



Office for People With Developmental Disabilities



Report to the Governor and the New York State Legislature

Regarding Recommendations of the Autism Spectrum Disorders Advisory Board

Courtney Burke, Chairperson

6/15/2021

June 15, 2021

Dear Friends and Colleagues,

In May of 2019, the Autism Spectrum Advisory Board (the Board) released a series of recommendations identifying ways for New York State to enhance autism supports and improve people's lives. Since the release of the report, Board members have held five meetings to discuss the State's progress toward achieving the Board's previous recommendations, advanced three new ones, and participated in a conversation with leadership from the Office for People With Developmental Disabilities (OPWDD) to discuss the Agency's response to the ongoing COVID-19 pandemic.

The Board's work was informed by presentations from experts on topics such as how technology can be leveraged to achieve greater independence, state agency initiatives to reach diverse communities, the challenges to recruiting Applied Behavior Analysis specialists in New York, the benefits of family support groups, and SUNY Empire College's efforts to create programs and foster an atmosphere accessible to and accepting of students on the Autism Spectrum.

This report represents nearly two years of work and builds on the original report released in May 2019. The document describes a new law directing the Board to identify strategies and methods of improving outreach and coordination of services for minority groups and highlight's the state's current efforts in that area, discusses progress in advancing the Board's first 10 recommendations, and adds three important new recommendations on actions New York can take to improve residents' lives. The Board has identified new issues to explore in the future, including research and available data on incarceration rates of individuals with Autism, continuing to find ways to reduce disparities in care, the impact of COVID-19 on education and social well-being, and connecting more people with Autism with the supports and service they need.

I am proud of the Board's work and its efforts to help spotlight issues of specific importance to the Autism community. I am also pleased with the strides made to ensure the meetings are accessible to the public. A number of self-advocates have been contributing greatly to the Board's work, and the webcast meetings are now accessible to those who utilize closed captioning and American Sign Language and are available for translation in multiple languages.

The work of the Board to improve the lives of New Yorkers living with Autism is 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 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 (ASD) diagnosis, and families seeking reliable information regarding available services and supports.

The members were originally tasked with several important duties including: studying and reviewing the effectiveness of supports and services currently being provided to people diagnosed with ASDs; identifying legislative and regulatory activity which may be required to improve existing service systems that support people diagnosed with ASDs; identifying methods of improving interagency coordination of services and agency functions; and other matters as deemed appropriate by the Board.

In 2018, Governor Cuomo signed into law Chapter 227 of 2018 which expanded the responsibilities of the Autism Spectrum Advisory Board to include a requirement to identify strategies and methods of improving outreach and coordination of services for minority groups including African American, Latino, and Asian children. This report is the first issued since the Board was assigned this important new duty.

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NEW YORK STATE'S EFFORTS TO IMPROVE OUTREACH AND COORDINATION OF SERVICES FOR MINORITY GROUPS

In 2018, a new law was enacted requiring the New York State Autism Spectrum Advisory Board to identify strategies and methods of improving outreach and coordination of services for minority groups including African American, Latino, and Asian children. To help inform the discussion, a presentation titled “Cultural and Linguistic Competence in the Developmental Disabilities System, highlighting New York’s ongoing efforts to improve outreach and coordination of services to minority groups, was delivered by representatives of the Office for People with Developmental Disabilities (OPWDD) and the Developmental Disabilities Planning Council (DDPC) during the August 2019 Board meeting.

The importance of the Board’s new charge is clear, as New York is one of the largest and most culturally diverse states in the nation. More than 40 percent of New Yorkers identify as African American, Latino, Asian, or Native American (U.S. Census Bureau, 2015). Given New York’s diversity, there is a clear need to enhance our intellectual and developmental disabilities (I/DD) system’s ability to provide quality, culturally competent, and linguistically accessible services and supports to individuals with I/DD and their families.

In New York City alone, more than 36 percent of the population is foreign-born, the highest percentage in nearly a century (The Newest New Yorkers, 2000). Similarly, New York State has an estimated 2.5 million individuals with Limited English Proficiency (LEP) (LEP; 5-Year American Community Survey, 2010-2015), ranking New York third in the nation for LEP population (Zong & Batalova, 2015). Within this population, Spanish and Chinese are the most widely spoken languages (U.S. Census Bureau, 2015).

Although research is limited for LEP individuals with I/DD, available research has revealed disparities in many areas for people with LEP and I/DD. These areas include health, education, employment, and housing. For example, students with LEP who have disabilities have among the lowest graduation rates in New York, and research has pointed to disproportionate representation patterns in diagnosing these students with intellectual disabilities (NYSED Graduation Rate Data, 2016-17). These identified disparities demonstrate both a need for focused work in cultural and linguistic competence and an opportunity to build a robust capacity within New York to meet the cultural competency and language access needs of individuals with I/DD and their families.

A Collaborative Approach to Diversity and Inclusion in the I/DD System

To address the need for greater cultural and linguistic competency in the I/DD system, OPWDD is embarking on a multi-faceted initiative. In response to Governor Andrew Cuomo’s Executive Order 187, a strategic plan will be submitted with four goal areas:

- 1: Develop Strategic Leaders
- 2: Recruit and Retain a Talented Workforce,
- 3: Foster an Inclusive Workplace Culture
- 4: Deliver Effective Programs and Services

The plan, now under final executive review, includes a four-year timeline and measurable outcomes for the agency and the larger I/DD system, to promote inclusion and equity.

