



**Health**

Testimony

of

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**Assistant Commissioner, Bureau of Developmental Disabilities, Division of Mental Hygiene  
New York City Department of Health and Mental Hygiene**

before the

**New York City Council Committee on Mental Health, Developmental Disability,  
Alcoholism, Drug Abuse & Disability Services**

on

**Intro 1236-2016**

June 5, 2017

250 Broadway, 16<sup>th</sup> Floor Committee Room  
New York, NY

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 support in New York City.

According to the U.S. Centers for Disease Control and Prevention, current prevalence rates for Autism Spectrum Disorder suggest that 1 in 68 children and 1 in 42 boys in the United States are on the autism spectrum.

The Department 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 care givers.

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 toddlers with developmental delays to realize their full potential. This program provides services to children from birth to three years of age with either a confirmed disability such as Autism Spectrum Disorder, or with a delay in physical, cognitive, communication, social-emotional, and/or adaptive development. In 2016, this program served approximately 30,000 eligible children citywide; this includes approximately 4,000 children with an ASD diagnosis. Early Intervention services are confidential, voluntary and free for families, regardless of income, immigration or insurance status.

Young 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.

Once children turn three years old, the Department of Education Office of Special Education becomes the primary autism service provider for New York City children. The Health Department complements this programming by contracting with providers to deliver added support outside of school hours for youth and their families and caregivers. In total, we contract with 70 non-profit organizations, including providers funded through the generous support of the City Council, to provide a range of recreational and socialization programs that help approximately 1,300 New Yorkers by offering meaningful activities that enhance the quality of living.

These programs are designed to reach individuals outside of school hours, both on site at schools and at other program locations in the community. Some of these 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. 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 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.

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 sponsors a new program in each borough to increase competitive employment for individuals with intellectual and developmental disabilities; including two programs that specifically target individuals with an Autism Spectrum Disorder diagnosis. To date, over 100 individuals with intellectual and developmental disabilities have been enrolled in Thrive programs, and of those, close to 50 have achieved competitive employment opportunities.

## **Intro 1236-2016**

Regarding Introduction 1236, the legislation being heard today.

Autism Spectrum Disorder is currently not a reportable condition in New York State, meaning that physicians are not required to report diagnoses to central reporting databases. This greatly limits the Department's ability to report on the prevalence of autism diagnosis.

The Department conducts the NYC Community Health Survey (CHS) annually to gather data on the health of adult New Yorkers, including neighborhood, borough, and citywide estimates on a broad range of chronic diseases and behavioral risk factors. The CHS is a timely surveillance instrument that is able to inform up-to-date agency priorities, and we determine the list of questions based on their ability to serve this purpose. However, the CHS does not always have the power to yield reliable prevalence estimates at the neighborhood level for diagnoses of low prevalence conditions. Existing CDC data suggest that autism spectrum disorders have a prevalence between 1 and 2 percent in children nationwide. If the rates are similar among New

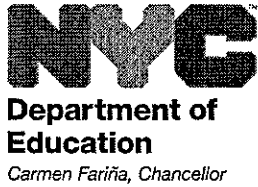
Yorkers, it is unlikely that the CHS would be able to reliably estimate autism diagnoses among adults at the Community District level.

Developing an accurate prevalence estimate in the City would involve a robust surveillance system that requires substantial investment including dedicated staff, technical infrastructure, and policy changes. We are happy to discuss this further with the Council and to explore ways to meet the intention of this legislation.

The Department would be happy to report to the Council on services provided to children with autism spectrum disorder served through the Early Intervention program and by organizations contracted by our Bureau of Developmental Disabilities, with appropriate controls in place to protect the children's confidentiality.

I want to thank the Council for their continued support of services for individuals with autism and their families in New York City. I also look forward to hearing the testimony of some of the autism service providers who are here today.

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



## Testimony of the NYC Department of Education on Intro. No. 1424

June 5, 2017

Good afternoon Chair Cohen and Members of the Committee on Mental Health, Developmental Disability, Alcoholism, Substance Abuse, and Disability Services here today. My name is Christina Foti, and I am the Chief Executive Director of the Special Education Office (SEO) in the Division of Specialized Instruction and Student Support (DSISS) at the NYC Department of Education (DOE). I am joined by Joshua Morgenstern, Deputy Chief Executive. Thank you for the opportunity to testify on Intro. No. 1424, in relation to autism reporting, and to discuss the DOE's work to support students on the autism spectrum.

