

Hello, my name is Maureen O'Grady. I am a Board Certified Behavior Analyst and a New York State Licensed Behavior Analyst, who is employed by New Alternatives for Children (NAC). NAC is an award-winning New York City-based foster care, health and social service organization that exclusively serves children with significant disabilities, emotional/ behavioral challenges and chronic illnesses. These children also live in poverty and have experienced or are at risk of abuse and neglect.

Established in 1982 in response to the problem of medically complex children languishing in hospitals beyond medical need, today NAC provides an integrated continuum of health and social services to support family preservation, reunification, and adoption for 2,100 at-risk children, siblings and parents annually in NYC.

Over 90% of NAC's children are African American and Latino. The circumstances of the families include poverty, homelessness, domestic violence, substance abuse, and mental health issues. The children's diagnoses include asthma, diabetes, cerebral palsy, autism, cancer, spina bifida and HIV/AIDS, among others. At least 50% of the children have more than one medical diagnosis and nearly 70% also have co-occurring mental/behavioral health issues. Medically complex children have higher instances of abuse and neglect, higher foster care recidivism rates, and poorer health and education outcomes than children without medical fragility. The birth families caring for these children have long histories of complex and deeply embedded socioeconomic problems, including poverty, homelessness, substance abuse, domestic violence, incarceration, and mental illness.

Many other agencies would say these children are too difficult to serve, but not NAC. This is an agency that believes in abilities and not disabilities; we consistently go above and beyond in treating the children in our care as if they were our own. This extra effort and care make all the difference. NAC's programs are integrated and comprehensive to ensure we meet the unique needs of every child who walks through our door.

For me, working at NAC has been a dream come true. I have always wanted to work with children in Foster Care, but did not see any opportunities because my specialty in Applied Behavior Analysis is not covered by Medicaid, in which all children in Foster Care are automatically enrolled. The only reason I have the opportunity to be employed by a Child Welfare Agency is because of an Autism Social Skills Grant, which covers service for 25 of our 164 children identified as having Autism Spectrum Disorder.

I provide Applied Behavior Analysis (ABA), which is backed by 50 years of research and is the only scientifically proven treatment for the behavioral symptoms of autism. Decades of research has proven that ABA can change people's lives, improving their communication and social skills while decreasing problem behavior and ultimately providing them with fulfilling lives, some of which are completely independent.

At our agency alone, we have 164 children and young adults with autism under the age of 21. 95% of these children have Medicaid. Many of these children have experienced fragmented health services, trauma, abuse, and/or medical and educational neglect. Nearly 40% of these children are non-verbal, and at least 50% have aggressive or self-injurious behaviors. These behaviors make them more likely to be in restrictive settings which may negatively impact their social functioning.

A key component of ABA therapy is Parent Training, which focuses on teaching parents to implement treatment programs to maintain consistency and promote generalization. Through commercial

insurance, following best practices, parents can receive 1:1 Parent Training with a Licensed Behavior Analyst for several hours per month. The parents of our NAC children are often unable to access services to improve their parenting skills. Through the Autism Program, we provide 2.5 hours a month of group Parent Training, in English and Spanish, to help educate parents about autism and special education services. Most of our parents are struggling with the same barriers as their children: lack of adequate services, living in poverty, having a mental health or medical diagnosis and this is on top of having a child with severe needs. These barriers make it difficult for our parents to consistently attend group parent training sessions, or if they do attend, to retain information that they have learned.

I receive weekly requests from Prevention and Foster Care staff for consultations about problem behavior with our ASD clients. 75% of those referrals are for children who are over the age of 5 (some are in their teens), who are not toilet trained or do not have a form of functional communication, or who display self-injurious or aggressive behaviors. Some of these clients received ABA through EI services but have Medicaid and therefore could not access ABA services after that.

In 2017, I received a referral for a 6-year-old male to join the social skills group. When I assessed him, I quickly realized that the social skills group would not be an appropriate placement for him. He was completely nonverbal, self-injurious (hit his head on hard surfaces, scratched his skin to the point of bleeding and consistently banged his body against walls), and was aggressive (would hit, kick, bite and scratch adults and peers). After consulting with his psychiatrist and case workers, we decided to give this child a private 1:1 ABA session, instead of enrolling him in the group. I did not have funding or room in my budget to supply this service, but this child desperately needed 1:1 and had no other means. I have worked 1:1 with this child since April of 2017, for 1 hour a week in our clinic. I introduced a simple communication board, consisting of 6 items that were highly reinforcing to motivate this client to request. Requesting when given a choice of 2 pictures has increased by 60%. Hitting staff has decreased by 28%, and identification of colors in an array of 2 has increased by 20%. Although we have had successes with this client, the frequency of service is much lower than what would typically be recommended for a child of his age and abilities. This child is now 8 years old, remains nonverbal, is not toilet trained and still engages in significant aggression and self-injury. It is clear that this child needed continued service after EI but was unable to access them.

In contrast, I work privately with a family in NYC who has access to ABA through their insurance. This child started services in 2017 at the age of 3 at 10 hours a week. This child received EI services. This child was not toilet trained, was nonverbal and self-injurious. Today at age 5, this child has increased independent requesting by 90% using an iPad communication system with 20 pictures, is making 15 verbal word approximations per session, has reduced their self-injurious behavior by 65% and is fully toilet trained.

The difference between these two children is heartbreaking. This is just one example of the 164 children we have at our agency who need this service. The children of New York who have Medicaid deserve equal access to these services at a frequency that is medically necessary for their overall improvement. I am here representing New Alternatives for Children on behalf of our autism population enrolled in Medicaid, asking you to set aside appropriate funds to cover the cost of intensive behavioral services for those who are most in need. We fully support the Governor's proposal to include ABA coverage for children with Medicaid, at a rate that is comparable to their peers from middle- and upper-income households.

I would also like to urge the committee to review 2017-18 session bills A-7632 and S-4599 in reference to LBA's working with individuals without autism diagnoses, as this continues to prevent the growth of available ABA providers in New York State. Board Certified Behavior Analysts (BCBA) are leaving New York State to deliver their services without scope restrictions, as NY is the only state to restrict the scope of Behavior Analysts. With the possibility of Medicaid coverage for ABA, an increased number of service providers will be needed. I strongly encourage the committee to review the above stated bills, in addition to the purpose of this testimony today.

