

WARREN COUNTY }
 }
STATE OF OHIO } S.S.

I, Lindsey Sodano, having first been sworn according to law and under and under the pains and penalties of perjury, herein states the following of which Affiant has personal knowledge:

1. I run a website and a Facebook page, both called End Ohio's Parent Penalty, that share news, public records, and opportunities for grassroots actions promoting fair and reasonable family caregiver policy in Ohio. See www.ohioparentpenalty.com and www.facebook.com/ohioparentpenalty.
2. The four personal stories contained in this Affidavit were provided to me anonymously by Ohio parents of minor children with Medicaid waivers.
3. These parents prefer to remain anonymous because they fear retaliation from the Ohio Department of Developmental Disabilities and/or their local county boards of developmental disabilities.
4. First Story:
 - a. I became my son's paid caregiver in May 2024. My son is 11 years old and has a rare neurodevelopmental disorder due to a genetic change. Clinically, he has diagnoses of epilepsy, autoimmune epilepsy, intellectual disability, autism, and a host of other conditions that impact every facet of his life. He is nonverbal and requires assistance for all activities of daily living.
 - b. My county conducted a provider search that yielded two providers. The first was an agency. The agency owner provided a direct care worker who clearly stated during the interview he did not want the job and there was no way he would agree to drive 45 minutes each way to work a 2-hour shift. The agency owner continued with the interview and told the direct care worker he would work the hours he was told to work. The agency owner also tried to convince me that I should change my son's county-approved care schedule to be more convenient for his agency. We didn't even get into questions about my son's care, though I had hesitations the candidate was able to complete the required caregiving tasks (and he admitted he was not willing to fill the hours). Thankfully, our SSA agreed this candidate was not "willing and able."
 - c. Our second interview was with an independent provider who admitted several times during the call that she hadn't read the job description and was unable to complete many of the medical tasks, such as checking ketones and providing daily injections of

EXHIBIT E

medication. This candidate was willing, but not able, to complete the required tasks for my medically complex son.

d. In addition to potentially exposing my child to an unsafe situation, the repeated 4-6 month provider searches gives families an air of the financial unknown. I am a busy mom of a child who requires round-the-clock 24-hour care. Carving out time to interview unqualified candidates requires me to find care for my child when he already has a willing and able provider. Requiring parents to conduct replacement provider searches every 4-6 months is not part of OAC 5160-44-32 and is against both the rights of the family members and the disabled individuals served by DODD. I ask you to please reconsider this unfair replacement provider search. According to OAC 5160-44-32, county boards are already assessing the health and safety of the individual by phone every 30 days and in person every 60 days. If these assessments show the individual's needs are being met and that parent caregiver is willing and able to continue providing services, there should be no replacement provider search, as this is not required by OAC 5160-44-32.

e. My son's current replacement provider search just launched. I specifically asked my county board if I had to reinterview the two previously interviewed unqualified candidates should they apply again, and I was told yes. This process is inefficient, antiquated, not required by the OAC, and is completely out of line with the mission statement of DODD: DODD's mission is to partner with people and communities to support Ohioans with developmental disabilities and their families in realizing their version of a good life. For my son with significant disabilities, living a good life is a life where he feels safe, happy, and loved. And if that can be provided by family members and close friends who know him best, I guarantee, even though he can't speak verbally, that fulfills his version of a good life.

5. Second Story:

a. We did an original provider search before I could become my daughter's provider. We had a few responses, but they were quickly eliminated as the applicants were not qualified.

b. My daughter is 9 years old and has two separate rare conditions. She is nonmobile and nonverbal, can't even hold up her own head. She requires full care including a special diet (for seizure control), G-tube feeds, proper positioning, diapers, respiratory assistance with multiple pieces of medical equipment, 24 prescriptions picked up a month dosed at the proper times and amounts, uncontrollable seizures, modified wheelchair van for transportation, and much, much more. Anyone caring for her has to be fully trained, which would take weeks.

c. After I was her provider for several months, our county board told me they had to put out an ad again to find someone to replace me. I have a detailed list of requirements for my daughter's proper care. I received 5 responses wanting an interview. NONE of them read the list of her needs or requirements. I don't understand how someone can demand a job interview without reading the job requirements first. I picked out some specifics and asked again if they met these requirements. They did not. Providers are clearly going through and checking boxes to state they are "willing and able" to meet the requirements of the state-mandated service plan without even glancing at the care needed. My child is too complex to just turn over to someone who is unwilling to read a simple description of her care.

d. These replacement searches for a "willing and able" provider are dangerous for children and aren't even mandated in OAC 5160-44-32. If this policy had ever gone through Ohio's rulemaking process, I would have sent public comments and spoken up at the hearing.