National Community of Practice on Cultural and Linguistic Competence

OPWDD is part of a nationwide Community of Practice (CoP) on Cultural and Linguistic Competence (CLC) in Developmental Disabilities. The five-year collaborative project, which began in 2017, is sponsored by Georgetown University and involves nine other states. The New York State CoP includes: The Developmental Disabilities Planning Council (DDPC), Disability Rights New York, The Chinese American Planning Council, Ibero-American Action League, The Strong Center for Developmental Disabilities UCEDD, The Rose F. Kennedy UCEDD, The Westchester Institute for Human Development UCEDD, and OPWDD.

New York State CoP members are dedicated to working collaboratively to provide culturally and linguistically diverse communities with better access to and information about the developmental disabilities network and I/DD services in New York State. Its strategy is three-fold and focuses on Spanish-speaking and Chinese American communities in New York State, with a goal of providing a better understanding of the I/DD service delivery system, and individual rights. A series of focus groups conducted by the CoP in 2018-19 identified the following priorities: a need for more engagement of communities with LEP, a need for more basic informational resources, and a need to address language access barriers.

Members of the CoP engaged in multiple activities following the needs assessment to begin addressing recommendations.

- Presentations were given at the Association of University Centers on Disabilities (AUCD) Conference in November 2019 and at a Peer Learning and Exchange Forum on “Disability Training for Interpreters - A Program of Special Significance” in December 2019.
- Trainings on “Diversity and Cultural Competence”, as well as “Linguistic Competency”, were conducted by team members to more than 400 participants for one of New York’s I/DD Health Homes in 2019 and 2020. Training on “Linguistic Competency” was also given to nearly 600 participants of a Regional Centers For Workforce Transformation event in 2020.
- Additionally, through regular peer exchange meetings with the larger CoP, NYS participants continue to support the initiatives launched within each of the represented organizations.

Language Access

In support of Governor Cuomo’s 2011 Executive Order 26 for language access services, OPWDD’s program of interpretation and translation services used video remote options to overcome challenges of the COVID-19 pandemic. In June 2020, OPWDD changed most

of its vendors, including vendors for telephonic interpretation and video remote interpretation. Video remote also proved helpful with American Sign Language interpretation, where there has been a significant geographic shortage of interpreters. Due to advancements made during COVID-19, overall translation and interpretation figures were lower than in 2019. In outreach to LEP individuals and families, OPWDD began tracking numbers of people served in Front Door sessions, with 247 people served in Spanish, Mandarin, Bengali, Polish, Arabic and Russian.

New Grant Funding Focuses on Outreach and Access to Services

In 2020, the DDPC and OPWDD reached agreement on a two-year, \$400,000 grant to be implemented by OPWDD. In January 2021, OPWDD will use grant funding to engage Community-Based Organizations (CBOs) and/or multicultural agencies to enhance the cultural and linguistic competency of informational materials about the OPWDD Front Door while increasing service authorization access and addressing cultural and linguistic barriers.

The grant activities will include subcontracting with CBOs supporting people with I/DD from the Spanish-speaking and Chinese American communities, reviewing Front Door informational materials for cultural and linguistic competence, modifying or creating new materials with grant funds, and creating a dissemination plan. All activities will be evaluated for short- and long-term progress and to expand best practices to address outreach to other language and cultural groups.

Ramirez June Developmental Disabilities Navigator Initiative

In August 2020, the New York State Office for New Americans (ONA) marked the first year of implementation of the Ramirez June Developmental Disabilities Navigator Initiative. This initiative, the first of its kind in the nation, is supporting immigrants with I/DD and their families by connecting them with service providers across the state, helping them to overcome challenges that may hinder their ability to thrive in the Empire State.

During the first year of the Ramirez June Initiative, the ONA Developmental Disabilities Navigator organized in-person and online trainings for participants who faced linguistic and cultural barriers accessing disability-related services. As a result of the Ramirez June Initiative trainings, 195 new Americans and NYS service providers reported they feel better able to support, and help others support, individuals with I/DD. The trainings were hosted by ONA's community partners, with support from OPWDD, and provided for interpretation in Mandarin, Spanish, and American Sign Language. The Ramirez June Initiative also created, translated, and distributed resources on topics such as disability services in New York State and the 2020 Census.

This three-year initiative, which started July 1st, 2019, is funded by a grant from the DDPC and led by ONA. Over the next two years, the Ramirez June Initiative will continue to grow and address the specific needs of new Americans with I/DD and their families in partnership with other state agencies and CBOs.

New Recommendations of the Autism Spectrum Advisory Board

The previous report listed ten recommendations that remain relevant. The Board added three new recommendations in 2021.

11. New York’s Citizen Preparedness Corps training for residents should include information specific for people with developmental disabilities.

New York’s Citizen Preparedness Corps gives residents the tools and resources to prepare for any type of disaster, respond accordingly and recover as quickly as possible to pre-disaster conditions. The Citizen Preparedness Corps training began in February 2014 and are led by the New York National Guard, working with experts from the Division of Homeland Security and Emergency Services’ Office of Emergency Management and Office of Fire Prevention and Control. The training course provides an introduction to responding to a natural or man-made disaster. Participants are advised on how to properly prepare for any disaster, including developing a family emergency plan and stocking up on emergency supplies. It is important that individuals with intellectual and developmental disabilities and their families be prepared to address their unique needs in the event of a disaster.

12. The New York State Autism Spectrum Disorders Board recommends that New York State agencies take concrete steps to ensure that policy decisions include consideration of equal access to services for all New Yorkers. To help further this goal, agency leaders should establish decision-making processes that solicit input from stakeholders representing service recipients from communities of color that lack equitable access to services.

