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Joint Committee on Health Care Financing
Commonwealth of Massachusetts

Dear Committee Members:

Thank you for the opportunity to come before you today. My name is Maura Sullivan. I am the Director of Government Affairs for The Arc of Massachusetts. The Arc's mission is to advocate for those with disabilities. Health care advocacy has been a focus of mine through The Arc for the last 4 years in my role as the Instructor and Director of Operation House Call. I teach medical students about the unique health care needs of people with intellectual and developmental disabilities including autism. I am wearing a third hat today and that is of a parent. I am the mom of three, my two youngest boys have autism and complex medical comorbidities. I am here today as a passionate supporter of Senator Barrett's bill S 2143 that will include disabilities in the Office of Health Equity.

Along with constituent testimony, I will submit to you today the research that shows the astounding disparities for people with I/DD and autism – for example, the most recent study last week that indicates people with autism dies 18- 30 years sooner than people without autism. We know that people with disabilities lack prevention, diagnosis and effective treatment due to a lack of access and expertise. These barriers can be overcome. But they need to be recognized and studied here in Massachusetts so we can effectively change the status quo. Our medical schools here in Massachusetts know they need to address these disparities and have come to The Arc for training.

The Arc's Operation House Call has been training medical students and health professionals through a model that provides foundational knowledge and experiential learning. I mention this because the medical school deans, medical students and 170 families across Massachusetts have rallied for this program's expansion because of stories like you will hear today. We have developed a program here in Massachusetts that has been recognized by the CDC and will be used as a national model. We need the support of the office of Health Equity to begin research and outcome measurement so that we can enhance and grow programs like this one. Massachusetts has the most excellent hospitals and medical schools in our country and our health care equity should be at the top as well. Across the board, this office can help make that happen by including disabilities.

My son Neil will be 15 years old in just a couple weeks. He cannot speak a word. He cannot tell me when something hurts. He reacts differently to pain. Just a few months ago he was very sick. I knew he needed to be evaluated. The doctors at the ER did try to examine him but when tests didn't come back conclusive they sent us home. Believe me, I didn't want him to stay but I turned him back around and I begged the doctors to do look further. With kids like Neil careful consideration and thorough evaluation is needed. Life threatening conditions can go unrecognized and untreated. Simple untreated ailments can become acute care crisis. Not only is this unjust but leads to exponential costs in emergencies and admissions. After a CAT scan Neil was rushed into emergency surgery for an appendectomy. His appendix had begun to micro perforate and we caught it in the nick of time. Being the mom of two boys with autism – I have dozens of stories of health disparity and health care failure but I have hope as I see my medical students learning, caring, growing confidence and interest.

Please pass Senate Bill 2143 favorably – it ties so closely to the work of the Arc and please contact me anytime to discuss this legislation and how it will help the Commonwealth address health disparities.

Thank you for your efforts and leadership and you time today. We count on you to hear our voices – from our most vulnerable to our strongest advocates.

Sincerely,

A handwritten signature in cursive script that reads "Maura Sullivan". The signature is written in a dark ink and is positioned centrally below the typed name.

Maura Sullivan, MPA
Director of Government Affairs
The Arc of Massachusetts
Program Director, Operation House Call

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