Testimony on SFY 24/25 Operating Budget

House Finance Health and Human Services Sub-Committee

Chairwomen Carruthers, Ranking Member Liston, and esteemed committee members,

I want to thank you for the opportunity to submit this written testimony.

My name is Grace Rice. My granddaughter is a resident of Hattie Larlham, Mantua, OH. I placed her there at the age of 6 because as her grandmother and legal guardian, at my age and with a fixed income, I was unable to financially and emotionally provide the 24/7 skilled nursing care she needed as a certified quadriplegic, non-communicative, tube-fed child requiring daily critical treatments and meds to contain her severe/acute seizure disorder as a result of her traumatic birth which resulted in her having cerebral palsy. I am BEGGING for you to consider the lives of all the children and adults who rely on the services of a DD. We need you to have compassion and know that the right thing for you to do is to adequately fund these DD facilities so these children and adults can also live the best life they possibly can given the mountain of issues and challenges they already have to try to live and enjoy life the same as you want for your own family. This is where we need to have sensible decisions that ensure all of those in need through no fault of their own can depend on entities like our Ohio State Legislatures to do the right thing for them. It should be no other way!

I placed Sophia at Hattie because I was no longer able to give her the 24/7 skilled nursing care she needed. She was born premature, and her birth was traumatic, resulting in cerebral palsy and an acute seizure disorder. Her paralysis affected a part of the brain that controls voluntary muscle movement, speech, and even sight. Fortunately, her sight is fine, but she is paralyzed and has little control over the movement of her arms, legs, feet, and hands. She is also tube fed and has compromised immunity and respiratory issues that require daily treatments and medications to avoid seizures and incidents of respiratory failure.

When I placed Sophia at Hattie it was one week after her 6th birthday. She weighed in at 32 pounds! She looked undernourished and neglected. She was not neglected; she could not hold her formula nutrition in her tummy long enough for it to digest before she would vomit it right back up. I lost count of the number of times I have called for EMS because of her very active seizure events where she has to be put on life support breathing ventilators to keep her going. It was exhausting and mentally draining for me, and Sophia and I felt very overwhelmed and defeated.

Then I heard about Hattie, had an intake interview, and saw firsthand how the staff interacted with the children, how clean and pleasantly decorated the building was, and how orderly (but not overly clinical or regimented) things seemed to be run (Honestly, I had prepared mentally for seeing something like one flew over the coo coo's nest) but, to my surprise, it was far better than I expected. I just got this feeling of relief and comfort thinking about moving her in.

Today, Sophia is 10 years old and weighs 70 pounds, and is 4'3" tall. She is learning to navigate her first power wheelchair (despite being certified quadriplegic) She goes for longer and longer walks in the gait trainer and responds so well to all the therapists and teachers and the work they are doing to help her physical and intellectual development. She can say Hi when she wants to, and she is thriving and happy and feeling love every day!!! I cannot praise Hattie enough for the excellent medical and personal care provided to her.

Thanks to Dr. Grossberg and his team the seizures are nowhere near as often as before. They figured out a better tube feed system and now she is gaining weight and retaining her nutrition. Her teachers and therapists have worked with her extensively and now she can voluntarily move her hands (albeit clumsily) to operate the joystick on the wheelchair and move her feet to walk in the gait trainer. Plus, she now has a very high-tech communication device "Eyegaze" to help her learn how to communicate her choices and preferences. It is truly amazing how far Hattie has bought her when you compare her state now to before she came to live at Hattie.

If I had to move Sophia out of Hattie Larlham due to funding issues, it would be the most horrible, disastrous experience for Sophia and me! I fear that she would not make it any further than the age she is now, because I do not have the skills, knowledge, physical and emotional wherewithal to care for her. Also, she is so closely bonded with the staff that I am sure she would grieve for them. She LOVES her DSPs and Nurses, and she is quite popular at Hattie. Whenever I visit, I feel like I am in the company of a little celebrity when everyone stops to greet her and talk with her and even give hugs.

I am praying that the Ohio State Legislators do the right thing and increase the funding to all the DD facilities in the state. That is the right thing to do from a humanitarian viewpoint and for children and adults who cannot willfully care for themselves and are totally dependent through no fault of their own...anything less than an increase in funding to keep these facilities going and enable them to retain personnel in order to continue providing safe, quality, compassionate care would be cruel, mean-spirited and shameful!

Growing up, my dad always drilled into us that charity begins at home! Our Ohio State Legislators owe it to their constituents (the children and adults in these DD facilities) and they need to do their part to ensure DD facilities that care for the weakest, sickest, and most vulnerable children and adults are given the same quality of care they themselves have and increasing the funding amounts would help facilitate to that end.

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