Increasing access to services for all New Yorkers is a goal that would be addressed through continued outreach to impacted communities and through engagement. Initiatives focused on language access, cultural competence, and information sharing, all strive toward the same end - building lasting relationships with stakeholders and fostering an accessible, effective, and equitable system.

13. The New York State Autism Spectrum Disorders Board recommends that New York State agencies review their service delivery systems to determine if services are being delivered in an equitable manner and inform the public of the results. Wherever data indicates an inequitable distribution of services exist, agencies should review relevant policies and procedures with the goal of improving access to services for underserved and marginalized communities.

Governor Andrew Cuomo’s Executive Order 187 underscores New York State’s commitment to “a culture of respect that values and promotes diversity, inclusion and equal opportunity” for all. To put this commitment into practice, OPWDD drafted a strategic plan, now under executive review, with four goal areas: Develop Strategic Leaders, Recruit and Retain a Talented Workforce, Foster an Inclusive Workplace Culture, and Deliver Effective Programs and Services. Data and tracking will be used to secure funding, measure progress, and continually set the course for important projects like the



Ramirez June Navigator Initiative and OPWDD Language Access services. Stakeholder involvement allows for ongoing review and feedback to ensure equal access, and equitable distribution of services.

Action on Previous Recommendations of the Autism Spectrum Advisory Board

1. Enhance Communications to Raise Awareness and Combat Discrimination

Focus Areas: Awareness and Acceptance of ASDs, 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 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 broad effort includes the development of a statewide awareness campaign highlighting people with ASD living and working in the community.

State Action on Recommendation:

The New York State Office for People With Developmental Disabilities (OPWDD) sought to implement the Board's recommendation. While actions for 2020 were limited due to the Agency's comprehensive response to the COVID-19 health emergency, 2019 was productive as OPWDD conducted three extensive public awareness campaigns aimed at educating the community about developmental disabilities, the unique abilities of people on the Autism spectrum and the importance of acceptance and full inclusion.

- In March 2019, the One of A Kind campaign used media, website and social media to showcase the abilities, talents and contributions of 31 New Yorkers who have autism and other developmental disabilities.
- In April 2019, in honor of Autism Awareness Month, OPWDD shined a spotlight on Autism, interspersing facts and personal stories on the website and in social media. The Spotlight on Autism campaign was featured in a large, multi-panel exhibit in the Marine Air Terminal Rotunda at LaGuardia airport in NYC.
- In September 2019, as OPWDD's presence at the New York State Fair that more than 1.2 million people attended, the agency invited fairgoers and the general public to tell us what their superpower is, in recognition that everyone has strengths and abilities.

OPWDD will continue implementing statewide public awareness campaigns of various themes to raise awareness and acceptance of ASDs throughout the year.

OPWDD Website Redesign

OPWDD launched a newly redesigned website at opwdd.ny.gov in March 2020, with a great deal of input from families, advocates and stakeholders. The new website better addresses the needs of the people supported by OPWDD, their families, providers, and the general public. It is mobile responsive and features improved design and navigation. What's more, the ny.gov platform features built-in accessibility features that make it easier for people with disabilities to navigate the site.

Use of New List Serve GovDelivery to Enhance Communication and Messaging

In May 2020, OPWDD began using a new list serve, GovDelivery, to communicate with individuals with developmental disabilities, their families, providers and other stakeholders. GovDelivery is a communications platform for the public sector that enables OPWDD to reach and engage with more people than ever, which was vitally important during the public health emergency. While we have already begun to grow our list of subscribers, we encourage more people to sign up for OPWDD updates here:

<https://public.govdelivery.com/accounts/NYOPWDD/signup/15127>

Autism Awareness Month Campaign

During the month of April 2020, which is Autism Awareness Month, OPWDD used social media outlets to ask others to show their support of the Light It Up Blue campaign for autism awareness by encouraging people who are staying safe and staying home during the COVID-19 public health emergency to share a photo of themselves wearing blue or creating a drawing of something blue and hanging it in their windows. OPWDD encouraged people to post their pictures on social media with #LightItUpBlue hashtag and tag @nysopwdd. In addition, posts by OPWDD throughout the month provided information about progress being made in testing, the importance of earlier diagnosis, increased awareness and advocacy. The campaign also supported Autism Speaks' Year of Kindness, and asked others to write or record a video of a kind and uplifting message to their followers on social media and tag and nominate three friends to post kind messages of their own.

Developmental Disabilities Awareness Month Campaign

Throughout March 2020, which is Developmental Disabilities Awareness Month, OPWDD used social media to highlight examples of how people with developmental disabilities have been assimilated into their communities through membership, employment, volunteerism and participation under the theme Invest in Inclusion. The agency also highlighted how everyone benefits from investing in people with developmental disabilities who make many important contributions to their communities. Seniors and officials at Carmel High School in Putnam County were featured for their autism-friendly 'silent' graduation ceremony in support of a classmate who has autism and is hypersensitive to loud noises. Also recognized were Fort Stanwix National Park (employing people with disabilities), Long Island village of Center Moriches (naming entrepreneur Keith Caputo Man of the Year), Clifton Parks Halfmoon Emergency Medical Corp (partnering with

volunteers from Lifesong), Shotts Gym and former professional boxer and Albany policeman Javier Martinez (mentoring people from Wildwood agency in the sport of boxing) and major retail chains such as Tommy Hilfiger, Nike, Kohl and Target (offering clothing specially adapted for people with special needs and including models with disabilities at the premier New York Fashion Week).

