



**Report to the Governor
and the
New York State Legislature**

Regarding Recommendations of the

**Autism Spectrum Disorders
Advisory Board**

**Courtney Burke
Chairperson**

May 2019

Dear Friends and Colleagues,

Over the past year, a committed group of advocates came together around the goal of identifying ways for New York State to enhance supports for people on the autism spectrum. Appointed by the Governor and empowered through legislation, the members of the Autism Spectrum Disorders Advisory Board (the Board) have crafted a series of recommendations meant to improve the lives of New Yorkers with autism.

A subcommittee of self-advocates helped shape the recommendations by providing insight from those who have lived experience with autism. Additionally, the Board held public forums to gain input from those around the State including many parent participants. Through this process, the recommendations developed in a way that reflects the input of those we serve.

New York State has an important commitment to serving individuals with Autism Spectrum Disorders, as well as their families, communities, and the dedicated advocates and service providers who help people have full and meaningful lives. Through the work of the Autism Spectrum Disorders Advisory Board key priorities for change have been identified, along with actionable solutions to advance them.

New York State presently provides services and supports to people on the spectrum in a variety of ways, reflecting a long-term programmatic effort to meet the needs of individuals who have complex needs and often require services from multiple State agencies. One of the recommendations of the Board is for greater interagency collaboration around comprehensive care for children, as well as general emergency preparedness, to strengthen cross-system collaboration. Additionally, the recommendations call for a roadmap to services to help make navigating the options easier. They also support advancements such as the greater expansion of telehealth and incorporation of assistive technology.

I encourage you to review this report in its entirety, as it captures the process of the Board by reflecting discussions of current State efforts in this area, summarizes public comment and provides a synopsis of the discussions of the self-advocate subcommittee. These recommendations are part of an ongoing process, and your feedback is always appreciated at asdadvisoryboard@opwdd.ny.gov.

Sincerely,

Courtney Burke

Chairperson, Autism Spectrum Disorders Advisory Board

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Introduction

In November of 2016, Governor Andrew M. Cuomo signed into law Chapter 469 of 2016 (Mental Hygiene § 13.42), which created the Autism Spectrum Disorders Advisory Board (the Board) to help provide guidance and information to New York policymakers, individuals with an autism spectrum disorder diagnosis (ASD), and families seeking reliable information regarding available service and supports.

The Members of the Board are tasked with several important duties including: Studying and reviewing the effectiveness of supports and services currently being provided to people diagnosed with Autism Spectrum disorders; Identifying legislative and regulatory activity which may be required to improve existing service systems that support people diagnosed with autism spectrum disorders; Identify methods of improving interagency coordination of services and maximize the impact and effectiveness of services and agency functions; and, other matters as deemed appropriate by the Board.

The composition of the board includes both appointed and ex-officio members:

APPOINTED MEMBERS

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

EX-OFFICIO MEMBERS

- Debbie Benson, New York State Council on Children and Families
- Donna Bradbury, New York State Office of Mental Health
- Sheila Carey, New York State Developmental Disabilities Planning Council
- Connie Donohue, New York State Department of Health

- Vicky Hiffa, New York State Office of Children and Family Services
- Kevin Smith, New York State Education Department
- Chris Suriano, New York State Education Department
- Dr. Helen Yoo, New York State Office for People With Developmental Disabilities

The Board, over the course of the past year, developed recommendations to address the below areas of focus:

- Awareness and acceptance of ASD
- Training for professionals
- Community supports
- Housing for people with ASD
- Employment opportunities
- Eligibility for services
- Diagnostic funding
- Regulatory barriers
- Cross agency coordination
- Collaboration on research
- Exploring financial hardships

Recommendations impacting these areas were developed to advance supports and services for people with autism spectrum disorders (ASD), as well as engendering community awareness and acceptance.

These recommendations were informed by the discussions of a workgroup of self-advocates, formed by the Board to provide first-hand input from people with lived experience with autism. A report denoting their input into the recommendations and other topics is found as an appendix of this report.

The Board's recommendations are contained in the next section of this report. The appendices of this report reflect findings regarding:

- Efforts in New York State to support people with ASD;
- Feedback from public forums held with locations throughout the state; and,
- Feedback from the workgroup of self-advocates with ASD asked to provide input into the recommendations.

Recommendations of the Autism Spectrum Disorders Advisory Board

1. Enhance Communications to Raise Awareness and Combat Discrimination

Focus Areas: Awareness and Acceptance of Autism Spectrum Disorders (ASD), Cross-Agency Coordination

New York State conducts ongoing campaigns designed to promote a greater understanding and awareness of disabilities to strengthen community acceptance and integration. Awareness campaigns such as OPWDD's recent *Welcome* initiative encourage people to get to know their neighbors and acquaintances with ASD, and a grant funded by the Department of Health and efforts of the State Education Department promote awareness of Early Intervention services for children.

The Board identified areas for improvement and opportunities for greater clarity among individuals, families, providers and the community at large. This includes the development of a Statewide awareness campaign highlighting people with ASD living and working in the community.

2. Supporting People with ASD Living in the Community

Focus Areas: Housing for People with ASD, Employment Opportunities, Eligibility, Community Supports

It is only natural that people with ASD be part of community life, just like anyone else. However, people with ASD sometimes have challenges related to their disability that can impact their ability to find appropriate living arrangements as well as find and maintain employment. State agencies offer assistance in finding needed services, such as OPWDD's Front Door process.

The Board recommends that New York State agencies, represented by members of the Board, develop an informational resource for individuals and families that lays out the service options offered by the various State agencies serving individuals with ASD. This should include a focus on housing and in-home support as well as employment. This "Autism Services Road Map" should help individuals and families understand the resources available to them and how to access them.

3. Increasing Collaboration Between State Agencies

Focus Areas: Training for Professionals, Cross-Agency Coordination

The Board reviewed steps that have been taken to integrate services and how State agencies work together to solve common issues. However, it became clear through these discussions that there are still opportunities for greater cross-system collaboration, especially in serving those with atypical challenges and diagnoses. Two areas identified in need of attention were comprehensive care for children; and, first responder and emergency services.

The Board recommends that a short-term Inter-Agency Cross-Systems workgroup be created to identify strategies for collaboration among multiple service systems and policy solutions to streamline cooperation around two issues raised by the Board.

The workgroup should consider the following areas for improved cross-systems coordination: ensuring children with ASD served in the system are supported in a holistic way by multiple service systems so that they are served most effectively; and, ensuring coordinated and comprehensive awareness of ASD in the context of first responder and emergency services. The workgroup should issue a report of its findings including the strategies and policy solutions identified.

4. Establishing Family Support Groups

Focus Areas: Awareness and Acceptance of ASD, Eligibility

Families who learn their child has an ASD diagnosis can undergo a range of emotions, and the challenges resulting from a child's disability can place strain on a family. However, families of children with ASD have long found support in each other, and organizations supporting parents offer crucial assistance in children's early years.

To facilitate discussions and form bonds, the Board recommends linking to or establishing regional family support groups so that families have the chance to be part of an inclusive, positive and supportive group dedicated to reinforcing family and dealing with the challenges that an ASD diagnosis can pose. Individuals with ASD should be welcomed in these groups as well.

5. Focus on Wellness By Supporting Proper Exercise and Nutrition

Focus Area: Community Supports

Good eating and exercise habits are important for all people to stay healthy, and the Board recognizes that this can take on special importance for people with ASD who can have challenges with dietary intake and exercise habits.

