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Testimony

H.B. 96

Ohio House Health Committee

Chair Schmidt, Vice Chair Keeter, Ranking Member Somani and members of the Health Committee, my name is Gary Tonks. I am the President/CEO of The Arc of Ohio. The Arc of Ohio is our state's oldest and largest volunteer lead organization, representing Ohioans with Intellectual/Developmental Disabilities and their Families.

The Arc created our first schools for children with disabilities, when children with disabilities in Ohio and across the nation, could be legally turned away at the school house door. As those children grew up, The Arc was instrumental in the creation of County Boards of Developmental Disabilities in 1967. As community services became available The Arc and our families laid the foundation for many of our not-for-profit services providers.

I have been an advocate with The Arc for over 50 years. I have personal experience as a family member and the longevity to know what life was like before a federal right to an education, before Medicaid, before Opportunities for Ohioans with Disabilities and the Department of Developmental Disabilities existed.

The smell of excrement still fills my nostrils when I think of the warehouses where parents were told to place their babies at birth. I think of children who became disabled because of polio, measles, chicken pox, RH factor, infections during pregnancy and a lack of prenatal care.

Medicaid, Waivers and advancement in medical care have significantly reduced mortality and improved the quality of life for those children and their families as children grow into adulthood.

But our families are scared. Most, if not all of you, are parents. Imagine being told at birth that your baby may not live. Your baby may never learn to walk or speak. Many of our parents wake up every day thinking, Is today the day he will choke to death? Is today the day his heart will stop? Is today the day no one shows up to help me and he has the final seizure?

Medicaid and Waivers are our lifeline. We are so appreciate of the increase you provided in the last state budget. It has dramatically increased the ability for a family to locate support. It has provided some stabilization, but it has not eradicated the challenge of finding a provider or a placement if a child has significant behavior and/or medical challenges. We cannot stop now in our support of Ohioans with developmental disabilities and their families.

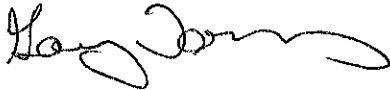
We are scared. On top of the care for a child with a disability, we now worry whether what has sustained us, will be taken away. We are scared for the children and adults, yet to even enter our support networks.

I want to say that, we in Ohio, have always cared for those unable to care for themselves. I cannot, because I am older enough to remember the warehouses, no right to an education and virtually no publicly funded community services.

We cannot go back. Thank you for a proposed budget that maintains what we have within the Department of Developmental Disabilities. Consider, however, the children and adults yet to be supported. Consider the young parent who is being told their baby may never walk, or speak. Consider the Ohioans currently supported by exhausted loved ones who have yet received support. Consider the direct support staff who still cannot afford rent or a mortgage; the direct support staff who have no health insurance.

We come to you for help at least every two years. Help us help ourselves and the thousands of Ohioans who cannot speak up for themselves. Please adopt a method of ongoing support for Ohio's Waivers that allows our families one more day of peace; one more day to be thankful to be an Ohioan.

I would be happy to answer any questions you may have.

A handwritten signature in black ink, appearing to read "Gary Tonks", with a stylized, flowing script.

Gary Tonks, President/CEO
The Arc of Ohio