6. Third Story:

a. As a mother of three autistic children, I was initially approved as a paid parent caregiver, which allowed me to ensure my children's unique needs were met. However, despite hiring a trusted part-time provider who my children were comfortable with, my county board of developmental disabilities informed me that I had to undergo a lengthy search for additional caregivers through an agency. My children were clear that they did not want a new, unfamiliar aide, and I was especially concerned after previous candidates used offensive language, such as comparing my autistic children to "normal" kids or describing them as only "a little autistic." These outdated and dismissive views were deeply upsetting and inappropriate.

b. Despite communicating my concerns and the emotional impact on my children, I was told that I couldn't be reinstated as their caregiver unless all other "willing and able" providers rejected the job, even though I already had a part-time provider in place. DODD's "guidance" document says parents who find a willing and able provider to cover some of the authorized care hours can work the remaining authorized care hours: "If a minor child/spouse requires 40 hours/week of paid support and after a provider search occurs, that provider can only complete 30 hours/week. The parent of the minor/spouse could provide the remaining 10 hours/week."

c. When I asked DODD officials for clarification on the rules, I received vague responses, leaving me confused and frustrated. The process has been dragging on for months, leaving our family in limbo. My children's voices and comfort were disregarded,

and I was effectively replaced, even though I already qualified under OAC 5160-44-32 and proved myself fully capable of covering their unmet needs. Now, we're left struggling to navigate a confusing system that seems more focused on bureaucracy than on what's best for the children it's supposed to serve.

7. Fourth Story:

a. I am the primary caregiver for my 15-year-old daughter, who has cerebral palsy, seizures, a G-tube, and a range of other complex medical needs. Before she was born, I worked as a nurse, but I left my job to provide full-time care for her. For the past 15 years, I've taken care of everything she needs, from continuous G-tube feeds to bathing and dressing her and making sure she gets out in the community every day if she's healthy enough.

b. My daughter was on the SELF waiver, but because of her significant needs, she was recently moved to the IO Waiver, which has a higher budget for Medicaid waiver services. As part of this change, I was told that I would need to find an external provider to replace me as her caregiver. I've been working through an agency as her paid provider since April, so this was a shock. The service coordinator told me that these new providers are supposed to give me a "break," but they also said I'm not allowed to leave the house while the "willing and able" provider is there—even though ODM Bureau Chief Jesse Wyatt stated in a webinar the reason strangers should be chosen in favor of parents is because caregiving "is not intended as an employment opportunity for parents."

c. On top of that, the service coordinator explained that the replacement providers can't do many of the critical tasks my daughter needs. They can't give her medication, they can't lift her, they can't bathe her, and they can't even change her diaper because she's at severe risk for fractures. One of the things my daughter loves most is getting out of the house and going places, but these providers wouldn't even be able to take her on outings. So how are they supposed to replace me when they can't do half the things that are listed in her Ohio Individual Service Plan (OISP)?

d. I already qualified to be my daughter's direct care worker under OAC 5160-44-32. There is no requirement in that administrative rule to attempt to replace me every 4-6 months. There is also no requirement in that rule to attempt to replace me when my child transitions from a SELF waiver to an IO waiver. This forced replacement process is not required by code, and it is putting my daughter at significant risk.

FURTHER AFFILIANT SAYETH NAUGHT.

Lindsey Sodano
LINDSEY SODANO, AFFIANT

12/12/24
DATE

LINDSEY SODANO, being known to me and having proven her identity to my satisfaction, did appear before me and execute the above Affidavit this 12 day of December, 2024, under oath and pursuant to the Laws of the State of Ohio.

Max
NOTARY



MAX DURANTE
Notary Public, State of Ohio
My Commission Expires
February 13, 2029