The Board recommends the creation of an wellness program available to individuals with ASD and other developmental disabilities, with specific focus on factors pertaining to ASD and developmental disability. The Board recommends that OPWDD consult with

an expert who specializes in nutrition and disability services to develop the program, to be hosted on the OPWDD website.

6. Better Support Telehealth Services Throughout New York State

Focus Area: Regulatory Barriers, Community Supports

Telehealth can remotely connect patients and healthcare providers, offering an important tool in facilitating access to health care as well as supporting comprehensive care and individual outcomes. Challenges have been identified regarding the adoption and delivery of telehealth services, including financial, statutory and regulatory barriers.

Governor Cuomo, in September 2017, signed a bill into law that expands the list of state-sanctioned delivery sites for telehealth to public, private and charter elementary and secondary schools, child care programs and day care centers. The legislation opens those programs to reimbursement from Medicaid and private payers.

The Board supports New York State in further taking a landmark step forward in February 2018 to expand access to telehealth services through a series of measures, including expanding the list of eligible originating sites so that patients can receive telehealth services in a wider range of settings, including their own homes. The Board supports State agency-specific regulatory changes to advance the use of telehealth services in New York.

7. Study How Assistive Technology Can Be Utilized More Fully

Focus Areas: Community Supports, Housing for people with ASD

Individuals with ASD and people with other developmental disabilities can benefit from a greater integration of assistive technology. Smart home technology, for example, can assist with basic activities of daily living, perform repetitive tasks, answer simple questions, and help provide monitoring to supplement staff and allow for more independent living. Discussion of the Board focused on the greater need for assistive technology to serve people in the least restrictive environments.

Advances in assistive technology over the past decades have been amazing in their rapid progress. The Board recommends convening a “Tech Summit” with a university sponsor focused on highlighting the opportunities offered by assistive technology and the gains in assistive technology research. The Tech Summit will cover assistive technology that can benefit individuals with ASD, as well as other developmental disabilities.

The Tech Summit should include a range of guest experts and open registration for admission to the public. The Summit should place a strong focus on innovative

technologies (such as smart homes), including phone apps specifically geared to people with ASD.

8. Increasing the Number of Clinical Professionals Serving Individuals with ASD

Focus Areas: Training for Professionals, Community Supports, Collaboration on Research

Governor Andrew M. Cuomo signed a law in 2014 which established a new state license for providers of applied behavior analysis¹ (ABA) services to individuals with autism spectrum disorder. The law established education, examination, and experience requirements, and restricted activities that may only be provided by Licensed Behavior Analysts (LBA) and Certified Behavior Analyst Assistants (CBAA). The law helps to ensure that individuals and families can access quality ABA providers while also ensuring State regulation and continuing oversight of these providers.

An issue identified by the Board was the growing demand for more ABA-licensed and certified providers capable of serving individuals with a range of Autism Spectrum Disorders. The Board recommends that a targeted communications campaign be developed to be shared with colleges and universities offering psychology and related programs. This campaign, directed toward aspiring clinicians, would be focused on helping students learn about ABA as an exciting career path.

The larger context of other therapies available to individuals with ASD should also be reviewed to identify strategies that can encourage the further development of professionals in other clinical specialties serving people with ASD.

9. Engage Cutting-Edge Research Around ASD

Focus Areas: Training for Professionals, Collaboration on Research

There has been a great deal of research into Autism Spectrum Disorders, however disseminating and digesting this information is a challenge. Recent findings offer hope and provide concrete takeaways, such as the benefits of parent participation in early intervention for autism. This research also offers insights into the early predictors of autism as well as many other topics.

To help individuals and families access information available about ASD, the Board proposes creating a “Research Bank”. The Research Bank will feature resources from

¹ Applied Behavior Analysis (ABA) is a behavioral technique and treatment approach which can be provided to people diagnosed with Autism Spectrum Disorder (ASD) or related disorders. ABA is one of several interventions that may be clinically indicated and effective for individuals diagnosed with ASD.

leading scientific journals and research institutions focused on ASD issues, such as the New York State Institute for Basic Research. The research bank will highlight evidence-based interventions and treatment proven to be helpful for people with ASD, to provide objective information so individuals and families can make informed choices. The information should be structured in an easy to understand format for use by non-professionals as well as professionals.

10. Review the Impact of New York’s Systemic, Therapeutic, Assessment, Resources and Treatment (NYSTART) In-Home Supports for Individuals with ASD

Focus Area: Community Supports

NYSTART is a community-based program that provides crisis prevention and response services to individuals with intellectual and developmental disabilities who present with complex behavioral and mental health needs. The service assists their families and others in the community who provide support when short-term crisis response is needed.

The NYSTART program offers training, consultation, therapeutic services and technical assistance to enhance the ability of the community to support eligible individuals and focuses on establishing integrated services with providers. Providing supports that help individuals to remain in their home or community placement is NYSTART’s first priority. NYSTART is in the process of being implemented statewide.

NYSTART is available to individuals with many types of developmental disabilities who have co-occurring behavioral health needs. As it reaches full implementation, the Board recommends an in-depth analysis of NYSTART to ensure that individuals with ASD who are accessing NYSTART services are receiving effective at-home supports. The review should consider the experiences of those served by the program in making this determination.

Appendix A: New York State Efforts on Behalf of Individuals with Autism & Their Families

This section outlines activities effectuated and coordinated by New York State government agencies which benefit individuals with autism spectrum disorders (ASD). Acronyms are used throughout to refer to the agencies; a glossary is provided below.

New York State Agency Acronym Glossary:

DDPC* - Developmental Disabilities Planning Council

DOH – Department of Health

OCFS – Office of Family and Children’s Services

OMH – Office of Mental Health

OPWDD – Office for People With Developmental Disabilities

SED – State Education Department

Note: The Council on Children and Families does not have an acronym—it is referred to as “the Council”

* The DDPC is a federally funded state agency

Awareness & Acceptance of People with ASD

OPWDD maintains ongoing campaigns that promote a greater understanding and awareness of disabilities as well as strengthened community acceptance and integration. Activities include agency participation in community events, public speaking, a robust social media campaign and website presence, and annual awareness campaigns such as the Welcome initiative (<https://opwdd.ny.gov/welcome>) that encourages communities across the state to welcome people of all abilities and helps plant the seeds of community inclusion and the Get Together campaign based in the spirit of togetherness and community integration (<https://opwdd.ny.gov/gettogether>).

The awareness campaigns form the basis of OPWDD presence at events such as local and statewide advocacy conferences and the Great New York State Fair, with 1 million visitors. OPWDD produces and distributes a brochure, Facts About Autism, which is currently being revised.

DOH developed public awareness materials under a grant from the U.S. Department of Health and Human Services, Health Resources and Services Administration. Materials focus on early identification of ASDs and the importance of early intervention services, and highlight the early signs of autism and how to refer young children to needed diagnostic and treatment services. Dissemination included brochures, posters and use of social media. Publications are available at:
https://www.health.ny.gov/forms/order_forms/eip_publications.pdf

Training for Professionals

OPWDD provides comprehensive training on serving people with developmental disabilities including autism to direct support professionals. OPWDD also partnered with the DDPC to produce a brochure to help first responders in responding to emergency situations involving people who have ASD.

In addition, in 2008 the Autism Task Force, a collaborative group including OPWDD and 10 state agencies, outlined a number of recommendations to improve supports for people with ASD, including the development of ASD-related training for professionals and families; information sharing among agencies, enhancing the service system to more effectively support individuals and families, and advancing scientific understanding of ASDs and the evidence base supporting best practices in the identification, assessment, diagnosis, education and treatment of people with ASDs.

