Written Testimony HB 96 Ohio House Health Committee

Chair Schmidt, Vice Chair Keeter, Ranking Member Somani and members of the Health Committee. Thank you for allowing me to provide you with my testimony for your consideration in regular cost of living increases for direct care staff and ongoing support of Ohio's Medicaid and Waivers systems.

My name is Amy Clawson, and I am writing to share the deeply personal journey of caring for my 28-year-old son, Tim. Tim has severe cerebral palsy and requires assistance with every aspect of his daily life. Despite his challenges, Tim is a bright, humorous, and incredibly strong young man who uses specialized equipment to support his independence. This includes a powered wheelchair, a high-tech communication device, a customized vehicle, a ceiling lift system, a custom bed, and accessible home accommodations.

Tim's medical needs are complex. He has muscle contractures, a G-tube, spinal fusion with resulting torticollis, and requires 12 different medications. He sees over a dozen specialists, including three therapists, and depends on a team of dedicated caregivers. Unfortunately, these resources are not always easy to come by. For over 18 years, I have personally recruited, trained, and managed his caregivers in hopes of giving Tim the fullest life possible. Yet, many caregivers leave after only a short time, unable to handle the emotional and physical demands of the job, especially given the low pay.

The search for reliable care has only become harder in recent years, as we have often found ourselves without help when we needed it most. Tim's size, age, and medical complexity, combined with the challenging compensation for caregivers, make it increasingly difficult to maintain a stable care team. My husband and I are Tim's primary caregivers, but we are growing older, and we fear the day when we are no longer physically able to meet his needs. The thought of Tim being forced into an institution or long-term care facility—away from the comfort and support of his family—breaks my heart and motivates me every day to prevent that from happening.

Through the Ohio Department of Developmental Disabilities and Ohio Medicaid, Tim has the opportunity to live independently in our family home. The funding he receives through his Individual Options (IO) Waiver is absolutely crucial, and we would be lost without it. The Waiver allows Tim to live in a setting that supports his dignity, independence, and personal growth. It's the reason he can stay in his own home with pets, friends, and family—an environment that fosters joy and connection.

However, without fair compensation for the dedicated caregivers who support Tim, it's becoming harder to maintain this quality of life. Tim's care staff are paid through his Waiver, and without sufficient funding, we face the real possibility of losing these vital supports. We are

especially concerned about the looming federal Medicaid cuts, which threaten the very foundation of care we rely on.

I want to take a moment to express our gratitude for the rate increases in 2024, which have helped retain Tim's care staff. These increases have shown that when direct support workers are paid a stable, livable wage, they are more likely to stay in the field and continue providing high-quality care. It's clear that investing in these workers leads to better outcomes for families like ours.

We are asking for your support in advocating for a state budget that prioritizes Ohio's Waivers and ensures fair compensation for direct care workers. These individuals are the backbone of Tim's care and of countless others across Ohio. With your help, we can ensure that families like ours continue to have the support we need to keep our loved ones out of institutions and thriving in their own homes.

Thank you for taking the time to consider our story and for supporting the future of Medicaid and direct care workers in Ohio. I am happy to answer any questions.

Sincerely,

Amy Clawson, mother and guardian Walton Hills, OH 513-617-6272