

Testimony Regarding the FY24 Operating Budget

April 11, 2023

Submitted by: Tracy L. Craig

To the esteemed Montgomery County Council and distinguished President, Councilmember Glass, I am honored to present my written testimony for your consideration. My name is Tracy Craig and I am here to represent countless parents across Montgomery County who have a child with intellectual and developmental disability. This is commonly known as I/DD.

My 8 year old daughter has I/DD. She was diagnosed with Down Syndrome during gestation. At the same time I heard "Down Syndrome," the lady on the phone asked me if I "wanted to terminate." That was the first day that I advocated for my daughter's best outcome. I have wandered through this process ever since— in search of a Northstar.

I am requesting funding to create an innovative, public-private partnership inside the Montgomery County Department of Health and Human Services that helps parents of children with I/DD to establish a plan for realizing their child's best life outcomes. This program should guide parents to their own Northstar— a holistic care plan that addresses education, health and personal development at every stage of the child's life. With parent voices anchoring discussion, Montgomery County will use this plan to customize an ecosystem of supports to wrap around each family of a child with a disability. This will help to ensure that each child in Montgomery County who has I/DD also has a Northstar to follow.

According to a recent study by the Centers for Disease Control and Prevention, 17.3% of children in the United States between the ages of 3 and 17 years of age have at least one developmental disability. This new study showed that 6.7% of U.S. children had two or more developmental disabilities.

"Developmental disability" is a broad term used to describe conditions which include intellectual disability, or cognitive difficulties, as well as physical, neurological and sensory deficits. Developmental disabilities are often lifelong challenges. "IDD" is the term often used to describe situations in which intellectual disabilities and other disabilities are present.

Down Syndrome is one of the common causes of intellectual disability. For the past 8 years, I have attended IEP meetings, talked with therapists and teachers, met physicians and specialists. Yet, no one is able to help me create a holistic view of my daughter's needs or define the best path to get her to college. Yes, college is our goal, because I know my daughter has what it takes. But I need HELP: Help to gather the pieces of our own puzzle; Help deciding which pieces are needed and at what times; Help finding the services we need; and help navigating educational, recreational, occupational and social programs that will benefit my daughter at every stage of her development.

I/DD is common among U.S. children, and often developmental disabilities occur together. The CDC indicates that these children have greater health needs and higher needs for services than children without developmental disabilities. However, early identification and coordination of services could be instrumental in improving the overall health of children with I/DD.

Sadly, I have discovered a gaping hole in the commonly-accepted approach to serving children with disabilities. There is tremendous, proactive effort placed on early intervention and assessment of

developmental delay. Similarly, the Individuals with Disabilities Education Act (IDEA) focuses on transitioning students to fruitful adulthood starting at age 14. However, there appears to be no concerted effort placed on children with intellectual and developmental disabilities who are in their formative years. The ages of 6 to 13 years are typically the most impactful years for socioemotional development to align with the acquisition of academic concepts. Yet, children with I/DD in this age range seem to be forgotten.

Now at 8 years old, my daughter has a deep understanding of language and life concepts— despite the difficulty of fully communicating what she knows. No one has been able to help me draw out her competencies, to unlock what she knows or how she learns. There is no disability ecosystem that places the child at the center and wraps support around the family to manage quality of life and life outcomes when there is a child with a diagnosis.

Families cannot begin to know what questions to ask when they receive a diagnosis; they need somewhere to turn for help. They need someone to walk with them into the unknown. Most importantly, they need to be sure that their child with a disability is reaching critical milestones on the path to the best life possible.

I believe that a publicly-funded program that will help parents to develop a holistic plan to realize this vision and acquire the best services for their child's unique set of needs is what is missing in Montgomery County.

It is a long walk from birth to adulthood. And when there is a disability, the road is rough. Parents shouldn't be afraid or feel defeated before they get started. Please provide us the resources to find the Northstar and create the best possible picture for our school-aged children with intellectual and developmental disabilities. Montgomery County has the resources, expertise and compassion to craft this type of innovative approach to fill in the gap for families like mine. I am asking for your help to bring this empowering concept to life. Thank you.