The DOE is committed to providing a comprehensive continuum of services to support children with Autism Spectrum Disorder (ASD). Our work has three areas of focus: to provide inclusive opportunities for students with autism to succeed in their home zoned schools; to develop strong specialized programs within local district schools that serve the individual needs of students on the spectrum; and, to provide targeted instruction to students with more intensive needs in District 75 settings.

As you are aware, the academic, behavioral and social needs of students on the autism spectrum can vary significantly from student-to-student and with a particular student throughout their educational career. The overarching goal of our work is to offer a broad range of supports and services enabling us to meet individual student needs with an appropriate level of support so that families, teachers and administrators can confidently move students with autism to less restrictive environments (LRE) as they develop students' social skills and modes of communication. This continual movement to LRE and access to typically developing peers will better prepare students on the autism spectrum for college, career, and independent living.

As per federal and State law and regulation, when we develop an Individualized Education Program (IEP) for a student with a disability, we determine the student's disability classification based on the category of disability that most significantly affects the student's educational performance. The 13 disability classifications for school-age students includes a classification for Autism, which is defined by federal and State regulations as *"a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age 3, that adversely affects a student's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences."*

For all students with disabilities, regardless of classification, the IEP includes detailed information about the student's cognitive abilities, social and emotional development and other characteristics. This is based on comprehensive evaluations conducted by the DOE, along with teacher and service provider reports, and information and any reports or evaluations presented by



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the student's parents. The IEP is provided to the student's parents and to all teachers and service providers, to ensure that all have an in-depth understanding of the student and their educational needs and characteristics. We develop programs of special education and related services that are customized to each student's individual needs and characteristics as determined through the evaluation process, and never solely on a student's disability classification.

This school year, there are 20,450 students with an IEP classification of Autism in New York City, 17,015 of whom are being served in DOE or charter schools. For a second straight school year, we have seen a 20 percent increase in the number of students with autism receiving services in a district school setting. These students receive individualized supports and services, including around 3,000 children who receive specialized instruction alongside their typically developing peers in a general education setting.

Included in this student population are over 1,000 children who are served in our ASD Nest Program. The ASD Nest Program was developed in collaboration with New York University's ASD Nest Support Project. The program serves students with ASD alongside typically developing students in a reduced class-size Integrated Co-Teaching (ICT) class, with one special education teacher and one general education teacher. Staff receive training in specialized teaching strategies for students with ASD, including Social Development Intervention, a program developed by NYU that uses evidence-based practices to support the social/emotional development of students with ASD.

Our district schools also serve nearly 450 students in our ASD Horizon program. The ASD Horizon Program was developed by the DOE in collaboration with the New England Center for Children (NECC). This program serves a maximum of eight students with ASD in a special class, with one special education teacher and one paraprofessional. As students develop necessary academic and social skills, opportunities for inclusion with typically developing peers are encouraged. ASD Horizon Program staff are trained in specialized teaching strategies for students with ASD, including the Autism Curriculum Encyclopedia (ACE), developed by NECC. ACE is an evidence-based program based on Applied Behavior Analysis (ABA), which supports the academic and social/emotional development of students with ASD. The growth of the ASD Horizon and ASD Nest programs each year is indicative of this administration's unwavering commitment to meeting the specialized needs of students with ASD in our city.

Students with autism who have more intensive needs in academic, social or physical development and/or management, are usually served in specific class settings in DOE's District 75, a Citywide network of specialized schools. Here, students acquire language and social skills, supported by speech and language and other therapists, as well as by augmentative and alternative communication supports. Classes have one special education teacher and one or more paraprofessionals. Many District 75 programs also offer opportunities for inclusion through strong partnerships with their co-located district schools. This school year, District 75 programs are serving nearly 11,000 students on the spectrum.