Plain Language Material

During the COVID-19 public health emergency, the need to communicate and speak more plainly with people supported by OPWDD and their families became readily apparent. OPWDD created plain language material (<https://opwdd.ny.gov/coronavirus-guidance/covid-19-plain-language>) to help the people they support and their families understand how to prevent the spread of COVID-19. OPWDD is working closely with the Self-Advocacy Association of New York State (SANYS) on the creation of other plain language materials as New York State reopens.

Americans with Disabilities Act

July 2020 marked the 30th anniversary of the landmark Americans with Disabilities Act (ADA), the world's first comprehensive law that guaranteed equal rights to people with disabilities, prohibited discrimination against them, and promoted accessibility to jobs, schools, transportation, communication and all public and private places that are open to the general public. To emphasize the importance of the ADA and celebrate how it has changed the lives of Americans with disabilities in a very positive way, OPWDD launched the social media campaign, "ADA30: It's Personal" which features personal stories about how the ADA has affected the lives of people with developmental disabilities in New York State. Lieutenant Governor Kathy Hochul joined members of SANYS for a conference call to hear firsthand from people impacted by the ADA.

1. 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. 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.

State Action on Recommendation:

OPWDD recently updated the Front Door Access Services guide to help people obtain needed services, including residential and in-home supports, as well as employment supports.

The New York State Education Department's ACCES-VR program provides pre-employment transition services (Pre-ETS) to students with disabilities, including students with an ASD, to assist them with an early start at career exploration and preparation for future employment. Pre-ETS include job exploration counseling, work-based learning experiences both in-school or after school, counseling on opportunities for enrollment in comprehensive transition or postsecondary education programs, work readiness training to develop social skills and independent living, and instruction in self advocacy.

Students with disabilities who are eligible for ACCES-VR services have been receiving Pre-ETS since 2019. In January 2020, ACCES-VR expanded its offering of these services to students with disabilities who are potentially eligible for ACCES-VR but have not yet been determined eligible, thus increasing the number of students receiving Pre-ETS and assisting them to develop skills to support their future employment.

OPWDD continues to utilize toolkits created in March 2019 for transition coordinators to provide to families of students who are preparing to graduate, as well as to school administrators and guidance counselors. This toolkit provides information and resources that will guide students and families in all areas of support they may need as they transition from school to adulthood. The toolkit is also available on OPWDD's website at <https://opwdd.ny.gov/community-involvement/school-transition-students-developmental-disabilities>.

Employment is an important part of the transition from childhood to adulthood, and OPWDD continues to work with local businesses and agency partners to promote greater opportunities for people with disabilities to be employed. The EmployAbility toolkit, created by OPWDD in conjunction with the Employment First Commission and available on the OPWDD website, has been updated. Businesses are also challenged to demonstrate their support by signing the EmployAbility Pledge, committing to being inclusive in their hiring and business practices.

OPWDD works closely with Governor Cuomo's Employment First Commission to make competitive, integrated employment the first option when considering supports.

- New York Employment Services System (NYESS) has made groundbreaking strides in helping individuals with disabilities to achieve successful employment outcomes through the Social Security Administration's Ticket to Work program. Through extensive work with SSA, NYESS has made key administrative changes to how the "ticket" of an individual is used in New York. Providers can work collaboratively with an individual to achieve an employment outcome financially beneficial to all parties. Services that do not achieve measurable outcomes are not rewarded. As a result, NYESS and its network of providers are now serving more

SSA beneficiaries and creating more employment outcomes than any other employment network in the country. There are a number of Customer Resources available to assist job seekers; a summary can be found on the NYESS website. (NYESS is a computer-based, cross-agency, case management application for tracking vocational services to individuals and can be an important resource in job development.)

- The Work Incentives Navigator (WIN) sends automatic notifications about benefits to individuals with disabilities who are receiving employment supports in New York and to the organizations that serve them. Providers access these notifications through a secure portal in the New York Employment Services System (NYESS). This portal has been created so organizations can assist individuals to take advantage of their programs. NYESS has developed notifications for several critical benefits, including the Medicaid Buy-In for Working People with Disabilities, Section 1619(b) and Section 301 of the Social Security Act, and the Earned Income Tax Credit (EITC). The WIN portal will be updated as new notifications are developed for additional benefit types. Additional information can be found at: <http://www.nyess.ny.gov/>

Another initiative is Chapter 542 of the Laws of 2019 which partially addresses the Board's recommendation for an Autism Services Roadmap. The law requires OPWDD to post information on the agency website regarding the process for individuals to obtain eligibility for services and to seek access to services, including, but not limited to, residential, respite, employment, habilitation, and self-directed services. This information can be found at: <https://opwdd.ny.gov/get-started>.

2. 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.

State Action on Recommendation:

OMH and OPWDD are currently collaborating on a number of initiatives and pilot programs designed to address the needs of people who require supports from more than one system. These efforts at cross-systems coordination are yielding some positive results for New Yorkers.

In the Buffalo and Syracuse area, OMH and OPWDD are developing inpatient psychiatric units with specialty care for treating individuals with co-existing mental health and intellectual/developmental disabilities such as ASD. These units will have enhanced staffing, including board certified behavioral analysts, speech and language services, and occupational therapy and be based in a behavioral model which can be taught and communicated at the next level of care.

