Senate Medicaid Committee Substitute House Bill 96 Cleveland Hearing and Speech Center Community Center for the Deaf and Hard of Hearing Jennifer Smith, Client Mother May 6, 2025

Good morning, Chair Romanchuk, Vice Chair Huffman, Ranking Member Liston, and members of the Medicaid Committee. My name is Jennifer Smith, and I offer my testimony today in my personal capacity as a concerned parent, seeking support of the budget amendment increasing funding for Ohio's Community Centers for the Deaf through the Department of Developmental Disabilities.

My daughter Ava is two years old and lives with two pathogenic variants that cause progressive bilateral hearing loss. Ava's hearing loss was detected during routine newborn hearing screening at one day old. Four weeks later, we packed her into the car and drove the one hour to her ABR test at Cleveland Clinic's main campus, where her hearing loss was confirmed. In an instant, our world was turned upside down. It has been two years and eight months since that diagnosis, and in that time we have been on a rollercoaster of MRIs, genetic testing, hearing tests, surgeries, audio verbal therapy, speech therapy, early intervention, music therapy, and more. By Ava's first birthday, she had attended more than 73 medical appointments. Throughout that journey, my husband and I were faced not only with medical decisions, grief, and confusion, but also an immediate need to learn a new language and culture in order to fully support our daughter. It was a lonely and isolating journey until we were connected with Cleveland Hearing and Speech Center, and their Community Center for the Deaf and Hard of Hearing. We were against the clock, could we learn and teach her a new language before she lost access to sound? We rushed to take her to the beach and Disney World- to know those sounds not knowing what the future might hold.

Ava received her first set of hearing aids at four months old. At the time, Ava's hearing aids were not covered by insurance, and her growing ears required new molds every couple of months. We had to secure two different sets of hearing aids within her first year due to loss progression, and that cost combined with ASL lessons and therapy sessions that were also not covered, put us into in a financial situation that we never expected, given our successful careers. We felt like we were going to have to choose between giving Ava access to her community, and forcing her to fit into ours. We sought out an audiologist with hearing loss in order to get guidance on where to turn next. She shared with us that 90% of Deaf children are born to hearing parents, and only 10% of those hearing parents learn sign language. We needed to be in that ten percent.

We connected with the Community Center for the Deaf and identified Deaf events where Ava could meet peers, be immersed in American Sign Language, and learn about her culture. The events are typically free or low cost, and have resulted in invaluable connection with families walking our journey. As a result, we are able to continue learning ASL through peers free of charge, have connected with resources to help with her transition to preschool, found medical providers who use ASL, and found parent support groups and play groups allowing all of us, as a family and individually, to thrive on our journey.

It is not lost on me that Ava will walk a hard road in her life. Perhaps some of you also have loved ones walking a different journey. From a young age, we are teaching her the importance of self-advocacy. That is why she is with me today, and while today is her first time in this room, I hope it will not be her last. We need Ava to have access to these Community Centers for the Deaf beyond her childhood so that she has the same opportunity to connect and advocate that led each of you to this room.

The first time that Ava went to a Hearing Loss playgroup organized by the Center, she looked at other children with hearing aids, cochlear implants, and bone anchored hearing aids all playing together, looked at me, and signed "same". It's profound, really. It's what we are asking you to save. The sense of belonging. Community Centers for the Deaf are not just services—they are lifelines. Please see my daughter, and all of the children and adults in this room and in this state who rely on the services that these Centers provide. Please hear them- in whatever way they communicate. They need these Centers to have the confidence to thrive and belong.

I'm before you today, because I need to tell my daughter that I did everything that I could. That I fought for her and her community. Last year, funding ended for the state's Deaf mentor program. Now, the Community center that we rely on, and all of them throughout the state, are at risk of devastating budget cuts. What is the message that we are sending to this community-to our community? Without sustained funding for these services, families are left isolated, and children grow up without the resources that help them communicate, build community, succeed in school, find meaningful work, and build full, connected, beautiful lives. Supporting this amendment isn't just about dollars—it's about dignity, opportunity, and the belief that every person deserves a place where they can thrive.

Please support funding to Community Centers for the Deaf through the Department of Developmental Disabilities so that Ava and her community can continue to thrive.

Thank you for your service, for your consideration of my testimony, and for your support of my daughter and our community.

Sincerely,

Jennifer Smith