The Institute for Basic Research (operated by OPWDD) offers training for professionals including doctors and first responders so they can effectively interact with and assist individuals with ASD in their official capacities. Autism Platform trainings for clinicians and staff include:

1) Autism Initiative: Training Series:

[https://opwdd.ny.gov/opwdd_community_connections/autism_platform/Autism Initiative Training Series](https://opwdd.ny.gov/opwdd_community_connections/autism_platform/Autism_Initiative_Training_Series)

2) Targeting the Big Three:

https://opwdd.ny.gov/opwdd_community_connections/autism_platform/background_initiatives_progress/asd_training_initiatives

NYS OMH funds Project TEACH (<http://projectteachny.org/>), which provides training, consultation, and linkage support to primary care and other prescribers. OMH has also conducted statewide grand rounds, webinars, as well as team training sessions with experts in ASD.

The Council on Children and Families is leading The New York State Pyramid Model Partnership (<http://www.p12.nysed.gov/earlylearning/BiggerPyramidOverview.docx>), the goals of which are to better support and teach young children and families social and emotional skills; to create a network of assistance for child care providers and parents concerning early intervention; and to provide information on the limitation of suspension and expulsion from early education programs. OCFS also developed an e-learning training session for childcare providers on early intervention and the resources that are available when working with a child from birth to three who is exhibiting atypical behavior for their age of development.

Through SED, Regional Adult Education Networks (RAEN) (<http://www.acces.nysed.gov/aep/raen>) offer training for Literacy Zones in Disability Awareness offered by the Center for Independence of the

Disabled in NYC. The training helps Literacy Zones attract and serve students with disabilities including ASD and is designed to help prepare staff across the state to serve individuals with various disabilities.

New York State Education Law requires that all persons applying for a teaching certificate/license as a special education teacher or school administrator who works in special education, complete course work or training in the needs of children with autism. The Regulations of the Commissioner of Education were amended in 2008 to detail the required components of course work or training; set forth the standards for course work and training; establish the application process for organizations seeking to become approved providers of the course work or training; and require the Department to develop a syllabus for providers offering course work or training. SED provides \$500,000 in IDEA discretionary funds annually to fund the Center for Autism and Related Disorders (CARD) to provide training and technical assistance statewide for the implementation of best practices for students with ASD. The Center provides regional seminars to school districts and parents on essential components of effective programs for students with ASD.

DOH's Best Practice Protocol for Early Screening of Young Children for Autism Spectrum Disorders (ASDs) by Pediatric Primary Care Providers (https://www.health.ny.gov/community/infants_children/early_intervention/autism/docs/best_practice_protocol.pdf) was developed to promote pediatrician's knowledge and understanding of ASDs and their adherence to American Academy of Pediatrics (AAP) guidelines for universal screening of toddlers for ASDs. The best practice protocols incorporate standards and guidelines issued by the American Academy of Pediatrics (AAP). A physician desk reference was also developed and is adapted from the online comprehensive version of the Best Practice Protocol. The BEI video series included a one-minute clip on early signs of ASD, which was aired in pediatric offices in summer 2017.

Community Supports

It is OPWDD's vision that people with developmental disabilities, including autism spectrum disorders, are seen as valued members of our communities, and that they have the support to live the lives they choose while experiencing good health, growth, and personal relationships. Emphasis is placed on providing opportunities for people to fully participate in their communities through their choice of residences, vocational or employment activities, volunteerism, community habilitation and also through participation and involvement in their communities.

OPWDD offers an array of services and supports to help people with developmental disabilities live in the home of their choice; find employment and other meaningful activities in which to participate; build relationships in the community, and experience health and wellness. OPWDD supports and services include:

- Help for people to live in a home in the community.

- Help for families to support their family member to live in the family home with respite and other family support services.
- Help for people who want to work in the community with employment training and support, volunteer opportunities, and other types of community engagement.
- And help for people who need intensive residential and day services.

People new to the OPWDD system can access services and supports through OPWDD's Front Door. Every person that is receiving OPWDD supports and services is supported to undergo a person-centered planning process. The goal of this process is to discover the particular abilities, wants, goals and needs of each individual served. Person-centered planning helps us turn the input of each individual and his/her caregiver(s) to build a lifestyle suited to his or her unique situation. OPWDD staff encourage and facilitate community involvement, as supported in their Code of Ethics (<https://opwdd.ny.gov/code-of-ethics/home>).

SED provides supports through local school systems to children with ASD (age 22 and younger). Local Title II Educational Providers partner with various agencies and organizations in order to facilitate learning for adult students who have ASD.

DOH Early Intervention services are geared toward young children (birth to pre-school) and are delivered where people live, in their home or other locations in the community. EI services are geared toward community living.

Housing and employment are major focus areas for community supports and services.

Housing

OPWDD currently provides residential supports to approximately 41,000 individuals with developmental disabilities. OPWDD has also developed a multi-year housing strategy designed to meet current and future need for residential supports by expanding certified and non-certified housing opportunities.

OPWDD supports apartments for independent living both through its self-direction program and by providing direct rental subsidies. Individuals receive appropriate wraparound services, such as community habilitation, to support them to live their lives in the community with needed assistance.

Supportive housing projects in development include projects eligible to receive funding under the \$20 billion Empire State Supportive Housing Initiative (ESSHI) affordable and supportive housing fund.

Employment

Almost 17,000 people are engaged in work-related and pre-vocational activities supported by OPWDD services, and another 10,000 participate in OPWDD's supported employment program, which includes services such as job coaching and on the job

support. OPWDD conducts outreach to the community and works with local school systems to educate high school students who have developmental disabilities and their families about options for finding a job that pays a good wage and offers rewarding opportunities.

OPWDD participated with the Governor's Employment First Commission to create the EmployAbility toolkit (<https://opwdd.ny.gov/employability>), to encourage and assist businesses interested in hiring people with disabilities.

ACCES-VR, as the state vocational rehabilitation agency, provides a wide range of vocational assessment, training, placement and employment supports to individuals with autism spectrum disorder, as well as supporting businesses in hiring, accommodation and retention.

ACCES-VR (<http://www.acces.nysed.gov/bpss/welcome-career-training-proprietary-schools>) also oversees and licenses private career schools. As part of this process, ACCES-VR receives from the school annual data on school success by obtaining the Occupational Education Data Survey (OEDS). This data includes completion rates and placement rates.

Eligibility for Services

The process to obtain eligibility for OPWDD services (https://opwdd.ny.gov/opwdd_services_supports/eligibility/faqs) is defined by New York state Mental Hygiene Law. Eligibility for services is the same for people with ASD as for those with any developmental disability.

OMH program regulations require a diagnosis of a designated mental illness for eligibility. This does restrict access to OMH services for those with solely an Autism diagnosis.

Individuals with ASD who apply for vocational rehabilitation services (ACCES-VR) have their eligibility (<http://www.acces.nysed.gov/vr>) determined based on having a significant impediment to employment. Once determined eligible, an individualized plan for employment is developed consistent with the needs of the individual to achieve a specific employment goal.

DOH's Early Intervention (https://www.health.ny.gov/community/infants_children/early_intervention/) and Applied Behavior Analysis (ABA) services are accessed through differing eligibility frameworks and described the programs, including the role of Licensed Behavior Analysts (LBAs) in term of the provision of ABA services and issues facing the workforce.