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The DOE also serves roughly 3,500 students with ASD who attend non-public schools. This includes students who attend private or religious schools and receive special education and/or related services through the DOE, and students who have IEPs that recommend specialized private schools approved by the New York State Department of Education to serve students whose needs are more intensive than can be addressed in a public school setting.

We remain committed to serving and supporting families of students with a disability before, during and after their child's school-age journey. Examples of these supports include: parent counseling and training for families of students with Autism; partnership with the Citywide education councils, including regular participation at their meetings; co-facilitation of parent trainings with advocacy groups and other Community Based Organizations; and ongoing support provided at the local level via the DOE's district-level teams and field support centers, and at individual schools. Of particular note, representatives from the DOE met with 1,721 participants at 17 "Turning 5 Kindergarten Orientation" sessions held across the five boroughs this school year. These meetings are intended to support families of students with disabilities through the transition to kindergarten, and included information about our ASD programs.

DSISS offers a wide range of professional learning opportunities through District 75 and the Special Education Office that are open to all special education teachers, related service providers, school administrators and paraprofessionals. Examples of professional learning topics offered are verbal behavior; designing effective classrooms for students with autism; teaching communication; and transition skills in the autism classroom. Through our partnership with NYU, we provide workshops for educators and administrators in community schools on autism basics, and strategies that work.

We are proud of our robust professional learning and specialized program offerings that continue to expand, and we continually search for innovative ways to support our students, especially in inclusive settings. This school year, we are partnering with NYU on a collaborative study group looking at current DOE practices in autism education in district schools. The group's goal is to make recommendations for models to better serve students on the autism spectrum in district schools. Having conducted site visits and interviews with teachers, administrators, and families, the study group will formulate recommendations that will be aligned with the vision of the Central office as well as with the needs of the educators and families who work with children every day. The group's recommendations, expected in July, will help inform the ongoing development of our programs for children with autism spectrum disorder.

I would now like to turn to the proposed legislation.

Intro. No. 1424 requires autism spectrum disorder reporting from the DOE. As part of DOE's commitment to ensure that parents, advocates, elected officials, and other stakeholders have helpful information regarding special education, in 2015 we worked with the City Council to enact Local Law 27, which requires the DOE to submit a comprehensive annual report. This report includes Citywide data on the number of DOE students who have an IEP disability classification of Autism.



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While we support the goal of the proposed legislation, we have concerns about singling out a specific disability as part of a report on student demographics. The proposed legislation seeks revisions to sections 21-957 and 21-958 of the NYC Administrative Code, Reporting on Demographic Data in the New York City Public Schools. These sections require reporting on broad categories of student demographic information. Intro. No. 1424, in contrast, seeks information about one category of disability. As such, we believe that a different section of the Administrative Code would be more appropriate for this type of reporting.

Though the DOE would not be able to comply with the proposed legislation as written, we look forward to working with the Council on revised language to reflect the additional demographic and district-level information DOE is able to report to the Council on students with the IEP disability classification of Autism.

Thank you for the opportunity to testify today. We look forward to our continued partnership with the City Council on this important work. We would be happy to answer any questions you may have.





**Ramapo for Children Testimony for Mental Health Committee requiring autism spectrum disorder reporting from the Department of Education**

Hello, my name is Alicia Barry; I am the Associate Director, Parent Education and Support with Ramapo for Children. I want to start by thanking the New York City Council for your longstanding commitment to supporting parents, caregivers, and children with Autism Spectrum Disorder.

Ramapo for Children is a New York City based agency with an extraordinary track record of serving children and the adults who work with them since 1922. Through direct service youth programs and highly regarded training programs for adults, Ramapo works on behalf of children who face obstacles to learning, including children of all abilities, enabling them to succeed in the classroom, at home, and in life. We do this by providing workshops and assistance to educators, youth workers, and parents to help them better manage and meet the needs of their children.

In addition to collecting data related to the diagnosis of individuals, we must continue to provide access to parent education and support. We have been a parent and caregiver education workshop provider of the New York City Council Autism Awareness Initiative for the past 8 years. Ramapo's workshops have served over 3,000 families impacted with ASDs. All of the Parents/Caregivers (100%) who have participated in Ramapo's behavior management workshops have reported that the training helped them feel less alone as caregivers of children with Autism Spectrum Disorders and provided them with techniques and tools they could use immediately to help their child. In the words of one parent, *"You were able to help me understand my son more in this one workshop than in the last four years of raising him. It was a struggle, but you made it easier."*

For many parents and caregivers, our workshops are the only opportunities they have to receive vital skills which meet the unique needs of their children, and make daily life less stressful. Our parent workshops are relevant and substantive, and they provide information that is relatable.