OMH, OPWDD, and the New York State Department of Education (SED) collaborated with Our Lady of Victory Residential Treatment Facility Intensive Treatment Program in Buffalo to create an innovative, short-term residential program with an educational component serving youth ages 12-21 who are dually diagnosed with developmental disabilities and a psychiatric illness. The program has been operating since 2018. OPWDD continues to participate in a cross-system collaborative task force with OMH, OCFS, and SED, to identify and design future initiatives.

OPWDD recently announced the opening of a new specialty mental health extended treatment unit (ETU) on the grounds of the former Bernard Fineson Developmental Center in Queens. The ETU will support adults over 18 years of age from the five boroughs of New York City who have both an intellectual and developmental disability and a mental health diagnosis and are ready to leave inpatient treatment. The new 12-bed unit is a "step down" unit, meaning that while the patients being cared for still require a high level of care and observation, it is not to the degree required in an inpatient psychiatric hospital setting. People served in the unit will come directly from inpatient psychiatric treatment. The extended treatment unit will fill an urgent need that has been identified in the New York City Metropolitan area among people with intellectual and developmental disabilities who receive OPWDD services and also have a mental health diagnosis. The ETU's opening is the culmination of three years of planning and collaboration among various regulatory and provider agencies including OMH, DOH, The New York City Department of Health and the Hospitals of Kings County.

OMH partnered with the Center for Autism and Related Disabilities (CARD) to promote Project ECHO (Extension for Community Healthcare Outcomes) Autism, an interactive tele-education network. The partnership provided training to licensed providers including clinic, day treatment, and residential programs.

OMH is also collaborating with Upstate Cerebral Palsy and national child psychiatry experts on an OMH-licensed mental health clinic to address polypharmacy in youth with mental health and intellectual/developmental disabilities. The launch date for the program has been delayed by the COVID-19 pandemic.

OPWDD, OMH, and OASAS, have also worked to improve collaborative relationships with county governments by working with the New York State Conference of Local Mental Hygiene Directors, Inc. (CLMHD). Each of these state agencies now participates in an annual “Agency Day” where Agency Commissioners and senior staff meet with local Directors of Community Services to discuss critical issues and exchange ideas on how to better collaborate to improve service outcomes.

State agencies are also collaborating with county leaders on workshops and presentations to foster a better understanding of specific topical areas. For instance, OPWDD hosts meetings with the county Directors of Community Services to discuss focus areas such as ways to improve data collection and integration and how to navigate legal issues and processes where a court of law issues Temporary Orders of Observation and Orders of Commitment.

In addition, OPWDD has improved its data collection and dissemination efforts regarding service utilization trends which can help inform local planning efforts. OPWDD staff are also meeting regularly with Directors of Community Services.

In 2019, New York State worked to comply with two new laws that seek to increase collaboration among various governmental entities for the benefit of individuals with ASDs and other developmental disabilities. Chapter 57 of the Laws of 2018 required OPWDD to consult with the Department of Health (DOH), the Office of Fire Prevention and Control, the Municipal Police Training Council and the Commissioner of the State Police to develop a training program and associated training materials to provide instruction and information to firefighters, police officers and emergency medical services personnel on appropriate recognition and response techniques for handling emergency situations involving individuals with ASDs and other developmental disabilities. The first responder agencies are responsible for implementing the training programs for the first responders under their various jurisdictions.

Complementing the first responder training requirements is Chapter 209 of 2018 which directed OPWDD to create a program to create ID cards to present to law enforcement officers, firefighters and emergency medical services personnel. The cards have the potential to help these professionals better understand and interact with people with developmental disabilities, including those with ASDs who may not be able to communicate their situation effectively. The cards are voluntary and can be requested through the OPWDD website. Since the initiative’s launch in February 2019, more than 12,500 cards have been requested and distributed to qualifying New Yorkers.

3. 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 connection, 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 supports and dealing with the challenges that an ASD diagnosis can pose within the family. Individuals with ASD should be welcomed in these groups as well.

State Action on Recommendation:

Family support groups can be an important source of information and support. Supporting parents can foster information exchanges and opportunities to connect families of a newly diagnosed person with families who have experience overcoming obstacles to accessing appropriate early intervention, educational, and habilitative services that are available in their local community.

In addition to providing networking opportunities which offer parents and caregivers a chance to interact with people living in similar circumstances, high quality support organizations often promote lifelong access and opportunities for people on the autism spectrum and their families, so they can be fully participating members of their communities.

In order to assist families who are seeking support, the Board has compiled a list of family support resources by region. A listing of such supports can be found in Appendix B on page 31 of this report.

During the October 2020 Board meeting, Janine Kruiswijk, Executive Director of the Autism Society of the Greater Capital Region, gave a presentation and led a discussion about how well-run family support groups work to meet the needs of today's families. The presentation stressed the value and importance of framing services as lifespan services where an organization works with people on all aspects of life, throughout their life. Family organizations must also be flexible as they adapt to changing situations and are responsive to a person's changing needs. Services that individuals and families find most useful include:

- Information and referral for families, adults, and professionals. Well-run organizations have trained staff who can connect individuals and families to community, social and health services. This is important as potential community supports can exist outside of the framework of traditional state-funded supports.
- Service navigation and facilitated enrollment. Supporting families who may not know where to find assistance when they first learn of an autism diagnosis is important. Families unfamiliar with New York's system of supports often seek to educate themselves about autism and, if seeking state services, may need guidance throughout the enrollment process.
- Skill-building and informational workshops. Successful family support groups often provide workshops on navigating the education system, behaviors,

communication strategies, transitioning to different situations, employment programs, service providers, and navigating the community at large.