Diagnostic Funding

OPWDD, together with Upstate University Hospital in Syracuse, supports the Margaret L. Williams Developmental Evaluation Center (<http://developmentalevaluationcenter.com/>) that provides comprehensive developmental and medical evaluations for children under age 7.

OPWDD also supports people with ASD by funding Article 16 clinics which provide diagnostic services, and psychological and psychosocial services; family support services including respite; self-direction that provides individuals and families the opportunity to choose the appropriate mix of supports and services that are right for them; and Intensive Behavioral Services (IBS).

The George A. Jervis Clinic (<https://opwdd.ny.gov/institute-for-basic-research/jervis-clinic>) at OPWDD's Institute for Basic Research also offers diagnostic evaluations for intellectual disabilities, autism, Fragile-X, Batten disease, cerebral palsy, seizure disorders, dementia, speech abnormalities, behavior abnormalities and progressive neurological and neurometabolic diseases.

The Department of Health offers a multidisciplinary evaluation through its Early Intervention program. If a child has communication difficulties, and for other reasons, they may be referred to the EI program for an evaluation to determine if they may have ASD.

Cross Agency Collaboration

OPWDD has led a number of cross agency initiatives including the EmployAbility initiative (<https://opwdd.ny.gov/employability>), NY Connects (<https://www.nyconnects.ny.gov/>), and START (<https://opwdd.ny.gov/ny-start/home>). OPWDD partners with OMH in the implementation of the START crisis prevention model, which supports people with dual diagnoses of developmental disability and mental health needs. OPWDD's recent transition to People First Care Coordination (https://opwdd.ny.gov/opwdd_services_supports/care_coordination_organizations) is built on cross systems collaboration to meet the holistic needs of people we support including health, behavioral health, medical and wellness needs.

OPWDD and SED co-chaired the NYS Interagency Task Force on Autism with 10 other State agencies from the Spring of 2008 through December 2009. This Task Force identified needs and developed recommendations around the interagency coordination of supports and services to maximize supports and services for individuals with ASD and their families in NYS. The Task Force reviewed national research and over a dozen reports from other state task forces on autism and obtained public comment to gain a better understanding of NYS's needs regarding individuals with ASD. Several families were interviewed, over 3500 individuals completed an online survey and seven regional public discussions were held in which nearly 120 individuals participated.

In follow-up to the NYS Interagency Task Force on Autism and in collaboration with several State agencies, NYSED was involved in a public information campaign. In the Spring of 2010, a brochure was developed titled "Autism Spectrum Disorders-What Everyone Needs to Know"
(<http://www.p12.nysed.gov/specialed/autism/ASDbrochure.pdf>)

NYS OMH is actively partnering with OPWDD and State Education in order to plan and implement two pilot projects for children and adults. The projects will consist of specialized inpatient units and specialized step-down units. These services will be available to individuals who are eligible for OPWDD services and also carry a mental health diagnosis.

The State Education Department (SED) worked with the NYS Department of Health on developing two videos for parents on the Early Intervention Program and the Early Intervention Steps. These videos provide more information about the program, the services they provide and who is eligible for those services. SED is also:

- Partnering with The Department of Labor to collaborate with Autism Speaks which is an organization that advocates for individuals with autism. The partnership is aimed towards increasing staff awareness and overcoming barriers in order to provide improved services.
- A member on the Interagency Accessibility Workgroup in which agencies at the State level are working together to assist locally funded services with accessibility for participants.

DOH is engaged in a partnership with the OCFS to develop infant/toddler policies and practices. The partnership has five main goals centered on ensuring infants and toddlers as well as families and the workforce are supported.

Through its Hard-to-Place/Hard-to-Serve Unit, the Council on Family and Children's Services accepts referrals of individual children and youth with ASD and serious to severe behavioral issues where assistance is needed to obtain the most appropriate services, minimize delays in arranging services or placement and resolve barriers to obtaining timely service delivery or placement. To effectively serve the needs of these children and youth, Council staff work with principal stakeholders and system representatives to discern and resolve critical issues and coordinate the response. In almost all cases, this requires a cross-systems effort.

Research

OPWDD supports the Institute for Basic Research (IBR), a well-known diagnostic and research center located on Staten Island.

Highlights of IBR's research specific to Autism include:

- Neo-natal intensive care studies to improve early identification

- Development of The Pervasive Developmental Disability Behavior Inventory (PDDBI) tool (<https://opwdd.ny.gov/node/572>)
- A brain and tissue sample bank for studies involving prevention and treatment
- Animal behavior models to observe the impact of stressors
- Studies on the effect of excessive folic acid during pregnancy
- Studies on prenatal exposure to stress
- Studies on beta blocker to treat challenging behaviors

DOH is conducting an evaluation of its Early Intervention program and is utilizing National Core Indicators indices to gauge its effectiveness.

Appendix B:

Summary of Input from Upstate & Downstate Forums Held by the Autism Spectrum Disorders Advisory Board in February 2018

This appendix summarizes the themes of public comment heard at the Board’s public forums—one held downstate, and one held upstate—in the month of February, 2018. The forums were well-attended by individuals with ASD, parents, other family members, providers, advocates, medical and emergency professionals, and others who came together to share their opinions and insights into the work of the Board. Attendees at seven forum locations provided input and were asked to reflect on the following questions:

1. What is working in terms of services for people with ASD, and what models would you like to see more of?
2. What can be improved of in terms of government inter-agency coordination?
3. How can people with ASD be more accepted in their communities and in the workplace?
4. What is one legislative or regulatory change that you think could make a great, positive impact for people with ASD?

In addition, written comment was received and analyzed along with spoken testimony.

Summary of Themes from Public Comment

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.

Respondents suggested developing public education campaigns to build awareness and acceptance, as well as interactive approaches such as holding meetings where people with ASD and the broader community come together. These meetings could potentially include recreational content, or “demo” sessions highlighting products that may be of interest to those with ASD. It was suggested that early education in schools is key in preventing discrimination, and that encouragement and supports should be provided for kids with ASD to take part in the school day and extracurriculars. It was also suggested that the Advisory Board be strengthened by incorporating the input of people who themselves have ASD.

Training for professionals including doctors and first responders so they can effectively interact with and assist individuals with ASD in their official capacities.

Respondents noted the need for enhanced training, for businesses as well as the general public, educators and medical practitioners to ensure their awareness of ASD. Respondents widely agreed that there is a need for first responders, including police, firefighters, EMTs and disaster recovery workers to receive education and training to increase their understanding of ASD. Respondents noted that turnover of direct support staff necessitated training to counteract the loss of institutional knowledge, and suggested annual and ongoing training for frontline care providers to keep up on the “state of the art” in supporting people with ASD.

Community supports to help people with ASD participate in a range of life and community activities they enjoy and find meaningful.

Many respondents characterized the integration of appropriate supports into people’s lives as essential to overall potential for learning and growth. Suggestions in this area include supporting additional in-home supports as well as recreational programs to support the integration of kids with ASD, including those who are newly diagnosed. Access to community-based emergency healthcare appropriate for people with ASD was noted as a crucial support, and the linkage of appropriate supports and housing options was noted as pivotal in establishing long-lasting, successful living arrangements. A new speech therapy service offered by ACCES-VR offers opportunities to help individuals socialize and interview for employment.

Housing for people with ASD with support services to meet their needs in the community.

