

Members of the Finance Subcommittee on Health and Human Services, my name is Kari Jones and I am the President & CEO of the Down Syndrome Association of Central Ohio. I represent over 1,200 individuals with Down syndrome—and their families-- in over 23 Central and Southern Ohio counties. Today I am also a voice for all of the Ohio Down Syndrome Associations- the Upside of Downs in Cleveland, the Down Syndrome Association of the Valley, the Down Syndrome Association of Greater Toledo, the Miami Valley Down Syndrome Association, and the Down Syndrome Association of Greater Cincinnati. Combined, our service area covers all of Ohio's 88 counties and the residents within them who are impacted by Down syndrome.

First, I am here today in support of the As Introduced Ohio Department of Developmental Disabilities budget. I am here representing the Ohio Down Syndrome Associations, however, I am also here as the sister to an incredible brother, Alex, who has Down syndrome and just turned 32 years old last week. Due to funding restrictions within Ohio, Alex has been on a waitlist for an Individual Options waiver, also known as an IO Waiver, for 14 years—nearly half of his life. Although he is an adult, he is missing out on a true “adult rite of passage” in moving into his own place and living a more self-determined life. Alex is a fairly independent guy—who can catch a cab to get to his full time job at Kroger and take care of his own personal hygiene. However, he requires needs like medication administration and meal preparation in order to live a healthy and safe independent life. In order to ensure proper care for Alex, my family will require staff that are highly qualified and well trained. Having an IO Waiver could fulfill these needs for Alex—but it also means that funding for increased staff wages, nursing oversight, and technology support will be critical in safeguarding his safety and health. While Alex is unique, his needs and story of decades in waiting isn't. It is time to change that—and you as members of this committee—have the power to change his life and thousands of others throughout Ohio—for the better.

Additionally, I am testifying as an opponent of drastic and incomprehensible changes proposed to the structure and limitation within the Bureau for Children with Medical Handicaps, also known as BCMH. Let me first say that I understand that there is a deficit within this line item that needs to be addressed. Although I am not in finance, I was raised by two CPA's and can understand simply that operating in the red can't be sustained. With that said, BCMH and it's safety net of financial support, is critical to a significant portion of the families I work to serve on a daily basis. Although Down syndrome is not a qualifying condition for assistance, congenital heart disease is. You may not know this, but nearly 1 in 2 of all individuals born with Down syndrome are also born with heart defects. This means that, in addition to receiving a life-changing diagnosis, half of all families are also told that their child will need cardiac intervention—often open heart surgery—very early on in their child's life. With the proposed changes, a family of four—with a household income of less than \$60,000—would be on the hook for tens

of thousands of dollars. This would—without a doubt—force families to choose poverty and debt in order to ensure care for their child. I have a daughter, Evelyn, who was born with congenital heart defects in 2015. I can assure you that it was a terrifying, brutal experience I wouldn't wish on anyone. My family has insurance, but her medical care and medications were exorbitant. BCMH was there for my family to help us with some of these expenses—which lifted a weight I can hardly describe. If this change in reduction of qualifying families adjusts to those under 225% of poverty level, what are families over that supposed to do? To future families, who are finding out prenatally that their child will have Down syndrome and CHD... what are they supposed to do? What kind of decisions do you think they may make knowing that this safety would not be there for them?

In closing, I implore that you carefully consider supporting no change to BCMH and the support it brings to thousands of families throughout Ohio. I urge you to realize the positive impact that is within your control in supporting the DODD budget as it was introduced. The people impacted—the developmental disability community and beyond—are vulnerable and need your support.

Thank you for your time this afternoon and I welcome any questions you may have.

Kari Jones
President & CEO
Down Syndrome Association of Central Ohio