher skillset that is worth much more than they get paid. We often lose providers quickly because they simply cannot continue working in such a physically demanding job (we are constantly pulling, pushing, and moving Tim's body for him). After all, right around the corner is a person with more basic needs and less demanding care. Additionally, and thankfully, my son has some high tech equipment that helps him. This equipment is very unique and requires some intense training and intuition by the higher qualified provider.

In closing, Mr. Chairman, thank you for caring about Ohioans, Developmental Disability services, and those with Complex Care needs. More than ever, individuals like my son are living

longer and need a more stable workforce that is incentivized to serve his complexities with the care compassion he deserves.

Thank you for the opportunity to share my family's story and I would be happy to answer any questions.

Sincerely,

Amy Clawson
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