

**Senate Medicaid Committee Testimony  
H.B. 33**

**Gary Tonks, President/CEO  
The Arc of Ohio**

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Chair Romanchuk, Vice Chair Wilson, Ranking Member Ingram and members of the Senate Medicaid Committee, my name is Gary Tonks. I am the President/CEO of The Arc of Ohio. The Arc is our states oldest and largest volunteer lead organization representing Ohioans with developmental disabilities and their families. Founded in 1950, The Arc of Ohio was intimately involved in the creation of special education in Ohio, many of our not-for-profit providers and HB 169 which created our County Boards of Developmental Disabilities.

As a family member, my involvement began as teenage volunteer in special education classes. During college I volunteered in a facility for children with disabilities. And, for almost 50 years I have served as a group home direct support professional (DSP), teacher, program director, local Executive Director and State Director in three states.

It has been my honor to support citizens of Ohio with developmental disabilities and their families for almost 26 years. While it has never been easy to recruit and retain direct support staff, we did what we had to do. We worked together to create and sustain a support network for Ohio's most vulnerable citizens.

Today, however, our support network, our families and the people we support, are in crisis. We are not just at a cliff, many of us have fallen over the edge. Programs have closed. Families are exhausted and people with developmental disabilities are not receiving the support they need.

Every week, at least one parent tells me, "I pray that my child will die before I do." Most, if not all of you, are parents. Imagine thinking that. Imagine praying for your child to die.

One of the joys of my job is to speak with families daily, but most of those conversations lately have been calls of desperation. A mother of two children with

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disabilities in Medina County called last week. She weighs suicide as one of the options to assure her sons receive the support they need. She cannot work outside the home and provide the support they require.

There is a mother in Dublin, diagnosed with stage 4 cancer. Her daughter has significant intellectual and physical challenges. She cannot have the regular treatments she requires for cancer because she cannot find staff to support her daughter, while she is at the hospital.

There is a family outside Cleveland, whose adult son has violent outbursts because he cannot verbally communicate when he is in distress. His mother wears a football helmet to protect herself when she must be alone with him, because direct support staff are not available.

There is a family in Northwest Ohio whose 15 year old son was severely injured in an accident. He requires assistance throughout the night to suction him and make sure he is still able to breathe. His young parents take turns staying awake all night because direct support staff and nursing is not available.

An older father in Circleville fractured his hip, yet continues to support his adult son with significant challenges. He often sleeps on the floor beside his son's bed so he can be close, if his son needs anything. Direct support staff are not available.

It is not uncommon for me to receive a call in the morning that goes like this:

“Gary, no one showed up. I can't get out of bed and I have to pee. I don't want to wet myself. Please help.” If the call was within Franklin County, I would absolutely try to help myself, but these calls are often from over an hour away. There are no support staff available.

Those of us at this table sometimes disagree as you do, but I can tell you that when someone is in need, when the lives of Ohioans with developmental disabilities are at risk, we work hand in hand. I can and I have reached out to each of these partners for help. I personally call providers of service when families are in crisis. Too often, the calls result in responses like this:

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“I am so sorry. We have empty beds but no staff, so we are not accepting anyone new.”

“Does this person walk? We can’t accept anyone that walks because we don’t have staff to follow.”

“We just closed that home. We weren’t able to staff it.”

And yes, beds, day supports and homes have closed. And where do the people that lived and worked there go? They typically go back home to families who made that difficult choice to place their loved one. A domino affect begins. At least one parent must quit his/her job because direct support staff are unavailable, sometimes placing the entire family in a financial crisis. Elderly parents face not only exhaustion, but risks to their physical health from lifting.

Most of us remember the exhaustion of early parenthood. Imagine today, you have felt that for 20, 30, or even 50 years. Our parents, our families, do what we do out of love, but we are at that cliff and some of us have already gone over the edge.

The Ohio Department of Developmental Disabilities and our County Boards currently support close to 100,000 Ohioans. The Centers for Disease Control estimates that about one in six or 17% of children aged 3 through 17 have one of more developmental disabilities. Early Intervention, Special Education, medical intervention and our Families have significantly reduced the number of Ohioans who need government support as they age, but those who do need help are desperate.

We have a moral obligation to help and that help is currently in the form of increased funding. We must increase our direct support staff wages to at least an average of \$20/hr. Others at this table will provide you with what it takes to get to that wage. I implore you with real stories of real Ohioans. Please help us.

Thank you for the opportunity to speak with you today. I am available for any questions you may have.