A number of respondents indicated a need to ensure individuals with ASD can access appropriate residential services and in-home support services, and that this is an area where substantial gaps in knowledge and services exist. Models proposed for housing options for people with ASD include those based on integrated living, intergenerational living, neighbor-supported living, and models used in serving the elderly.

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.

Respondents noted that, while sometimes difficult to obtain, employment opportunities for those with ASD offer empowerment and foster independence. The need to have appropriate support services while working was noted as an integral part of paid work opportunities, as well as volunteering or internships. Respondents noted a need for greater social skills training and the need to ensure kids with ASD can gain more skills before the end of high school. It was also noted that there is a need for more volunteer opportunities for those with ASD, and that training should be provided for community businesses employing or seeking to employ people with ASD.

Eligibility for services and how people with ASD gain access to supports.

Respondents noted several issues related to eligibility and access:

- There is inconsistency in access to a range of therapeutic programs based on county, insurance plan, and Medicaid eligibility
- Lack of Telehealth availability hinders/discourages changes in care that could be beneficial
- Access to supports after age 21 can lessen and young adults can have trouble finding employment or social connections
- A need for more of psychiatrists and ABA clinicians

Diagnostic funding to ensure appropriate diagnosis of ASD.

It was noted that private insurance and Medicaid may not pay for diagnostic testing for those who may have ASD, leaving the cost up to nonprofit providers or state government entities. Additionally, families reported needing assistance in navigating the system from diagnosis to identifying appropriate services at different stages of life.

Regulatory barriers that can be overcome to allow changes which improve the efficiency and function of the service system for people with ASD.

Respondents noted legislative and regulatory action would be needed to impact the following issues:

- Serving individuals with co-occurring mental health and ASD diagnoses
- Assisting more doctors to operate in New York State by relaxing medical practice regulations
- Developing better ways to fund comprehensive ASD evaluation and outpatient care
- Ensuring appropriate services can be provided in school settings

Cross agency coordination to synergize the efforts of the various state service systems that support people with ASD.

Many respondents noted a need for greater coordination between emergency services and other services people with ASD receive. Better coordination between OMH and OPWDD for those with behavioral health challenges as well as ASD was suggested to meet the needs of people with co-occurring disabilities, and training at OMH facilities on the co-morbidities associated with ASD was suggested. Greater coordination between local governments and school districts on Early Intervention and children's services were suggested, as was an interagency task force group to support the sharing of ideas. Some respondents called for improved case management services that could serve as a single point of contact for navigating multiple systems.

Collaboration on research so that the causes of ASD are better understood.

Respondents suggested continuing and increasing research into the causes and treatments for ASD, including on medical conditions associated with autism (e.g. epilepsy).

Exploring financial hardships faced by families of a child with ASD, including services not covered by insurance.

Families noted difficulties in obtaining certain services, such as housing and behavioral health services as well as respite services. Both efforts at linking individuals and families to resources available to them and enhancing resources where needed were suggested. Respondents suggest the Board advocate for insurance coverage for Applied Behavioral Analysis as well as for ongoing Speech, OT and PT services.

Appendix C:

**SELF-ADVOCATE FEEDBACK TO THE DRAFT RECOMMENDATIONS
of the Autism Spectrum Disorders Advisory Board**

Those noted below have done a service to the Autism Spectrum Disorders (ASD) Advisory Board and New York State by providing their feedback on the Board's draft recommendations. Their insights as self-advocates and individuals on the autism spectrum, as well as leaders within the broader community of thought and practice around ASD, lend the reader of this report the opportunity to better understand how the Board's recommendations relate to the needs and goals of people who have lived experience with ASD.

**Members of the Autism Spectrum Disorders Advisory Board
Self-Advocate Workgroup:**

Kristin Thatcher

Stephen Katz

Justin Robbins

Michael Gilberg

Mike Tripodi

Sean Culkin

Through the suggestions, opinions and personal experiences raised through the group's discussions, approaches and ideas that seek to promote acceptance and respect throughout society were surfaced. Foundational to these discussions was advocacy for establishing supports and services for autistic people which maximize pathways for personal growth and foster individual possibilities. Such possibilities include real and achievable goals for inclusion, relationships, and wellness.

The below high-level concepts were themes throughout the discussions and provide a framework for the empowerment of autistic people.

Independence & Relationships

One of life's greatest goals is independence, including living independently with the right supports and having personal autonomy to determine the course of one's own life. Relationships and friendships are a crucial part of life and people should be supported to attain social skills as well as skills for independent living and employment.

Adults & Children

Autistic children are featured prominently in many areas of research, service and publicity, however there is an equal need to support autistic people throughout their lifespans. Greater focus on adolescents, teens, adults and seniors with ASD can accomplish this.

Awareness & Acceptance

Society is strongest when the gifts and talents of all people are included, and when all people are treated with dignity and compassion. The acceptance of differences is key. Greater community outreach and support are needed to foster inclusive and supportive communities, as well as to ensure that autistic people know the resources available to them.

Neurotypical Values & Tolerance

One size fits all does not apply. While autistic people seek to succeed and prosper within the broader community, it is also the responsibility of the broader community to not impose unwanted views or actions on autistic people.

Self-Advocate Feedback:

Original Recommendation Text:

The Self-Advocate Workgroup generally supports the draft recommendations of the Board and offers the comments and suggestions contained on the next pages of this report.

A note about language

The recommendations of the Board are written using people-first language. The goal of people-first language is to put the person before the disability in a respectful manner, so instead of saying “Jim is non-verbal,” it would be “Jim communicates by...” With regard to ASD, people first language would describe someone as “having autism” or being a “person with an autism spectrum disorder” as opposed to saying “Jim is autistic” or “Jim is an autistic person”.

However, the self-advocate group requested that person-first language not be used in summarizing their responses, and suggested the use of “autistic people” throughout instead of “people with autism” in the recommendations. This is both for reasons of empowerment and taking ownership of the word, as well as wanting to avoid making autism sound like a disease as opposed to an identifier of an individuals’ personal identity.

The goal of respectful and accurate communication is the same in both considerations, by different rationales. This note is included to explain the inconsistency in language throughout the report.

Self-Advocate Feedback:

1. Enhance Communications to Raise Awareness and Combat Discrimination

- Autistic people need to be seen as part of the community so that myths and misunderstandings can be discarded. Openness is critical to building community.
- Awareness is passive; autistic people and others on the margins of society must be brought into its center. The need for acceptance is greater than the need for awareness. People do not want to be looked down on by others.
- Ensure additional outreach to women, people of color, and other underrepresented groups. Autism is sometimes inaccurately viewed as a condition not affecting diverse populations.
- There are common areas of difficulty associated with ASD such as needs for support with employment, executive functions, and social skills. But, there are also advantages to being on the spectrum to highlight including having great skills and much to offer community employers.
- Non-profit providers should be included in the awareness campaign as well as state agencies. Ensure that people on the spectrum with an appropriate background consult and lead in the effort. Priority should be placed on messages coming from people on the spectrum as it comes from the heart and will have greater meaning.
- Provide presentations in schools to children so they understand what disability is and are exposed to it so they will be more accepting. Hold community meetings where autistic and non-autistic people can get together to interact and get to know one another.
- Focus on individuals throughout their lifespans, not just children but also adolescents, teens, young adults, adults, and seniors.

Original Recommendation Text:

1. Enhance Communications to Raise Awareness and Combat Discrimination

New York State conducts ongoing campaigns designed to promote a greater understanding and awareness of disabilities to strengthen community acceptance and integration. Awareness campaigns such as OPWDD's recent *Welcome* initiative encourage people to get to know their neighbors and acquaintances with ASD, and a grant funded by the Department of Health and efforts of the State Education Department promote awareness of Early Intervention services for children.

