

Chairman Hackett, Vice Chair Huffman, Ranking Member Thomas and members of the Senate Finance Subcommittee on Health and Medicaid, my name is Rebecca Syner. I am here today to urge you to please remove section 5123.603 in the state budget that creates senseless legislative oversight of a private nonprofit corporation, Disability Rights Ohio.

Disability Rights Ohio is an independent organization designated by the governor, regulated by federal law as the Protection and Advocacy system and Client Assistance Program in Ohio to investigate instances of abuse and neglect and to protect the rights of people with disabilities. No other private advocacy or legal organization is subject to this type of review.

DRO helps elevate the voice of self-advocates and gives individuals and organizations a resource they need to be effective in their advocacy. They have helped me fight for my daughter's rights as a person with disability. My daughter, Sarah Syner, has developmental delays, autism, a severe seizure disorder, and Stage III Chronic Kidney Disease (CKD) along with other diagnoses. For 3 ½ years she was enrolled in the FDA approved clinical trial for the new seizure medication, Epidiolex (cannabidiol) at the University of Cincinnati Medical Center. Although it reduced her seizures by about 50%, she continues to have daily seizures and often requires the use of rescue medication when her seizures don't stop on their own or she stops breathing for an extended period of time during the seizures. In addition, she recently completed her third chemotherapy infusion designed to stop the progression of kidney failure due to her CKD.

For two years the Ohio Department of Developmental Disabilities (DODD) denied the nursing services she had been receiving to provide her care and instead insisted that aides would be able to provide that care at a lower cost. These denials came in spite of documentation in daily logs of her extensive needs and four letters from doctors (the neurologist who chairs the Comprehensive Epilepsy Center at the University of Cincinnati, her neurologist from Ohio State University, her nephrologist who is an Associate Professor of Nephrology at Ohio State University, and her primary care physician) indicating that nursing care was needed and if not provided properly would adversely affect her health and could be life-threatening. DODD discounted those letters and said that just because a doctor orders a service that does not mean it is medically necessary. Since this was not acceptable to me, I reached out to DRO. For two years, they provided invaluable help and resources as I prepared for our State Hearing and, the second year, our Administrative appeal. I had initially tried to reach out to local attorneys, but each one said that they did not have the expertise to handle this type of case and referred me to DRO. Only DRO was able to provide the information and assistance I needed to help my daughter retain her needed services. My daughter may have disabilities, but her life is valuable and her rights are still vitally important.

Disability Rights Ohio has been an invaluable organization fighting for her rights and those across Ohio. People with disabilities deserve an independent voice to uphold laws and fight against discrimination, without retaliation.

I urge you to support people with disabilities and ask you to eliminate this damaging provision from the state budget. Thank you for your time.