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Achieve with us.

*For people with intellectual
and developmental disabilities*

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Testimony: Rates for Family Stabilization Services

September, 2017

Dear Secretary Sudders and EOHHS Officials,

My name is Maura Sullivan. I am the Director Government Affairs for The Arc of Massachusetts and parent of two wonderful young men with autism and complex medical conditions. Thank you for the opportunity to share my comments today on the proposed rates for Family Stabilization Services 101 CMR 414.00. The Arc of Massachusetts (The Arc) is a statewide advocacy organization representing 200,000 individuals and their families with 18 chapters in the state. Its mission is to enhance the lives of people with intellectual and developmental disabilities, including autism, and their families. We fulfill this through advocacy for community supports and services that foster social inclusion, self-determination, and equity across all aspects of society.

My brief testimony today will focus on the inadequate rates to implement Family Stabilization Services and the effects these rates have directly on individuals and families that The Arc represents. The Arc is grateful for the cost-adjustment-factor (CAF) of 2.72% for rates that were due for review on July 1, 2017 that is being applied in accordance with the Chapter 257 Settlement Agreement but we are equally concerned that the rates across many codes do not allow for adequate staffing, retention of staff, meaningful community inclusion and safety of the individuals served.

The Arc is especially concerned with the delivery of services for individuals with more severe behavioral challenges and/or complex medical needs in a residential, day and community setting as well as in the home. We support ADDP's testimony in regards to the rates not addressing costs associated with quality of care, especially supervision. We see these rates as not fully able to support and reflect an individual's choice or allow compliance with Olmstead. Although we understand the need to slow the growth of the Mass Health budget, this is not the place to save.

The Arc has prioritized legislation to develop a registry of caregivers who have been substantiated of abuse of an individual with autism or I/DD. We know these stories of abuse or neglect all too well and we also know better supervision and training will decrease these horrible occurrences. The workforce continues to be a growing concern as recruitment and retention of staff becomes more difficult – and the results are devastating to families and individuals who suffer without help or with poorly trained and/or poorly supervised staff.

The Arc in Massachusetts Includes the Following Local Chapters:

Berkshire County • Bristol County • Brockton Area • Cape Cod • Center of Hope Foundation
Charles River Center • EMarc • Greater Haverhill-Newburyport • Greater Lawrence • LifeLinks • Greater Plymouth • Greater Waltham
• Minute Man AHS • Northeast • The Arc of Opportunity (North Central) • South Norfolk County • South Shore • The United Arc

We are advocating for rate adjustments so that it is possible to bring individuals with autism and challenging behaviors into their community and to prioritize their safety. We encourage more discussion about families in high need or crisis and how these rates do not support more intensive supports. Individuals like my son need more help to remain safe and to accomplish integrated activities. Integration is not only required by CMS for the benefit of all individuals but it is, of course, beneficial to our society to have experiences with a range of individuals with disabilities.

The Arc supports the need to review the 29 codes outlined in ADDP's testimony today. We also agree that there needs to be transparency in the rate setting process so that valuable feedback can be obtained through the organizations on the ground.

I truly fear what services will look like when we can't retain staff, offer real community experiences safely, support individuals in their homes or have available transportation. My oldest, Neil has behavioral challenges including impulsivity, aggression, PICA (eating non edibles) and bolting. He is non-verbal, has epilepsy, uses specialized augmentative communication and needs cueing and prompting for almost all activities. The type of supports he needs lay heavy on providers when rates are not adequate.

In conclusion, all our constituents depend on The Arc to help ensure individuals and families like my own can have true and safe inclusion in our community. They depend on providers to support them through crisis and across the lifespan.

Thank you for your continued support for families and individuals with autism and I/DD. We urge you to support their rights for equity here in the Commonwealth of Massachusetts through careful review and consideration of our testimony and the testimony of ADDP.

Regards,

Maura Sullivan, MPA, Director of Government Affairs

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