The Board identified areas for improvement and opportunities for greater clarity among individuals, families, providers and the community at large. This includes the development of a Statewide awareness campaign highlighting people with ASD living and working in the community.

Self-Advocate Feedback:

2. Supporting People with ASD Living in the Community

- Make explicit the goal of helping autistic people to live as independently as possible and place focus on how to achieve independent living and employment.
- Focus on directing people through the options using a clear and concise process.
- Include groups such as Independent Living Centers and other parts of the autism community. It is very important to include resources available through community organizations as well as those provided through the State in the Road Map.
- Coordinate with not-for-profit organizations to provide information on affordable housing more specific to the needs of those on the spectrum.
- There should be vetting for NFPs linked into these efforts to ensure they are reputable.
- Include a listing of all relevant programs the State provides and consider a toll-free number to help people get information about services.
- Those with milder autism or who are diagnosed later in life may not be eligible for government services. It is important to raise awareness about the higher and lower ends of the autism spectrum.
- Autistic people may not be able to earn enough money independently to afford housing or qualify for employment supports.

Original Recommendation Text:

2. Supporting People with ASD Living in the Community

It is only natural that people with ASD be part of community life, just like anyone else. However, people with ASD sometimes have challenges related to their disability that can impact their ability to find appropriate living arrangements as well as find and maintain employment. State agencies offer assistance in finding needed services, such as OPWDD's Front Door process.

The Board recommends that New York State agencies, represented by members of the Board, develop an informational resource for individuals and families that lays out the service options offered by the various State agencies serving individuals with ASD. This should include a focus on housing and in-home support as well as employment. This "Autism Services Road Map" should help individuals and families understand the resources available to them and how to access them.

Self-Advocate Feedback:

3. Increasing Collaboration Between State Agencies

- Also include emergency management as a group to target, as well as other agencies involved in emergency response. Autistic people can behave differently than they normally would in tense, high risk situations and act a manner that may be confusing to first responders (e.g. become silent or otherwise behave in a way that may seem peculiar to police who do not recognize they have autism.) Having a card to provide first responders identifying their disability can help.
- Police and courts may be insensitive to the needs of autistic people if they do not understand the disability. Training should be geared to judges and prosecutors as well.
- Autistic people can sometimes find themselves accused with the worst assumed about them, even if they are a victim of crime. This reflects uneven prosecution of other marginalized groups as well.
- Groups to target for inclusion in this recommendation include State Fire, State EMS, local fire departments and ambulance corps.
- Previous trainings have been challenging to disseminate to these decentralized agencies so strategies should be developed to get information in the hands of first responders. This could be done by building it into the EMT curriculum. Autistic people should be part of the development process.
- Presentations to schools by autistic people can help younger people learn about autism and why someone with ASD might be in trouble and what can be done to help calm them.
- This recommendation should be broadened beyond children to include teens and adults.

Original Recommendation Text:

3. Increasing Collaboration Between State Agencies

The Board reviewed steps that have been taken to integrate services and how State agencies work together to solve common issues. However, it became clear through these discussions that there are still opportunities for greater cross-system collaboration, especially in serving those with atypical challenges and diagnoses. Two areas identified in need of attention were comprehensive care for children; and, first responder and emergency services.

The Board recommends that a short-term Inter-Agency Cross-Systems workgroup be created to identify strategies for collaboration among multiple service systems and policy solutions to streamline cooperation around two issues raised by the Board.

The workgroup should consider the following areas for improved cross-systems coordination: ensuring children with ASD served in the system are supported in a holistic way by multiple service systems so that they are served most effectively; and, ensuring coordinated and comprehensive awareness of ASD in the context of first responder and emergency services. The workgroup should issue a report of its findings including the strategies and policy solutions identified.

Self-Advocate Feedback:

4. Establishing Family Support Groups

- The goal should be to strengthen and support already established groups; to find gaps; and to establish groups where needed to fill those gaps.
- There are a number of resources in New York City and throughout the State for families, including existing family support groups supported by provider agencies and other organizations. To avoid duplication, it may be preferable to link to existing groups rather than establish new ones. The groups could help parents realize that there will be good and bad days, but to be realistic, and to keep going through struggles they may have.
- Parents are concerned with who their children will become and seeing adults with autism can help them realize that their children will be OK after they are grown. Success does not look the same for every person and autistic people can do and be anything non-autistic people can do, however it is important to not set expectations too high or too low.
- Autistic people should be included and welcomed in the family support groups. It may also be pertinent to establish clubs or other groups specifically inclusive of autistic people.
- Family support is an underutilized resource in special education. School districts should provide more in-depth training for parents and SED mandates for training should be revisited.
- Doctors should provide information to families—pamphlets, information on support groups, etc.—at the time an autism diagnosis is made. It is important the scientific, therapeutic and medical aspects be made known for parents raising a child on the spectrum. They should be informed about early intervention supports. Parents can find solace in each other and doctors can broaden the conversation.

Original Recommendation Text:

4. Establishing Family Support Groups

Families who learn their child has an ASD diagnosis can undergo a range of emotions, and the challenges resulting from a child's disability can place strain on a family. However, families of children with ASD have long found support in each other, and organizations supporting parents offer crucial assistance in children's early years.

To facilitate discussions and form bonds, the Board recommends linking to or establishing regional family support groups so that families have the chance to be part of an inclusive, positive and supportive group dedicated to reinforcing family and dealing with the challenges that an ASD diagnosis can pose. Individuals with ASD should be welcomed in these groups as well.

Self-Advocate Feedback:

5. Focus on Wellness By Supporting Proper Exercise and Nutrition

- With regard to nutrition, it was suggested that universities or YMCAs be consulted with to develop healthy diets for people based on their condition, and that not-for-profits be engaged in the overall effort.
- With regard to exercise, different options should be offered so people can choose what they like—yoga, Zumba, etc. It can be difficult to find a way to fund gym memberships.
- Autistic people may hesitate at participating in competitive sports or have concerns with bullying and prefer less competitive modes of exercise. Some people have an emotional response regarding physical fitness. There needs to be a way to help people overcome bad experiences with physical coordination.
- In addition to nutrition and exercise, teaching self-care to individuals with ASD is an important consideration. It can be difficult to establish healthy habits and a good routine. Hygiene, washing clothes, etc. are important to establishing good habits for self-care. The focus on hygiene should be increased.
- There was lack of consensus on if the program should only be offered online. In-person classes to train agencies on health, exercise, etc. could supplement this. The online program offers the best mode for distribution. The system should allow parents to sign up their kids and adults could sign up themselves to learn from each other.
- Autistic people may have issues with food textures and other sensory issues. A more integrated approach to health and wellness could be approached in a sensory-friendly way and could include other aspects such as executive function.

Original Recommendation Text:

5. Focus on Wellness By Supporting Proper Exercise and Nutrition

Good eating and exercise habits are important for all people to stay healthy, and the Board recognizes that this can take on special importance for people with ASD who can have challenges with dietary intake and exercise habits.

The Board recommends the creation of an wellness program available to individuals with ASD and other developmental disabilities, with specific focus on factors pertaining to ASD and developmental disability. The Board recommends that OPWDD consult with an expert who specializes in nutrition and disability services to develop the program, to be hosted on the OPWDD website.