The ensuing discussion touched on issues such as the impact of aging in the autism population and the lack of research in the area so families and policy makers can better meet a person's changing needs. The discussion also included topics such as psychiatry needs and education around antipsychotics, funding for direct advocacy or for attorneys to help families engage with the education system, and drawbacks associated with distance learning as school districts seek to safely provide supports during the COVID pandemic.

4. 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 a 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, and for it to be hosted on the OPWDD website.

State Action on Recommendation:

In response to the Board's recommendation, OPWDD is taking steps to address both the exercise and nutrition component of healthful habits. In September 2019, OPWDD partnered with the New York State Office for Parks, Recreation and Historic Preservation and Special Olympics New York to bring people together for fun, healthy activities regardless of level of ability, while promoting the accessible opportunities available at parks across the state for "Get Together Day." Between 700 and 1,000 people were estimated to have attended special events at seven state parks for fun, healthful activities that encouraged everyone's participation regardless of level of ability. "Get Together Day" also showcased the ever-increasing range of accessible opportunities available at state parks. To help facilitate the event, park staff offered special programs including tours, nature walks, bocce, kayaking and fitness activities.



In addition, Letchworth State Park has been participating in a public-private partnership which includes a fundraising campaign to build an Autism Nature Trail (The ANT). The goal of the ANT is to provide a recreational Trail within the park that allows visitors with autism and other developmental disabilities to push boundaries, explore new activities and develop skills. To date, the campaign has raised \$3 million of the projected \$3.7 million needed to construct the Trail and aid in ongoing maintenance, operations and programming. The Campaign to Build the Autism Nature Trail at Letchworth State Park is supported by several organizational partners within New York State, including the New York State Office of Parks, Recreation & Historic Preservation, the Natural Heritage Trust, Camp Puzzle Peace, Letchworth State Park, and the Perry Central School District. Additional information about this first in the nation trail can be found at <https://autismnaturetrail.com/>.

In October 2019, OPWDD launched a series of webinar trainings designed to guide Dietitians, Habilitation Specialists, Nurses, Speech Language Pathologists, and Occupational Therapists in the OPWDD system on how to teach cooking skills to adults with ASD and others with intellectual and developmental disabilities. Cooking skills can and will improve the nutrition quality of people’s diets while providing them with a key life skill. These presentations demonstrated cooking utensils and use of small appliances that assist with independent food preparation, recipe design and tips, and provided staff with tools to promote independent living.

The presentations focused on the health-related trends for adults with ASD and IDD including gastrointestinal issues, obesity, cardiovascular disease and risk factors, the immune response, polypharmacy, and disordered eating. Areas of disordered eating were also discussed including food rigidity, sensory based, and binge eating. Topics such as dietary intervention and coordination of care to assist with treatment of those with ASD and IDD were also included in the presentation.

In December of 2019, the New York State Board of Regents amended State Education Department regulations to create an exemption from the age and four-year limitation for students participating in inclusive athletic activities. Prior to this change students who remained in high school after their 19th birthday were prohibited from participating in school sponsored athletic events. This change enables students with disabilities, including individuals on the Autism Spectrum to continue participating in inclusive athletic activities until they graduate. A student who is enrolled in grades 9 through 12 and has not yet graduated from high school may continue to participate in inclusive athletic activities beyond the age of 19 and beyond four consecutive seasons of an inclusive athletic activity if the superintendent of schools or chief executive officer of the school or school system determines that the student meets the following criteria:

- Such student is a bona fide student of the high school for which the student wishes to participate in inclusive athletic activities and has not graduated from high school; and
- Such student is otherwise qualified to compete in the inclusive athletic activities for which he or she is applying for an exemption; and
- Such student has undergone an adequate health examination by the director of school health services, and the director of school health services has determined that the student's participation in such activities will not present a safety or health concern for such student.

5. Better Support Telehealth Services Throughout New York State

Focus Area: Regulatory Barriers, Community Supports

While not a replacement for in-person services, Telehealth can remotely connect patients and healthcare providers, offering an important tool in facilitating access to healthcare 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, childcare programs and daycare centers. The legislation opens those programs to reimbursement from Medicaid and private payers.

The Board supported 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.

State Action on Recommendation:

Part of New York's emergency response to the COVID-19 pandemic included the use of Executive Orders and state agency regulatory actions to expand the circumstances where individuals could receive and service providers could be reimbursed for providing telehealth services. This additional flexibility provided state agencies and providers opportunities to innovate and better understand the circumstances under which telehealth can be successful and which circumstances do not translate well to the telehealth service modality.

Throughout the emergency response period, OPWDD provided guidance and support to Article 16 clinic providers and providers of waiver services in the applicability of telehealth-based service delivery. Some of the flexibility included:

- Expedited and expanded use of telehealth modalities (visual and audio, synchronous) to deliver therapies in disciplines such as Physical Therapy, Occupational Therapy, Speech/Language Therapy and behavioral health services, leading not only to the maintenance of service consistency but also provider-based learning opportunities regarding the efficacy of discipline-specific service delivery via telehealth modalities;
- Use of the telephonic modality (audio only) for assessment, monitoring, evaluation and management services, allowing individuals to access consults, test results and urgent assessment needs;
- With the easing of federal Centers for Medicare & Medicaid Services (CMS) rules on the location of the provider at the distant site and originating site (location of the patient), services using telehealth modalities have been provided to those with dual Medicaid and Medicare eligibility, and providers have been reimbursed for such services; and
- Remote provision of some waiver and habilitation services by providers.

