



Written Testimony submitted by Filomena Nelson on 3/15/17

Dear Representative Romanchuk, Finance Subcommittee on Health & Human Services,

I am a resident of West Chester, Oh, and the parent of a 23-year-old son, Gregory. I am writing you with my testimony regarding the Ohio Department of Developmental Disabilities proposed budget, specifically the proposal to Increase the Waiver Reimbursement to cover Complex Care needs.

This past Saturday, Gregory was asked to review a movie at the Reel Abilities Film festival. This festival, held in Cincinnati, showcased films that share stories of the lives of individuals with disabilities. Gregory was excited to be a part of the festival as he viewed it as experience for his desired career in social media. However, being a part of the festival required that someone dress and groom Gregory, feed him through his feeding tube, position him in his power wheelchair, get his chair into a modified Honda Element and drive him to Cincinnati. Once at the festival, this individual needed to set up and troubleshoot, if necessary, Gregory's augmentative communication device/laptop, which he uses for speaking and for typing. As both my husband and I were out of town, one of Gregory's personal care aides provided Gregory with what he needed. Even if we were able to take Gregory, he appeared more capable, mature and professional when not seen with his parents.

This is just one day and one example in which Gregory relies on the services of highly qualified aides. He lives on Wright State's campus, 45 minutes from our home. Gregory has complex needs in that he is bright (3.7 GPA from high school and 3.0 at Wright State) and he is completely dependent on others for all his daily living skills due to his cerebral palsy.

Over a year ago, two other parents and I approached Director Martin about the need for an incentive to attract individuals who would choose to work with individuals with complex physical needs. We knew there was a behavioral add-on rate for aides providing services to individuals with behavioral issues. We felt the complex physical needs were as unique and as demanding a need as the behavioral.

In recruiting for Gregory, we interviewed individuals who were providing recreational services, companionship, etc. to disabled individuals and earning the same waiver reimbursement rates as those who work with Gregory. The physical work was much lighter and the need to operate technology such as \$40,000 power wheelchairs or a \$9000 speech device was not required. We found we could not compete with families who were offering the same pay for "easier" work.

Over the years, we learned recruitment was not the only issue. We have lost providers when families whose loved one requires less assistance approached them. Again, the same rate of pay when the work is easier physically and the knowledge base is not as high is very attractive. With the current Overtime issue facing reduction of hours for personal care aides, we have heard aides say if they have to cut down on the hours, they are going to choose to work with the easier clients.

This is not just an issue for families. In November, I presented this complex rate proposal to the

Butler county board of DD. At that meeting, several homemaker personal care agencies expressed support because they are struggling to find aides who are willing to work with individuals with complex physical needs. There has also been support for this rate increase throughout the state as communities prepare for individuals who choose to move from ICF's. These individuals often have complex physical needs and when they move into their communities, they will require the services of those aides who are willing to do the "heavy" work. This pool of aides is already small and will shrink even more.

Technology is much more complicated than it may appear. Gregory's wheelchair can be put into a standing position making the use of restrooms much smoother for him and his aide. His speech device operates on a sophisticated language program that both Wright State and Xavier accepted as a foreign language credit for admissions. In order for Gregory to succeed in classes, his aides need to be tech savvy in connecting his devices by blue tooth, submitting assignments online, etc.

Safety and inclusion in his community are vital to Gregory's well being. Understanding how to operate and support Gregory in his wheelchair as he travels around campus and the community is critical.

I appreciate you providing me the opportunity to speak with you today. We feel strongly that there needs to be an incentive to attract and a reward for those who are willing to continue to work with individuals with Gregory's complex needs.

Sincerely,

Filomena Nelson

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