



*For people with intellectual  
and developmental disabilities*

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**Achieve with us.**

Tracy Atkinson  
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## **Testimony before the Joint Ways and Means Committee**

**March 16, 2018**

Good Morning,

My name is Maura Sullivan, I am the Director of Government Affairs for The Arc of Massachusetts. I am also the mom of two fantastic teenagers with autism and complex medical conditions. It is an honor to be here and represent families like mine. Thank you for the opportunity to share my testimony on the proposed 2019 Department of Developmental Services budget.

I'll start with my sincere thanks for your support of last year's Turning 22 allocation. This funding is a life line for young adults with autism or intellectual and developmental disabilities. The Arc's 2019 budget "ask" is attached with my testimony and you will see an explanation of the needs related to each family support line items as well as day and employment, community residential, transportation and autism omnibus.

I would like to tell you about how the family support DESE/DDS line item has helped and continues to help my family. I will also address the concerns about our community residential programs as they relate to individuals like my son with severe behavioral and medical issues.

My son, Neil (now 16) has always had challenging behaviors since he was a toddler. He is nonverbal, often aggressive, sometimes self-injurious; he has Crohns disease, GI reflux, and

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epilepsy. He uses a augmentative communication device and he needs cueing and prompting for most activities. – He is the bravest person I have ever known and when he communicates his love for me in his own special way - I feel the greatest joy I can ever imagine knowing. With the help of the DESE/DDS funds I was able to keep Neil living at home with his family and delayed a residential placement. When Neil was 10 our school system recommended an out of home placement but for 6 more years I kept him home with an average allocation of 15,000 dollars per year. If Neil had been residentially placed, the cost to the commonwealth would now be 1.5 million dollars. I am so grateful for the years of caring for Neil. Those funds helped me and my family stays strong and resilient.

Meaningful supports make sense for the commonwealth and for families who are raising and caring for individuals with autism or I/DD. Massachusetts is currently ranked 35<sup>th</sup> in the nation in terms of annual family support dollars per family. We have over 18,000 individuals living at home and 9,000 of them are adults.

When I think about my Neil as an adult in a residential setting, I am especially worried. The types of supports he needs do lay heavy on a residential and day program. The Arc is advocating for a budget increase in the residential line item partly so that it is possible to bring individuals with challenging behavior into their community. I truly fear what services will look like when we can't retain staff, provide enough training and offer real community experiences safely.

Thank you to the chair and the entire committee for your leadership and support for the disability community. I urge your careful review and consideration of our budget requests.

Regards,



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