

Proponent Testimony
House Bill 141
House Health Committee
May 7, 2025

Chairwoman Schmidt, Vice Chair Deeter, Ranking Member Somani and Members of the Committee, my name is Sara Steines Newstead. I live in the Cleveland suburb of Bentleyville, Ohio. I am testifying today as a parent of a son with disabilities and medical complexities, and as Managing Partner of Genesis Health Consulting, which specializes in designing systems to improve child and family health.

As a parent and child health expert, I have seen the incredible impact and value of early childhood education and care programs for children with disabilities and medical complexities. I was living in Milwaukee, Wisconsin, when I was pregnant with my younger son, Henry, and learned that he would be born with Down syndrome and congenital heart defects. My husband and I grappled with many fears and unknowns during that time. However, one of the things that gave us courage and confidence was that Milwaukee had several organizations specifically designed to care for children like Henry, along with their typically developing siblings. One of these organizations is Penfield Children's Center, which has served the Milwaukee community for over 55 years, providing early childhood education, behavioral health and therapies, and special care nursing services. Knowing Penfield was in our community made it easier for our family to picture our new normal, for my husband *and* me to stay employed, and to access the services Henry would need to grow and thrive.

When we chose to return to my hometown in Northeast Ohio to be near our extended family, we were shocked that organizations like Penfield were nowhere to be found in the greater Cleveland area. Without this resource, we looked to our community's early childhood centers. We spoke with 13 different early childhood centers within a 10-mile radius of our house, looking for a center willing and able to welcome Henry into their classrooms. 12 of the 13 declined, stating that caring for a child with Down syndrome and a feeding tube required more than what they felt they could provide. The 13th center offered to enroll him, but only if we paid for a full-time aide to accompany him. We estimated that enrolling Henry at that center would come close to costing \$60,000 a year, between hiring a full-time personal aide and tuition. We ultimately hired a caregiver recruitment firm to find a qualified professional to care for Henry in our home, a relative savings around \$50,000 each year.

The most unusual thing about our story is that we could scrape together the financial resources to cover this cost for our family. According to the US Census Bureau website, Ohio's median family income in 2023 was \$69,680. So many families who look like ours do not have the option of hiring help. Instead, parents leave the workforce to care for their child full time, rely on public programs and subsidies for assistance, or are forced to leave their child with a person or center that is not prepared to meet that child's needs, leading to safety risks and further delays in care or development.

As Managing Partner of Genesis Health Consulting, I've worked directly with Penfield Children's Center and studied similar programs in cities across the US. I have seen the data that shows their positive impact on child health and education, their cost-effectiveness, and their indirect value to workforce training, parenting supports, and system navigation. The evidence strongly supports the passage of HB 141 as a smart and effective investment of taxpayer dollars.

As a parent, I will always remember the contrast between my experience in Milwaukee and Cleveland. When I walked the halls of Penfield Children's Center six years ago, I felt excitement and relief knowing there was a place for Henry where he would be welcomed and supported, and that our life, while looking a little different, would be okay. A few months later, searching for care in Cleveland, I'll never forget how it felt to hear "no" over and over from centers in Northeast Ohio, independent caregivers, and community resources, either because they declined to care for Henry or because the solution I needed did not exist. The logistical day-to-day challenges of that time were overwhelming. But the sense of isolation and exclusion, simply because of Henry's DNA, broke my heart.

I support the passage of HB 141 as a necessary first step to ensure that children and families across Ohio receive the care and support they need in their communities, as valued members of those communities.

Thank you.