Some of the vehicles for telehealth expansion included:

- Executive Order 202.1 – Waived provisions of PHL 2999-cc and regulations promulgated thereunder by OPWDD, OMH, and OASAS to expand providers, practitioners, modalities and technologies. This enabled OPWDD providers to provide HCBS waiver services via telehealth once day habilitation programs closed.
- Executive Order 202.5 – Waived Education Law provisions permitting out of state practitioners to practice in NYS during the pandemic response. This can be accomplished via telehealth if all applicable standards are met.
- DOH Special Addition Medicaid Update for Telehealth During COVID-19 – Permits Medicaid billing for expanded distant and originating sites, telephonic encounters, and services provided via telehealth by all Medicaid providers. This document has been updated several times since its original issuance in March 2020.
- OPWDD 1915(c) Federal Medicaid Waiver Appendix K – Permits the delivery of OPWDD HCBS waiver services via telehealth until March 2021.
- The Office of Civil Rights in the federal Department of Health and Human Services waived its enforcement of HIPAA privacy requirements where providers are engaged in the good faith effort of providing services via telehealth. This has permitted providers to utilize platforms without a BAA in place first and to utilize

platforms that are not public facing that do not meet HIPAA privacy standards. This waiver will expire after the COVID-19 emergency.

- Medicare – CMS has expanded access to telehealth for people on Medicare by temporarily expanding both distant and originating site definitions, expanding qualifying services, permitting services for new patients to be delivered via telehealth where previously only established patients could receive services via telehealth, expanding provider types that can deliver e-visits, and removing certain limits and requirements for the frequency of telehealth visits. It is unclear whether any of these expansions will remain in place after the COVID-19 emergency. While they are in place, they expand access to telehealth for dual eligible individuals.
- OPWDD is working to issue its ADM for OPWDD-specific guidance on the use of telehealth.

The NYS DOH also issued a number of guidance documents pertaining to the use of telehealth in the Early Intervention Program during the declared state of emergency for COVID-19. Links to these materials can be found on the [DOH website](#).

To help determine the effectiveness of the telehealth modalities being used during the ongoing COVID pandemic, OPWDD sought feedback from a wide variety of stakeholders through focus groups and discussions with family advocacy groups and service provider representatives. Many of the family advocacy organizations polled their members and shared the results with OPWDD.

The feedback yielded mixed results as many felt remote service delivery worked very well while others saw limited benefits. The efficacy of remote service delivery varied by the type of service being delivered, the functional capacity of the service recipient, and the availability of appropriate technology such as telephones, computers, access to the Internet or high-speed Internet, and the technological prowess of the service provider. Key findings and takeaways from stakeholder feedback include:

- Many individuals lack access to technology (phones, computers) or Internet, while others need staff support to successfully make use of remote services.
- Remote services should remain an option for those for whom it works well. Efforts should be made to further expand and develop services to better meet the range of individuals' needs.

Providers and staff vary in their ability to tailor remote services to people's needs. As a result, any increased reliance on telehealth would benefit from efforts to ensure that staff receive appropriate training in order to maximize the positive impact on people receiving services through this modality. In addition to the regulatory actions cited previously, two new laws were signed. The budget agreement adopted in April 2020 authorizes Care Coordination Organizations (CCOs) to utilize telehealth and authorizes the OPWDD Commissioner to approve additional acceptable modalities to deliver telehealth including audio communications, online portals and survey applications. Chapter 124 of the Laws of 2020 allows for telehealth modality for delivery of a needed and approved service to an individual through audio only but only applies when there is federal financial participation.

The New York State budget adopted in April 2021 further expands access to services delivered via telehealth. The new law changes the definition of “distant site,” to allow any site within the United States or US territories to be a distant site for the purpose of delivery and payment of telehealth.

6. 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.

State Action on Recommendation:

While no “Tech Summit” was sponsored in part due to the COVID-19 pandemic, the Board did have an opportunity to learn more about how assistive technology is being deployed in New York. During the December 2019 meeting, Board Members discussed the findings of an assistive technology workgroup of self-advocates and witnessed a presentation by New York Alliance for Inclusion & Innovation regarding the usage of assistive technology. Please see Appendix C on page 35 for more information on the workgroup. New York State OPWDD is exploring the potential for a “virtual” technology fair in the future.

The Alliance presenters defined assistive technology as any device or product that helps a person with an I/DD perform a task that would otherwise be difficult or impossible. This definition includes any pieces of equipment, products or systems that can help increase, maintain or improve someone’s functional capacities. Useful devices can be as low-tech as a magnifying glass or as high-tech as proprietary computer software and hardware. The assistive technology industry continues to expand and create solutions that promote independence for people with disabilities.

The presentation stressed the importance of using a person-centered approach when determining what benefits assistive technology can provide. This begins with an

assessment of the individual's skills, wants and abilities. The individualized assessment phase must determine if the individual can or will actually use the device, if the individual and the people in their lives such their Circle of Support or Direct Service Professional (DSP) understand its use, and which goals can be achieved through the use of assistive technology.

Once in place, the individual, and if applicable, members of their support circle and DSPs must also be educated on the usage of assistive technology to ensure that individuals' needs are being met. The assistive technology constantly changes and some equipment needs occasional maintenance or recalibration so people who make a point of revisiting their tools, skills, and goals, will get the most benefits from assistive technology.

