Testimony

of

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of the
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Alcoholism, Drug Abuse & Disability Services

on

“Autism: Culturally Competent Care and Family Support in NYC”

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Good morning Chairman Cohen and members of the Committee. I am Janice Chisholm, Assistant Commissioner for the Bureau of Developmental Disabilities at the New York City Department of Health and Mental Hygiene. I am pleased to be here today to testify on autism care and family support in New York City.

Autism Spectrum Disorder is among the fastest growing diagnoses for individuals with developmental disabilities in the United States, purportedly increasing as rapidly as 10 to 17 percent a year. According to the U.S. Centers for Disease Control and Prevention, current prevalence rates suggest that 1 in 68 children and 1 in 42 boys in the US are on the autism spectrum.

Autism Spectrum Disorder presents an important public health concern. The Department of Health works on behalf of individuals with developmental disabilities, including individuals with Autism Spectrum Disorder, by promoting early diagnosis and intervention, and providing assistance to individuals, family members and caregivers.

Early identification and treatment can lead to lifelong improvement in health, development, and functioning for children with Autism Spectrum Disorder, especially when early services are followed by effective transition to coordinated health, mental health, educational, and community supports. The Department’s Early Intervention Program is a federal entitlement program governed by Part C of the Individuals with Disabilities Education Act. This comprehensive program supports infants and children with developmental delays in their efforts to realize their full potential. This program provides services to children from birth to three years of age with a confirmed disability such as Autism Spectrum Disorder, or with a delay in physical, cognitive, communication, social-emotional, and/or adaptive development. In 2015, this program served approximately 30,000 eligible children citywide. Early Intervention services are confidential, voluntary and free for families, regardless of income, immigration or insurance status.

Children are referred to the Early Intervention Program if developmental surveillance or screening done by the child’s pediatrician suggest the possibility of Autism Spectrum Disorder. Once referred, the program provides a comprehensive multidisciplinary evaluation that includes observation of the child’s behavior and developmental skills, informed clinical opinion, and the use of standardized tools or a structured observational assessment. If a child receives a confirmed diagnosis, the program works with the child’s family to develop an Individualized Family Services Plan. This plan authorizes services that typically include Applied Behavioral Analysis, an intensive form of individualized special instruction, along with speech therapy, Physical Therapy and Occupational Therapy depending on the child and family’s unique strengths and needs. Parent supports and training are often provided as well.

In addition, the Department oversees contracts with 40 providers, including providers funded through Council designations, to provide services to residents who have been diagnosed with Autism Spectrum Disorder and their families. These providers offer a range of recreational
and socialization services that help individuals to thrive by offering meaningful activities that enhance the quality of living.

The Department’s autism services complement programming carried out through the special education programs of the Department of Education, and provide added support to families and caregivers. Some programs are designed to further socialization experiences, foster community integration, and enhance interpersonal communication and peer relations. Other programs provide educational enrichment and academic support as well as opportunities to reinforce and practice skills learned in the classroom. For example, the Edith & Carl Marks Jewish Community House of Bensonhurst Afterschool Center serves children ages 5-12 in Brooklyn by providing academic supports through individual and group tutoring and a reading and support center. These supports integrate youth development, social and emotional learning, and academic skill building to strengthen the lessons their clients learn in school.

The programs overseen by the Department are designed to reach individuals outside of school hours, both on site at schools and at other program locations in the community. For example, New York State Chapter of the Arc serves youth in Manhattan between the ages of 12-21 years through a City Teens program that meets at a local book store to embark on sports, cultural, and community field trips. These excursions offer fun activities while enhancing independence and socialization in the community.

An important feature of these programs is that they provide both direct services for individuals with Autism Spectrum Disorder, and also indirect services that support families and caregivers. Some of these direct services include homework assistance, organized community service and volunteering opportunities. Yet others provide social skills groups, like Mosholou Montefiore Community Center, which has created an inclusion program that combines specialized and individualized services for Bronx youth with Autism Spectrum Disorder with extensive interaction with typically developing peers. This program offers arts & crafts, drama, sports, golf, dance and game room activities to enhance socialization skills. Another program, at the Jewish Community Center in Staten Island, offers yoga and swimming sessions for children 6-12 years old.

Some of the indirect services that support families and caregivers include respite services, autism awareness education, coping skills and behavior modification for parents and siblings, and navigation assistance for families seeking to access other available support. Along with its social skills programming, Quality Services for the Autism Community offers customized training sessions for Queens families, including parent training and sibling support groups. These supports enable family members to gain understanding and share experiences so that they, in turn, can better support their loved ones.

We know that if we are to reach all New Yorkers, autism services must be culturally accessible. This is why our contracted providers are required to offer services that are culturally and linguistically appropriate to the individuals served. When applying to become a provider, applicant groups were asked to specify personnel linguistic and cultural competence, and to detail plans for addressing the needs of individuals and families who are not English-language proficient. In addition, to better support the needs of their clients, we require these providers to
seek and maintain effective collaboration with key internal and external partners, including community-based organizations, schools and educational organizations.

Finally, individuals with Autism Spectrum Disorder and their families will also benefit from many of the ThriveNYC initiatives. For example, we are working to create more employment opportunities for individuals with intellectual and developmental disabilities. This initiative will sponsor new programs in each borough to increase competitive employment for individuals with intellectual and developmental disabilities. We look forward to sharing more about this program as it develops.

I want to thank the City Council for their continued support of services for individuals with autism and their families in New York City. I look forward to hearing some of these providers testify today.

Thank you again for the opportunity to testify. We are happy to take questions.