Self-Advocate Feedback:

6. Better Support Telehealth Services Throughout New York State

- Anything that expands healthcare is a good thing. This should be broadened to also include adults as opposed to just children.
- Children with ASD's healthcare should be better integrated into their school program.
- Doctors should not diagnose remotely.
- There is a lack of awareness about telehealth and what it can do. Communities should be shown the benefits for autistic people.

Original Recommendation Text:

6. Better Support Telehealth Services Throughout New York State

Telehealth can remotely connect patients and healthcare providers, offering an important tool in facilitating access to health care as well as supporting comprehensive care and individual outcomes. Challenges have been identified regarding the adoption and delivery of telehealth services, including financial, statutory and regulatory barriers.

Governor Cuomo, in September 2017, signed a bill into law that expands the list of state-sanctioned delivery sites for telehealth to public, private and charter elementary and secondary schools, child care programs and day care centers. The legislation opens those programs to reimbursement from Medicaid and private payers.

The Board supports New York State in further taking a landmark step forward in February 2018 to expand access to telehealth services through a series of measures, including expanding the list of eligible originating sites so that patients can receive telehealth services in a wider range of settings, including their own homes. The Board supports State agency-specific regulatory changes to advance the use of telehealth services in New York.

Self-Advocate Feedback:

7. Study How Assistive Technology Can Be Utilized More Fully

- New technologies available are fantastic, however some may see their use as a limiter on a person. For example, someone who uses assistive technologies (AT) applying for a job may be seen as having an extra issue the employer may feel concerned about. Reducing stigma around use of AT is important to overcome this.
- AT should empower the individual but not to control them. AT can be used for both good and bad, and it is often situational. Consent of the individual is key.
- Many autistic people are nonverbal and use AT to communicate. Assistive Technologies (AT) need to be individualized and age appropriate. It is not one size fits all. Technology should be used appropriately so it is not replacing human interaction. Friendships and relationships cannot be replaced.
- Making AT available to police, fire and first responders will aid in disaster response. Someone who must leave their home rapidly may not have needed AT with them and disaster centers and emergency rooms could have spare, common forms of AT.
- While not everyone with ASD uses the Internet, there are benefits in all learning how to.
- AT should be widely available throughout the State and not limited to one location.
- It will be important for people to be able to personally try out or experience different types of AT through interactive exhibits at the Tech Summit.
- Locations outside of Albany or multiple locations should also be considered.

Original Recommendation Text:

7. Study How Assistive Technology Can Be Utilized More Fully

Individuals with ASD and people with other developmental disabilities can benefit from a greater integration of assistive technology. Smart home technology, for example, can assist with basic activities of daily living, perform repetitive tasks, answer simple questions, and help provide monitoring to supplement staff and allow for more independent living. Discussion of the Board focused on the greater need for assistive technology to serve people in the least restrictive environments.

Advances in assistive technology over the past decades have been amazing in their rapid progress. The Board recommends convening a “Tech Summit” with a university sponsor focused on highlighting the opportunities offered by assistive technology and the gains in assistive technology research. The Tech Summit will cover assistive technology that can benefit individuals with ASD, as well as other developmental disabilities.

The Tech Summit should include a range of guest experts and open registration for admission to the public. The Summit should place a strong focus on innovative technologies (such as smart homes), including phone apps specifically geared to people with ASD.

8. Increasing the Number of Clinical Professionals Serving Individuals with ASD

- Support for Applied Behavioral Analysis (ABA) was voiced by some participants, including one who is a certified ABA therapist. ABA is a reward system for doing things correctly (e.g. preparing a meal.)
- ABA is a good thing as long it is done ethical manner.
- Other therapies should also be included. Suggestions:
 - VB ([Verbal Behavior](#)) which uses the same principals as ABA to teach language skills
 - [DIR/Floortime](#) and [SON RISE](#) (other less invasive behavior therapies) for children
 - [CBT \(Cognitive Behavioral Therapy\)](#) and DBT (Dialectical Behavioral Therapy) for adults²

Continued on the next page...

8. Increasing the Number of Clinical Professionals Serving Individuals with ASD

Governor Andrew M. Cuomo signed a law in 2014 which established a new state license for providers of applied behavior analysis¹ (ABA) services to individuals with autism spectrum disorder. The law established education, examination, and experience requirements, and restricted activities that may only be provided by Licensed Behavior Analysts (LBA) and Certified Behavior Analyst Assistants (CBAA). The law helps to ensure that individuals and families can access quality ABA providers while also ensuring State regulation and continuing oversight of these providers.

An issue identified by the Board was the growing demand for more ABA-licensed and certified providers capable of serving individuals with a range of Autism Spectrum Disorders. The Board recommends that a targeted communications campaign be developed to be shared with colleges and universities offering psychology and related programs. This campaign, directed toward aspiring clinicians, would be focused on helping students learn about ABA as an exciting career path.

The larger context of other therapies available to individuals with ASD should also be reviewed to identify strategies that can encourage the further development of professionals in other clinical specialties serving people with ASD.

² CBT is a psycho-social intervention that is the most widely used evidence-based practice for improving mental health. Guided by empirical research, CBT focuses on the development of personal coping strategies that target solving current problems and changing unhelpful patterns in cognitions (e.g. thoughts, beliefs, and attitudes), behaviors, and emotional regulation. It was originally designed to treat depression, and is now used for a number of mental health conditions. CBT and its cousin DBT have been successfully used with adults on the spectrum to help develop coping mechanisms for maladaptive thinking and resolve practical issues.

8. Increasing the Number of Clinical Professionals Serving Individuals with ASD (self-advocate feedback continued)

- Concerns were raised regarding the misapplication of ABA therapy and other sometimes damaging methods being termed as ABA however having no clinical value.
- There was one opinion that the goals of ABA, even when applied therapeutically, may not be consistent with the goals of the autistic individual and instead be used as a method of control. On the other hand, it was noted that ABA can help people to learn a variety of skills and has been found to be of benefit by other participants.
- The notion that autistic people must be “fixed” was found to be insulting and potentially leading to ostracization and segregation. “Normal” is an artificial concept.
- There should be safeguards in place to ensure that people are treated properly and ethically with their well-being as the first concern. Those with intellectual impairment and those who are nonverbal should be safeguarded against improper therapies.
- Certain behaviors (flapping hands) should simply be tolerated by society and the general public. Other behaviors that are harmful to the person obviously need to be addressed.
- Increasing the level of services for autistic people is important as the population grows. Schools and colleges should be part of providing these services as well.
- Related: the practice of organ discrimination against disabled people should be ended.

The below guiding values were written by one of the self-advocate participants.

1. The goal of all therapies should be to the benefit of the autistic individual, not the associated neurotypical people.
2. Physical contact from others without informed consent by the autistic person is unacceptable unless there is an imminent or ongoing threat of physical harm.
3. All therapeutic effort should be towards providing the autistic person the skills to survive and thrive in an overwhelmingly neurotypical world.
4. All therapists should be taught about the social model of disability, neurodiversity, and the history of the disability rights movement. Therapies should be rooted in the social model.
5. All efforts must be made so that the autistic person receiving therapy can communicate their needs and wants and be understood.

