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Interested Party Written Testimony for Substitute House Bill 96

April 1, 2025

Thank you, Chair Stewart, Vice Chair Dorilla, Ranking Member Sweeney, and members of the Finance Committee, for the opportunity to provide written testimony today. My name is Sandra Black, and I live with my two daughters, Nora and Naomi, in Centerville, Ohio. Naomi has multiple and significant disabilities caused by a brain tumor that was diagnosed only weeks after she was born. On behalf of my family, please accept this testimony regarding Substitute House Bill 96.

Families who have children with disabilities or high medical needs often have only one parent working because the needs of the child - specialized daily care, therapy and medical appointments - are extraordinary. For many special needs families, there is only one parent because the divorce rate among families affected by disability or chronic illness is as high as 87 percent, which is nearly twice that of average families.

My family has consisted of just one parent for the last thirteen years. For several years, we survived on my part time income. However, reducing my hours at work to manage Naomi's appointments and therapies meant that I also forfeited health insurance. Naomi is now fifteen years old and has required far more care after treatment for the brain tumor than I could have anticipated. The many disabilities she lives with have resulted in numerous changes over the last ten years related to her method of education delivery as well as frequency and intensity of therapies. Her care needs are continuous and in 2017 eliminated the opportunity for me to work in any additional capacity.

Our family has relied on Medicaid to meet all of our health care needs. With caregiving for a special needs child comes chronic stress which can often lead to medical problems such as heart disease, hypertension, obesity, depression and type 2 diabetes. Medicaid is the only resource for health care for me as a full time caregiver, as well as for many other special needs families and those who provide care to them or to other children and adults with disabilities.

I am concerned that the trigger language related to Medicaid could have a detrimental impact on many Ohio single parent special needs families as well as the direct care providers and other essential workers living on low wages. Should the language remain unchanged, an exemption for these segments of the population is needed to protect caregivers, essential workers, single parents of special needs families and direct care providers. Medicaid must continue to be available, without delays or disruptions, to Ohioans who care for other Ohioans.

As a disability inclusion state, Ohio must continue to provide the resources necessary to direct care workers and caregivers of special needs children, as well as all essential workers who provide care to others and individuals with disabilities. The elimination of health care for the caregivers in Ohio would cause a catastrophic ripple effect on thousands of Ohioans, particularly children and families. Children and adults with disabilities must receive the health care they need in order to thrive and become their most independent and productive selves.

Thank you again for the opportunity to submit testimony for House Bill 96. Please contact me if you have any questions or would like to learn more about my family's experience.

Sincerely,

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