

March 22, 2017

Dear Chairman Romanchuk and Committee Members,

I am here today not only to speak to you about my son, Joe, but on behalf of many other mothers throughout the state who were gifted with children like my son and who need support from the Ohio Department of Development Disabilities (DODD) and Medicaid to help raise them.

Individuals with mild, moderate, and severe disabling conditions and their families have challenges you, as able bodied citizens, cannot begin to comprehend. Many of you will never live the life or face the tough choices families make each day in order to support their family member within their home. This is Joe's story.

When Joe was born we thought we were taking home a perfect baby boy. Little did we know that at 4 ½ months we would begin a 27 year journey that took us from Ohio to ST. Louis to Georgia and back to Ohio before we would unravel the mystery of his disabling conditions. After years of misdiagnoses, in 2015 we were told he had a mutation on gene GNA01. To date, there are only 28 known cases in the world and nearly all of them present differently...Joe being the oldest at 28 years. His condition is degenerative.

Having a GNA01 mutation has caused grand mal & tonic seizures and prevent him from speaking, but it has also caused his mitochondrial DNA to malfunction which we believe has led to his chemical fragility, neurogenic bladder, obstructive sleep apnea, scoliosis, muscular atrophy, dislocated hip, contractures (knee & elbow), reflux, aspiration, osteopenia & quadriplegia.

He requires total assistance to sit up, change positions, scratch an itch, or perform any of the tasks a human being naturally performs for themselves throughout a day. He has a pharmacy full of medications we deliver though a G-tube inserted in his stomach, receives supplemental nutrition via pump feedings at night, is catheterized every 8 hours & is required to use a bi-pap machine to keep his airway open when he sleeps. As a result of these complex, intense needs he requires a skilled level of care provided by highly trained home healthcare aides (HPC) during the day & since 1998, overnight nursing provided through the Medicaid Private Duty Nursing program.

Joe was enrolled on Ohio's Individual Options (IO) Waiver program September 6, 1993 at the age of 5. As a result of this program Joe has been able to live within his community and experience as normal a life as we could provide for 23 years with all of these needs being met in his home at a cost less than that of an Intermediate Care Facility (ICF).

Joe is happy, safe, and free to choose what activities he wants to enjoy inside & outside his home, at will. Over the years his HPC staff have not only attended to his complex personal and medical needs, but have done so while helping him to participate in a boy scout troop and go camping, attend various functions though an adapted recreational organization (sailing, kayaking, bicycling), go horseback riding & swimming, attend movies, concerts and various other age appropriate activities with his peers. To date they continue to seek opportunities where he can passively participate (library, community festivals, sports events, etc.) and which enrich not only his life but the lives of those around him.

The complex severity of Joe's disabling conditions supports the message of what is possible when the right funding & services are in place. There is no doubt without these fundamental home based services he would be in an institution and because he was misdiagnosed until May 2015, it is my belief he would not have survived childhood.

Joe came here with me today because he hopes seeing him and hearing his story will help you understand how he has benefited from the IO waiver program and to encourage you to pass the DODD budget, as requested, to afford individuals, like him, a CHOICE to live outside an institutional setting by providing funding & services designed to enable home/community based living as outlined in the ADA Olmstead Decision of 1999.

Two years ago Ohio made history by awarding the DODD an additional \$286M in state and federal monies. Much of this funding was used to expand opportunities for Ohioans with disabilities to experience life within their communities. Once again DODD is asking for an additional \$122M to continue with the initiatives started two years ago as well as to open up opportunities now being realized due to an increase in the 'community' population of individuals with disabilities. I know funding is tight in this budget but I also know progress is being made by the DODD toward a sustainable delivery system that will not only benefit individuals with disabilities, now and in the future, but presents opportunity and moral tenet to the non-disabled population who can acquire untold friendship and knowledge from individuals like my son. The latter of which I consider to be a 'priceless' tangible consequence.

George Washington Carver said "No individual has any right to come into the world and go out of it without leaving behind distinct and legitimate reasons for having passed through it."...let your commitment to the Intellectual and Developmentally Disabled population through the passing of the DODD budget as it stands, now and in the future, be the reason you are here.

With kind regards,  
Kim Kelly (Mother and Guardian of Person for Joseph Lavalle)  
Joseph Lavalle

3593 Braidwood Drive  
Norwich Twp., Ohio 43026  
(614) 527-9772