Too frequently, parents have little access to information and support to help their children. Parent education and support is a low cost, high impact, efficient way to ensure these New Yorkers have access to assistance. Ramapo, as an itinerant service provider, targets underserved areas and travels to all five boroughs. Working with families for whom this is often their first access point to support on how to manage the challenges of raising a child with a disability. We respond to the racial, socioeconomic, multigenerational, and cultural diversity of New York City. Our workshops have served working parents, grandparents, immigrant populations – Russian, Latino and Chinese, from Mott Haven to Staten Island to Bensonhurst, just to name just a few. We partner with hospitals, community centers, and public schools. Every year, we identify new groups of New Yorkers who are parenting children with disabilities and set up workshops to bring information and support to them in their neighborhood.



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*Building Relationships, Inspiring Success.*

While our programs have allowed us to reach many diverse parent populations, there are communities who still await help and need it desperately. In addition, each day there are new parents who receive a diagnosis of ASD for their young children - these parents need immediate help to understand this diagnosis and quickly learn skills and utilize tools to support their children.

We are hopeful that you will understand how much the support provided through parent and caregiver education means to families who are impacted by ASDs. I thank the New York City Council for their time and support.



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THE CITY OF NEW YORK**

Appearance Card

I intend to appear and speak on Int. No. \_\_\_\_\_ Res. No. \_\_\_\_\_

in favor  in opposition

Date: \_\_\_\_\_

(PLEASE PRINT)

Name: Amber Levanon Seligson

Address: DOHMH

I represent: \_\_\_\_\_

Address: \_\_\_\_\_

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Appearance Card

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in favor  in opposition

Date: 6/5/17

(PLEASE PRINT)

Name: Vanice Chisholm

Address: 42-09 28<sup>th</sup> St. Qns, NY

I represent: DOHMH

Address: 42-09 28<sup>th</sup> St, Qns NY

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in favor  in opposition

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Name: Cheryl Lawrence

Address: DOHMH

I represent: \_\_\_\_\_

Address: \_\_\_\_\_

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Name: Marie Casalino

Address: DOHMH

I represent: \_\_\_\_\_

Address: \_\_\_\_\_

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 in favor  in opposition

Date: \_\_\_\_\_

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Name: JOSHUA NORGENSTEIN

Address: 52 CHANDLER ST

I represent: DEPT OF EDUCATION

Address: \_\_\_\_\_

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**THE CITY OF NEW YORK**

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I intend to appear and speak on Int. No. \_\_\_\_\_ Res. No. \_\_\_\_\_  
 in favor  in opposition

Date: \_\_\_\_\_

**(PLEASE PRINT)**

Name: Allia Barry

Address: 49 west 33 street, 5th floor

I represent: Ramapo for children

Address: 49 west 33 street, 5th floor



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Appearance Card

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in favor  in opposition

Date: \_\_\_\_\_

(PLEASE PRINT)

Name: CHRISTINA FOTI

Address: 394 E. 8th Street Bk, NY 11218

I represent: NYC Department of Education

Address: 52 Chambers Street NY, NY 10007

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I intend to appear and speak on Int. No. \_\_\_\_\_ Res. No. \_\_\_\_\_

in favor  in opposition

Date: \_\_\_\_\_

(PLEASE PRINT)

Name: Christina Foti 5/2017

Address: Chief Executive Director

I represent: Special Education Office

Address: DOE

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Appearance Card

I intend to appear and speak on Int. No. \_\_\_\_\_ Res. No. \_\_\_\_\_

in favor  in opposition

Date: 6/5/2017

(PLEASE PRINT)

Name: Josh Morgenstern

Address: Deputy Chief Executive

I represent: Special Education Office

Address: DOE

Please complete this card and return to the Sergeant-at-Arms