Re: HB 155 Ohio Achieving a Better Life Experience Act (ABLE Act)

Good morning, committee members. My name is Stephanie Hoffer. I am a professor at the Ohio State University Moritz College of Law, a member of the board of directors of the Down Syndrome Association of Central Ohio, and a mother to George, a bright and loving four-year-old boy with Down Syndrome. I appear before the committee today in support of the ABLE Act.

My current research focuses on the intersection of Medicaid eligibility requirements and tax law, a subject in which I have a personal interest. As we approach the fiftieth anniversary of Medicaid,¹ and the twenty-fifth anniversary of the Americans with Disabilities Act,² there still exists no comprehensive means of safeguarding the quality of life of individuals like George.

A 2010 national survey revealed that more than eighty percent of family caregivers of individuals with developmental disabilities provided transportation and cooking; seventy percent provided support with financial affairs and recreational activities; sixty-nine percent administered medications, and sixty-one percent aided in personal hygiene.³ Eighty-four percent of these families reported difficulty in finding reliable home care providers;⁴ eighty percent did not have enough money to pay for care,⁵ and only eight percent received private insurance funds to cover the cost of providing such care.⁶ Failure of the private market for disability-related services is clear, making legislative action justified in this context.

In Ohio, most of the disability-related services meant to help individuals like my son live and work in the community are funded through Medicaid, even though they are not medical in nature. Because access to Medicaid is limited to only the poorest of our State’s citizens, and because family financial support is a strike against Medicaid eligibility, claimants typically must rely on other forms of public assistance, such as public housing and food assistance programs.

⁴ Id. at iv.
⁵ Id. at 24.
⁶ Id. at 12.
It is worth repeating this point: family financial support counts against Medicaid eligibility. Imagine the heartbreak of being forced to choose between keeping your child out of the welfare system and safeguarding that child’s ability to live and work outside of an institutional setting. Not a day goes by that I do not feel already the harshness of this choice. If I want to pay my son’s rent, or help him with his groceries, Medicaid will stand between us, forcing him to rely on you instead of on me.

Although federal law provides a special needs trust regime for individuals like George, it is of little comfort. Ohio law provides that these trust funds may not be used for “basic necessities” including “essential food, clothing, shelter, education and medical care . . .”. Furthermore, the trustees of these trusts have the discretion never to make a payment. There is no support standard though which a beneficiary could compel a distribution of funds, even when a beneficiary has earned them with his own two hands. No legislator would propose such a restrictive regime for a typically-abled child. What, then, about disability justifies the government’s demand that I deny my son support for shelter, clothing, and food as a price for access to disability-related care?

And while it is true that Ohio provides a buy-in program for Medicaid, and that some individuals with disabilities can gain access to support services through the program, it is available only to people who work and whose wages are limited. There is, however, no reason to think that people who work have a greater need for disability-related social services than those who don’t. In fact, in the disability community, the opposite is likely to be true. As a result, Medicaid buy-in is an incomplete solution to perverse financial planning incentives created by Medicaid eligibility restrictions.

Passage of the ABLE Act would solve this problem for most families. As a parent, I could ensure, at least to the extent permitted by the contribution limit, that my son has a roof over his head and food to eat; that he receives these things from his loving family instead of the State; and that resort to non-disability related forms of public assistance comes only on a truly rainy day.

The State stands to lose very little through passage of the Act, and in fact, it may see gains. First, funds remaining in the account at the end of a beneficiary’s life will be used by the State to offset the expenses of providing care. Second, families may provide support to loved ones who would otherwise be welfare claimants. Third, federal law allows Ohio to contract with other states to provide ABLE account management services on a fee basis and thereby defray cost of the Act.

The current state of law is too costly to families, whose emotional health, family bonds, and finances suffer. And these costs are imposed solely on the basis of disability. Passing the ABLE Act will lessen the burden on families while creating gains for the State in other areas. I urge you to please let me care for my son. Remove Medicaid-imposed barriers to family support for George and others like him by voting for this Act.

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7 See O.A.C. § 5123: 2-18-01(c).