

Testimony on H.B. 465  
by Lindsey Sodano  
End Ohio's Parent Penalty  
Pay Family Caregivers National Coalition  
4/14/2024

Chairwoman Schmidt, Vice Chair Miller, Ranking Member Denson, and members of the Families and Aging Committee,

My name is Lindsey Sodano, and I am testifying as both a family caregiver to a child with profound developmental disabilities and an advocate for the well-being of disabled children across the United States. I want to express my sincere gratitude for the opportunity to offer testimony in support of H.B. 465. Lauren's Law represents a critical expansion of the protections established under Esther's Law, specifically aimed at enhancing the safety and dignity of residents in intermediate care facilities.

I would like to focus my testimony on just one line of this bill, Sec. 5166.201 (A)(2), which stipulates that under a newly designed Medicaid home and community services waiver, "A parent or other family caregiver may receive payment for services provided regardless of the age of the waiver participant." For my family and for hundreds of others across the state who are suffering under Ohio's recent "provider of last resort" rule, OAC 5160-44-32 (E)(1)(a), this is the most crucial line in the bill.

I work with Pay Family Caregivers National Coalition, a grassroots organization of 4,000 family caregivers and over 41,000 petition signers who are fighting to keep profoundly disabled children out of institutions. Over the past two years, I have researched the barriers these children in Ohio and across the U.S. face when trying to access home and community-based waiver services.

At the state level, we participated heavily in every public comment opportunity throughout the drafting of Ohio's "provider of last resort" rule in 2023, flooding ODM and DODD with hundreds of comments and personal stories about the risks to Ohio's severely disabled children if the state failed to implement a fair and reasonable paid family care worker program. Hiring family caregivers to work as direct service professionals is an idea which CMS Deputy Administrator and Director Daniel Tsai called "the silver lining of the pandemic." Indeed, the National Association of State Directors of Developmental Disabilities Services and the National Association of Medicaid Directors recently stated that paid family caregiver policy "yields great benefits; it increases the supply of potential support workers, and often a legally responsible individual is the person best positioned to provide successful supports."

Despite our best efforts and the full support of CMS, we were not successful in removing the harmful “provider of last resort” clause, OAC 5160-44-32 (E)(1)(a), or the highly abnormal new rule that removes due process and appeal rights from individuals who have family caregivers, OAC 5160-44-32 (J). As a result, Ohio now has the most restrictive “provider of last resort” policy in the nation, and county boards of developmental disabilities are using this rule to replace long-standing, dedicated, highly experienced parent caregivers with clearly unqualified and inappropriate employment agencies.

Why would county boards want to do this? After all, the state has already ruled that family caregivers are cost neutral when compared to non-relatives. There’s no money to be saved. Why remove a trusted, reliable care worker and replace them with a revolving door parade of random strangers, especially when it comes to bathing, diapering, and menstrual care of vulnerable, nonverbal young women? Why turn away family care workers when the provider shortage is so critical? Indeed, one year ago, the Ohio Association of County Boards sent one of its lobbyists here to warn the Finance Subcommittee on Health and Human Services that Ohio’s provider shortage was so severe that all the providers were quitting “and nobody will be there to take their place.” Two weeks later, that same lobbyist seemed much less concerned about the provider shortage when he launched a campaign to push for a statewide total ban of parent caregivers.

There’s a simple explanation for this behavior. DODD announced that if the disabled child’s parent rejects any county-approved employment agency for “whatever reason,” the parent must then personally work the already-authorized care hours as a DSP but without any pay. County boards stand to save money by approving children for waivers, authorizing a certain number of care hours, and then arranging it so that those care hours go unused. As the Arc of Ohio CEO Gary Tonks warned DODD and ODM in 2023, “County boards have made it very clear that they do not want this rule to go through, and I believe this is their attempt to eliminate this option for many parents.”

Ohio’s opposition to providing Medicaid home and community-based services to profoundly disabled children runs deep. In fact, one county board employee confided to us that counties avoid delivering waiver services to children because the children live longer than adults, which means they cost more money over time. This expresses a disturbing yet common county board perspective that the extended life expectancy of disabled children is a burden rather than a God-given miracle. As a result of this line of thinking, children are 22% of Ohio’s population but receive less than 1% of waiver funds.

The rollout of Ohio’s new “last resort” policy in January of 2024 has been an absolute nightmare for dozens of children across the state. Kids are confused about why they must bathe or go to the bathroom in front of multiple random strangers, with no ability to choose the worker – or even the *gender* of the worker – to whom they must expose their bodies. Girls feel threatened by the prospect of having their intimate feminine care tasks performed by an ever-changing parade of unfamiliar adult men.

Lauren's Law seeks to end this nightmare by creating a "family first" waiver that considers family care workers as the *first* resort, not the last resort. However, it's important to note that a brand-new waiver isn't even required to correct this problem. CMS fully endorses paid family caregivers on *all* waivers, and there is no requirement for Ohio or any other state to institute a "provider of last resort" policy. CMS Director and Deputy Administrator Tsai promised, "We will tell the states in extra bold letters that there are absolutely no federal barriers to paying parents and legal guardians as paid caretakers." States such as Virginia are taking action to respond to desperate families' cries for help: Virginia's General Assembly just unanimously passed a bill banning "provider of last resort" statewide, which Gov. Youngkin has now signed into law. We need Ohio to do the same.

In closing, I implore you to prioritize the well-being and civil rights of Ohio's disabled children by taking swift action to rectify this situation, whether by creating a new "families first" waiver or through legislation that directs ODM to remove the two anti-family care worker lines in OAC 5160-44-32 that have caused so much grief, fear, and trauma to so many children across Ohio in the past few months. I thank you for your thoughtful consideration to ensure the health and safety of these children, who, despite their longer life spans, are, in fact, miracles, not burdens.