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Dear Representative Robert Cole Sprague and the Finance Subcommittee on Health and Human Services:

The purpose of our letter is to first express our appreciation for the support services the State of Ohio and our County of Summit have provided to citizens with developmental disabilities and their families in the past. We also applaud the consideration being given to expand some of these services to help more Ohioans with developmental disabilities live with the dignity, respect, and freedom they deserve. Secondly, we want to express our concern regarding plans to eliminate Independent Providers from the support options available to those who qualify for DD waiver services.

Background Information:

Our daughters Maria (DOB 12/20/1986) and Bianca (DOB 1/20/1992) are the youngest of our 8 children. Both have multiple disabilities and are our only two children still living at home with us. We do have legal guardianship of our daughters. It is our intention to have them live with us as long as possible – hopefully many, many years into the future. Both of our daughters have been fortunate to qualify for DD waivers.

Maria's primary diagnosis is autism spectrum disorder. She also has profound developmental delays, a seizure disorder, and cortical vision impairment. She is dependent on others for all activities of daily living including bathing, grooming, dressing and eating. She wears incontinent products at all times. She requires skilled intervention and support for sensory integration, adaptive behavior skills, and effective communication strategies. Several years ago, Maria was the victim of abusive situations at her day program and while being transported by agency transportation providers. Maria's trauma was so significant that it took nearly a year before she was able to tolerate activities beyond the safety and security of our home. She overcame these horrible experiences only through the intervention of a specific autism approach called the S.U.C.C.E.S.S. Approach. All of our family members as well as independent providers have been trained in this intervention technique. The training has been at our expense but was well worth it since it has given Maria her life back. Our independent providers have been willing to be trained in this method which has been so effective for Maria. This additional training beyond basic certification requirements would unlikely be welcomed or supported by agency providers.

Bianca's primary diagnosis is L3-L4 myelomeningocele (spina bifida). She is also hearing impaired (wears hearing aids), vision impaired (vision correctable to 25/50 with prescription lenses), and significantly cognitively impaired. Bianca wears braces on her legs and uses a walker for her primary mobility needs. At times she does use either a wheelchair or power scooter depending on activity demands. Bianca has balance problems and does occasionally fall when she is walking with her walker but seldom experiences any significant injury. Bianca has difficulty with some fine motor tasks (e.g.,

writing or printing, opening containers, cutting up food). Bianca self catheterizes to empty her bladder every 2.5 to 3 hours. She sometimes needs reminders to follow appropriate hygiene protocols. Bianca has a Malone stoma to help manage her neurogenic bowel. Bianca undergoes a bowel irrigation procedure using this stoma and a Malone catheter every evening. Bianca needs assistance in placing the catheter and hanging the irrigation bag. Bianca is then independent completing the irrigation (45 minute procedure) and can bathe herself and wash her hair independently in our adaptive walk-in tub. Bianca wears an indwelling catheter attached to a leg bag throughout the night. She is independent setting this up needing only occasional supervision or assistance to retrieve dropped items. Bianca can dress and undress herself but needs help getting her shoes on over her braces. She cannot tie her own shoes. She sometimes needs help brushing her teeth adequately, combing her hair, and caring for her complexion. Bianca also has variable behavioral challenges involving personal interactions, judgment, and awareness of safety precautions.

Both girls are dependent for money and time management. Maria is dependent for food preparation. Bianca can assist with certain meal prep tasks.

#### Our Concern Regarding Proposed DD Budget

It takes very uniquely qualified providers to meet both of our daughters' complex and very different needs. Consistency and specialized training beyond basic certification requirements are critical considerations for us in identifying providers that are qualified to provide the care our daughters need when other obligations necessitate our reliance on others to care for them when we are not available. Key to identifying, procuring, and sustaining qualified consistent providers is a fair wage which appropriately compensates people for the very crucial and challenging job of caring for individuals with multiple disabilities. Our daughters have received excellent services from their Independent Providers, both in-home Independent Providers and transportation Independent Providers. Our Independent Providers have been reliable, compassionate, committed, and skilled individuals eager to learn, work hard, and value and respect our daughters. The only problem we have ever had with providers, other than the abusive situation alluded to earlier, was when the "portal" lead us to secure transportation services from Hands Of Care, an agency that was later suspended by the state for fraud and criminal activity.

Our experience has been that Independent Providers give a much higher quality of care, demonstrate greater integrity and work ethic, are more committed to person-centered support services, and are more willing to avail themselves of additional training to meet the unique needs of our daughters than the agency providers we have utilized in the past.

At a time when Ohio State Legislature has moved toward championing school choice for parents of Ohio's school children, it follows that this same freedom of choice should be allowed for parents and families of individuals with developmental disabilities. Individuals with developmental disabilities and their families need to determine the manner in which waiver certified care providers are accessed. For some, that very well could be obtaining services through an agency. But for others, like us, those services are best obtained through Independent Providers that recipients and/or their guardians can train to meet unique and specific needs.

Thank you for your kind attention. Please contact us if you have any questions or if we can be of assistance in any manner pertaining to services for developmentally disabled citizens of Ohio and their families.

Sincerely,

Gretchen and Pat Kennedy