Self-Advocate Feedback:

9. Engage Cutting-Edge Research Around ASD

Focus Areas: Training for Professionals, Collaboration on Research

- Greater focus should be placed on research that expressly focuses on improving quality of life for autistic people. Research based on genetics and chemistry has value but autistic people need different help to live their lives.
- There is a lack of research on girls and women on the spectrum and this leads to under-diagnosis or misdiagnosis. ASD can manifest in girls and women in different ways than men. It is crucial that more women be included in research.
- A great deal of research is done on children, however more research is needed for adolescents, teens, adults and seniors for a continuum of learning throughout the lifespan.
- There is a good deal of research about workplace, however more needs to be done regarding community living.
- Assembling a research bank is a large task and involves curating dense and technical papers etc. To compile and put this information in a format accessible to non-scientists will be a very significant effort.
- Some individuals do not have the Internet so the Resource Bank should also be available through libraries. Individuals and parents can have difficulty finding information on their disability, which adds to confusion and can impact self-esteem.
- There are levels of agreement/disagreement on what is good versus bad research (e.g. around ABA,) and this complicates the task. There must be checks in place to make sure the research is legitimate and not junk science (e.g. the false claim that vaccines cause ASD).

Original Recommendation Text:

9. Engage Cutting-Edge Research Around ASD

There has been a great deal of research into Autism Spectrum Disorders, however disseminating and digesting this information is a challenge. Recent findings offer hope and provide concrete takeaways, such as the benefits of parent participation in early intervention for autism. This research also offers insights into the early predictors of autism as well as many other topics.

To help individuals and families access information available about ASD, the Board proposes creating a "Research Bank". The Research Bank will feature resources from leading scientific journals and research institutions focused on ASD issues, such as the New York State Institute for Basic Research. The research bank will highlight evidence-based interventions and treatment proven to be helpful for people with ASD, to provide objective information so individuals and families can make informed choices. The information should be structured in an easy to understand format for use by non-professionals as well as professionals.

Self-Advocate Feedback:

10. Review the Impact of NYSTART In-Home Supports for Individuals with ASD

- There was support for the paradigm of START being focused on the needs of the individual first and its emphasis on prevention so it is not just dealing with crises.
- Education to prevent and avoid crises is essential, including educating families, the community and first responders including police.
- Self-direction as an individualized model can help meet people's specific needs and be tailored to those needs in such a way that they can help before a crisis and put in place supports to prevent or address crises.
- One member who is a first responder did not realize START exists and more should be done to get information on the program to the public. There are many instances where fire, ambulance or police departments are dispatched to address the needs of an Emotionally Disturbed Person (EDP) where the person has no real issue but needs to be calmed down. In these instances, START may be a more appropriate resource either for prevention or crisis response.
- Community paramedicine is a similar program that deals with health concerns as opposed to behavioral health. In this model, a paramedic or other medical professional can be dispatched to the location of a person in need to avoid using the emergency system.
- An adequate level of awareness could possibly be achieved if each criminal justice or emergency system first responder was trained on issues impacting autistic people annually. Medical professionals tend to be more well-informed than other first responders.

Original Recommendation Text:

10. Review the Impact of NYSTART In-Home Supports for Individuals with ASD

Focus Area: Community Supports

NYSTART is a community-based program that provides crisis prevention and response services to individuals with intellectual and developmental disabilities who present with complex behavioral and mental health needs. The service assists their families and others in the community who provide support when short-term crisis response is needed.

The NYSTART program offers training, consultation, therapeutic services and technical assistance to enhance the ability of the community to support eligible individuals and focuses on establishing integrated services with providers. Providing supports that help individuals to remain in their home or community placement is NYSTART's first priority. NYSTART is in the process of being implemented statewide.

NYSTART is available to individuals with many types of developmental disabilities who have co-occurring behavioral health needs. As it reaches full implementation, the Board recommends an in-depth analysis of NYSTART to ensure that individuals with ASD who are accessing NYSTART services are receiving effective at-home support. The review should consider the experiences of those served by the program in making this determination.

In addition to discussion of the recommendations, there was discussion of housing, employment and education.

Self-Advocate Feedback on Housing

- The goal and underlying ethos should be for people to live as independently as possible and build skills to enable them to do so.
- Many autistic people live independently however may be underemployed. Or, they may not have the independent living skills to live on their own and need something more intensive. Some people may not qualify for OPWDD services.
- The following discussion of college housing contains many key points generalizable to broader community life:
 - For individuals who go to college, living in a dorm can be a struggle (e.g. trouble with keeping a regimented schedule.) Having services and supports, such as independent apartments for people with disabilities, next to a college with wraparound supports was noted as a solution. Additionally, colleges could hold classes on life skills all could benefit from (e.g. doing laundry).
 - Autistic people should not be separated from the public and should be able to belong to the college environment. It should be integrated so people can learn from each other as part of the community around the college.
 - Autistic people may have different needs so it was suggested housing projects need to be more focused than generally for people with disabilities. There are entities that wish to fund housing for autistic people who may back off if it is opened to all people with disabilities. While participants voiced strong support for integrated, community-based housing, an opinion was also voiced that ASD-only housing was demanded by some who prefer communal living and should be available as an option. Some such programs currently exist.
 - In response to the last point, an alternative viewpoint was offered. One participant who attended a boarding school for kids with ASD said it was a shock when he left school and had no idea how to function in the neurotypical world, including socializing with other children and living in New York City. While some people may need isolation with other people on the spectrum, college is a time to live with and be with diverse people.
- In New York City there are a lot of resources but there is not one place to go for information on them.

Self-Advocate Feedback on Employment

- Finding employment can be difficult for autistic people. It is important to teach and prove to companies that people with disabilities of all kinds have the skills to do jobs in the world of competitive employment better than other people. Sometimes people are not given a chance and it is important to teach companies the value of people with disabilities as employees. Having the right supports in place can show employers what people with disabilities are capable of as employees.
- Autistic people need to be able to access training for employment skills as well as soft skills to prepare them for the future. Self-direction of services allows some people to choose a provider to work toward their employment goals in an individualized way. However, not all people are eligible for this support (through the OPWDD waiver) because they may not have cognitive impairment sufficient to justify eligibility for OPWDD waiver services.
- Hiring autistic people should not be seen as charitable but rather a smart business practice.
- Sub-minimum wage should be phased out to ensure all people are paid a fair wage.
- Community meetings should be scheduled to discuss and spread awareness, combat discrimination and gain greater acceptance.
- It is crucial that staff working to support the employment goals of autistic people listen to the person and gain a deep understanding of their goals. Support staff should support people to plan a way to achieve their goal while realistically explaining the barriers and what it would take to overcome them so people can make informed choices of how to proceed.
- Reasonable accommodations must be made by employers, but there are also factors affecting everyone (e.g. appropriateness of resume) which impact autistic people as well. Job seekers must be reasonable in terms of what jobs they apply for and should be educated to seek employment based on their skills and abilities.
- Coordination is needed between agencies so that if someone is receiving OPWDD supported employment they do not lose their social security Ticket to Work inadvertently, as well as better coordination with ACCES-VR.

Self-Advocate Feedback on Education

- Many parents of kids under 21 do not know what services are available to them that school districts will pay for. Parents with fewer personal financial resources are less likely to take proactive steps.
- Some parents do not want their kids to receive services which can put them at a disadvantage. Parents should be counseled on the importance of getting needed services for their children. Self-advocates could speak with parents.

Self-Advocate Feedback:

Original Recommendation Text:

- A better system is needed to refer children aging out of the school system at age 21 to other service-providing agencies so there is no interruption of services. Parents and students are often unaware of these opportunities. The goal of this transition should be to help the person determine their range of goals and the direction they want to work toward, with support put in place to support those goals and ambitions.
- There are concerns regarding bullying and schools should work to better protect students with ASD.