

Autism Spectrum Disorders Advisory Board Report

October 1, 2017

Introduction

Per Legislation (Mental Hygiene § 13.42), the Autism Spectrum Disorders Advisory Board was established. The composition of the board includes both appointed and ex-officio members:

APPOINTED MEMBERS

- Courtney Burke (chair)
- Stephanie Andrews
- Mary Elizabeth Boatfield
- Andrea Bonafiglia
- Mary Lou Cancellieri
- Charles Massimo
- Robert E. Myers III
- Sara Mae Pratt
- Patrick Paul

EX-OFFICIO MEMBERS

- Helen Yoo, New York State Office for People With Developmental Disabilities
- Chris Suriano, New York State Education Department
- Donna Bradbury, New York State Office of Mental Health
- Vicky Hiffa, New York State Office of Children and Family Services
- Connie Donohue, New York State Department of Health
- Sheila Carey, New York State Developmental Disabilities Planning Council
- Debbie Benson, New York State Council on Children and Families

- Kevin Smith, New York State Education Department

The Board will meet quarterly and generate findings and recommendations. This report represents the organization and plan forward for the Board. Additional planning activities and public outreach will occur in addition to this initial report.

Charge of the Group

The Autism Spectrum Disorders Advisory Board's charge is focused on four areas defined in legislation:

- (1) Study and review the effectiveness of supports and services currently being provided to people diagnosed with autism spectrum disorders;
- (2) Identify legislative and regulatory activity which may be required to improve existing service systems that support people diagnosed with autism spectrum disorders;
- (3) Identify methods of improving interagency coordination of services and maximize the impact and effectiveness of services and agency functions; and
- (4) Such other matters as may be deemed appropriate by the members of the board.

At the first meeting, Member of Assembly Santabarbara joined the group and provided a statement, summarized as follows:

This is an exciting day and thank you to all members. The Board has the potential to lead the way as with Autism Action New York¹. We have done a great job with

¹ Autism Action NY is a five-point plan aimed at increasing job opportunities; providing independent housing options; improving access to information; assisting in communication; and, creating a centralized location for services in New York.

awareness, which we must turn into action. We have done that by creating this Board through legislation.

Autism is a disability which affects each person differently, posing unique challenges both big and small. I often hear of the hardships of families caring for a loved one with autism. Today, one in 45 boys is affected by autism. This also impacts adults, and services are needed. Some services are working, and others can be improved upon.

Other states and countries have called my office inquiring about this Board. The report produced will go to the hands of lawmakers. We want best practices and guidance in one document. The purpose of the Board is to pass information to the Governor and lawmakers so everyone is on the same page. This effort will help thousands of families; thank you to members and the Governor.

Work to Date

The initial membership of the Board met on September 28, 2017. At that meeting, members of the Board heard presentations from New York State agencies with a role in providing services to children and adults with Autism Spectrum Disorder (ASD).

This level-setting meeting will be followed by a robust schedule of activities that will engage both the members of the Board as well as the public in helping to set the State's direction in supporting people with ASD and their families.

The agenda for future meetings entails:

- A more in-depth discussion with the state agencies serving those with ASD
- Developing a work plan
- Holding public hearings
- Issuing a report

The Role of New York State Agencies in Providing Services to People with ASD

State agency representatives provided introductions to their respective roles in providing services to people with Autism Spectrum Disorders.

- The Office for People With Developmental Disabilities (OPWDD) serves over 36,000 individuals with autism. OPWDD funds both traditional, agency-provided supports and self-directed options. Services provided by the agency include family support services, assistive technology, community habilitation, self-direction, clinical services including those for behavioral health, day (employment) and residential supports.
 - The Institute for Basic Research (IBR), represented by Dr. Helen Yoo, is under the auspices of OPWDD and conducts research in disabilities including Fragile X syndrome, Batten Disease, Alzheimer's and ASD including challenging behaviors. IBR also operates the Jervis Clinic, providing diagnostic and other services for people with ASD.
- The Council on Children and Families' role focuses on cross-systems issues. They accept referrals for hard to place children from any source (parent, school, etc.) Their role is one of coordination between parties.
- The Department of Health (DOH) is the lead agency for Early Intervention (EI) services. There are approximately 8,900 individuals diagnosed with ASD in the EI system. EI services are used, on average, for 18 months by an individual and can include service coordination, clinical services, speech therapy, and family training.
- The Office of Family and Children's Services (OCFS) provides services through three divisions: childcare (daycare), juvenile justice, and child welfare. Bridges to Health (B2H) provides services to kids with ASD.
- The Office of Mental Health (OMH) serves people with ASD and co-occurring mental health disabilities (but cannot by law serve those with only ASD and not a mental health disability).
- The State Education Department (SED) has oversight responsibility for public schools serving people with ASD, including an extensive monitoring system. The agency's priority is ensuring students are in the least restrictive environments. They fund the Center for Autism and Related Disabilities.
- The Developmental Disabilities Planning Council (DDPC) is a federally funded state agency focused on all developmental disabilities including some ASD-specific projects. The DDPC designs and tests new programs, including those that support people with autism such as community-based behavioral health supports.

Focus Areas

The initial themes of discussion which the Board will focus on and for which more information will be presented by state agencies are:

- **Awareness and acceptance of ASD**, centered on the extent to which the public understands and is welcoming of people with ASD in communities across the state;
- **Training for professionals** including doctors and first responders so they can effectively interact with and assist individuals with ASD in their official capacities;
- **Housing for people with ASD** with support services to meet their needs in the community;
- **Regulatory barriers** that can be overcome to allow changes which improve the efficiency and function of the service system for people with ASD;
- **Employment opportunities** for people with ASD, both from the perspective of job training as well as supporting businesses which desire to employ people with ASD;
- **Eligibility** for services and how people with ASD gain access to supports;
- **Cross agency coordination** to synergize the efforts of the various state service systems that support people with ASD;
- **Diagnostic funding** to ensure appropriate diagnosis of ASD;
- **Community supports** to help people with ASD participate in a range of life and community activities they enjoy and find meaningful; and,
- **Collaboration on research** so that the causes of ASD are better understood.
- **Exploring financial hardships** faced by families of a child with ASD, including services not covered by insurance.

Other noted focus areas for the group include:

- Supporting families of children with ASD;
- Obtaining statistical and other information for the members' edification;
- Determining additional grant funding opportunities; and,
- The effectiveness of different therapeutic treatments for people with ASD over time.

Next Steps

The Board will develop a work plan based on the noted themes, which will be expanded upon by state agencies that will provide more information on the identified topics.

The Board preliminarily discussed holding public meetings, potentially one upstate and one downstate, and will establish a means for communication with the public. There was general agreement with the establishment of an email address and holding of public forums.

The group meets four times per year according to legislation, and the winter meeting will focus on further information sharing from state agencies. Another meeting is planned for Spring of 2018, at which time the means for gathering public input will be considered.

Previously generated documents on statewide support for people with ASD will additionally be reviewed, including the Taskforce on Autism document produced by OPWDD.