Testimony on HB 33 (FY24-25 State Budget) By Jason Jolley, Ph.D., Parent and Board Member Athens County Board of DD March 28, 2023

Chairman Edwards, Ranking Member Sweeney, and members of the Finance Committee, thank you for the opportunity to appear here today to testify on House Bill 33.

My name is Jason Jolley. I am a resident of Athens County. In my professional capacity, I serve as a Professor at Ohio University's Voinovich School of Leadership and Public Service. I am here today in my personal capacity as the proud father of three children, two of whom are served by the Athens County Board of Developmental Disabilities.

In fact, I feel confident saying that it is Ohio's developmental disabilities system that led me to put down roots in this state, and the reason I stand before you today. As you might be able to tell from my accent, I am originally from North Carolina. When I was presented with multiple employment opportunities at colleges across the country, the deciding factor for me choosing Ohio University came when I was introduced to the amazing team of professionals at the Athens County Board of Developmental Disabilities and Beacon School.

Unfortunately, the system that brought me and my family here to Ohio is at risk of collapse if action is not taken in this state budget to support a \$20 average wage for Direct Support Professionals (DSPs).

As Vice-President of the Athens County Board of DD and a board member for both the Ohio Association of County Boards of DD and The Arc of Ohio, I hear the stories of families like mine every day as they navigate this crisis. Today I am here to share my family's story on their behalf.

My oldest daughter, Abigail, is 16 years old. She has autism and has had profound intellectual disabilities her entire life. A recent test at Nationwide Children's Hospital determined Abigail has a nonverbal IQ of 31. Abigail still wears diapers, needs assistance with feeding herself, and requires someone bathe her, clothe her, and change her diaper. She is unable to do any of these things for herself.

Allie, our youngest daughter, is 13 years old. Allie also has autism. When Allie was 5 years old, she could read, do math, talk, and run around like most typical children. Allie began to lose her skills starting around age 6. She was diagnosed with Rett Syndrome, which causes girls to lose their speech and lose their mobility. Now, Allie rarely speaks, engages in behaviors that are difficult to manage, such as breaking items, fecal smearing, and harmfully squeezing our cats and dogs. Allie needs regular assistance at home. She requires 2 to 1 staff at school, and she now needs assistance feeding herself, bating, getting dressed, and changing her diaper, which she also now wears just like her sister.

Having children with developmental disabilities is difficult. However, my family has been able to manage these difficulties thanks to support from Direct Support Professionals (DSPs) who work in our

home. While we faced an occasional staffing challenge over the years, we had received reasonably consistent support until just a few years ago.

Today, we face constant staff turnover and have changed provider agencies multiple times due to lack of staffing. We have had five (5) different provider agencies staff our home in just the last 2-3 years. Four of those provider agencies stopped providing services because the rate didn't allow them to pay their staff a high enough wage to work with both of our children. Our current provider agency barely has enough staffing to cover our shifts, and we live in constant fear that tomorrow will be the day that we receive another notice that our world will turn upside down once again and we will have to start over from scratch to find a new provider.

Even with our current provider, we face a crisis every time a DSP is ill or takes a day off when the kids are out of school. While Allie has 2 to 1 support at school, we have been unable to secure 2 to 1 support on weekends for her at home. This means that she cannot safely leave the home on the weekends to go to the park, to play outside, or even to ride to McDonald's for ice cream and fries. Allie is a big fan of fries.

My wife and I have become very close with the DSPs who work and have worked in our home. The low wages faced by DSPs is a barrier to them continuing to work in the field, especially with wages at other comparable state positions and even some entry level private sector jobs paying \$20 or more per hour.

Recently, we had a young woman working part-time in our home as a DSP. She also worked part-time in a local pizza place as a cashier. We asked her if she would consider working more hours, as we had a need and our daughters liked having her as a DSP. The young woman came from an impoverished family, and she let us know that she made more money working at the local pizza place as a cashier than she made working as a DSP in our home.

These are the types of challenges families in Ohio face every day, as DSPs can make more money working as fast-food cashiers, retail workers, and in other far less-demanding jobs than they can assisting Ohioans with developmental disabilities.

My wife and I are determined that our children will live with us into their adulthood and be active members of our community as long as possible. Yet, I am fearful about the long-term prospects of them remaining in our home as adults given the provider crisis, which is growing worse every day.

For these reasons, and on behalf of the thousands of Ohio families who are dealing with this crisis on a daily basis, I urge you to increase the reimbursement rate for DD providers. By allowing them to be able to afford paying an average DSP wage of \$20 per hour, your action will help families like mine secure adequate staffing, receive the necessary support for their children they need, and help support those Ohioans with developmental disabilities who are not as fortunate to have the stable home environment my family can currently provide.

Thank you for hearing my concerns. I would be happy to answer any questions you may have, either here today or one-on-one after this hearing has concluded.