The presenters highlighted the range and kinds of technologies available. For example, assistive technology can be as standard as a smart phone calendar application that notifies an individual of upcoming meetings or appointments or a specialized application created specifically to meet someone's needs such as ensuring accurate information sharing among the individual, their family, and even support staff.

Durable medical equipment such as augmentative communication systems, power wheelchairs, and environmental modifications such as ramps or converting vehicles to be operated without foot pedals are often categorized differently than "enabling technology" which promotes more independence. Examples of enabling technology include smart phones, tablets, etc. and helpful applications that can help with reminders, assist with travel and cooking or turn speech to text and vice versa. Other types of enabling technology consists of stand-alone units to perform specific tasks. Examples include medication dispensing units, video doorbells, dusk to dawn lightbulbs, and home sensors that can detect when a stove is turned on, when a door is open, or when water is running or leaking from a faucet. An appropriately modified or adapted home can make a big difference in giving someone the confidence and ability to live life more independently.

7. 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 analysis (ABA) services to individuals with ASD. 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 ASDs. 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.

State Action on Recommendation:

During the July 2020 Board meeting, Dr. Deborah Napolitano, Legislative Chair of the New York State Association for Behavior Analysis (NYSABA) and faculty at Daemen College in the ABA Department, presented information to the Board regarding the supply of Licensed Behavior Analysts in the United States and in New York. The data presented confirmed the Board's assessment regarding the ongoing shortage of these skilled professionals, with New York having the fewest behavior analysts per 100 individuals with ASD in the Northeast.

Behavior Analysis is the science of behavior, with applied behavior analysis (ABA) being the application of the science. ABA generally involves teaching individuals more effective ways of learning meaningful life skills that ultimately leads to improved quality of life. The science is broadly applied and can be effective for teaching skills, identifying the reasons or barriers to behavior change, and often provides collaborative approaches families can utilize to help people positively interact with others and the environment around them. Treatment approaches based on ABA have been shown to be effective on a variety of populations including individuals diagnosed with ASD, Prader Willi syndrome, Traumatic Brain Injury (TBI), Down syndrome, attention deficit hyperactivity disorder (ADHD), drug addiction, and many other diagnoses.

According to NYSABA, New York's supply of Licensed Behavior Analysts will continue to lag behind other states unless the scope of practice that New York professionals are legally authorized to engage in is put in line with the other states with licenses in the profession. Of the 31 states that license behavior analysts, New York is the only state to limit the scope of practice by restricting licensees to only serve individuals who have an ASD diagnoses.

This restriction can result in Licensed Behavior Analysts seeking employment in other states where they can also provide ABA services to those diagnosed with Down syndrome, TBI, ADHD, Prader Willi syndrome and others who could benefit from their services. NYSABA further contends that the restricted scope of practice effectively limits New York's pipeline to train future behavior analysts as the fourteen colleges/universities (17 programs total) that teach ABA in New York train students to only work with individuals with ASD. Prospective students, therefore, often seek programs in other states and never return to New York to practice because they are unable to utilize their full skillset and knowledge base.

To help address New York’s shortage of Licensed Behavior Analysts, NYSABA and other organizations support legislation to expand the scope of allowable practice in New York. Additional information can be obtained from NYSABA at NYSABA.org.

8. Engage Cutting-Edge Research Around ASD

Focus Areas: Training for Professionals, Collaboration on Research

There has been a great deal of research into people with ASD, 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” to disseminate the information.

State Action on Recommendation:

A listing of various research institutions was created and can be found in Appendix D on page 37 of this report. Providing the public with a directory of where new research results can be found instead of providing actual recent studies will help ensure that families have access to newly released information.

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 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.

State Action on Recommendation:

Based on the recommendations of the Board, OPWDD developed a data inquiry for the START Information Reporting System (SIRS), to conduct a high-level review of cases from NY START that involved individuals diagnosed with ASD. All NY START teams are required to enter data on NY START enrolled individuals into SIRS which is a comprehensive collection of de-identified clinical data that can be queried specific to ASD as the primary developmental disability diagnosis.

OPWDD staff met with the Center for START Services at the University of New Hampshire in April and May of 2019 to identify and discuss the potential data parameters to be pulled from SIRS. The results indicated that 47% (N= 1,117) of the individuals served through the NY START programs had a diagnosis of ASD. The average age of adults served by NY START with ASD was 26 years old, and for children with ASD the average age was 13 years old. There were more males with ASD served (79%) than females (21%). Most children and adults with ASD receiving NY START services lived at home with their family (96% and 60% respectively).

The average number of psychiatric diagnoses (excluding ASD) was 2 for adults and 1.8 for children. The average number of medical diagnoses was 1.7 for adults and 1.6 for children with ASD. Individuals with ASD reported taking an average of 2.6 psychotropic medications, as compared to 2.9 for individuals with no ASD diagnosis. The average number of stressors identified on the Recent Stressors Questionnaire, which is a tool administered to all individuals/families accessing NY START services, was not significantly different for children and adults with ASD (8.3 stressors) and those without a diagnosis of ASD (9.6 stressors). The data clearly indicates that both children and adults with ASD are successfully accessing NY START services across all four regions where these services are currently available.

Strategies to gather more information regarding satisfaction with crisis services among individuals with ASD are currently being explored to determine where program improvements can be made.

The name of the START program in NYS has recently been changed to Crisis Services for Individuals with Intellectual and/or Developmental Disabilities (CSIDD). The name change coincides with the program's inclusion in OPWDD's Federal Medicaid waiver agreement with the Centers for Medicare and Medicaid Services (CMS), but the START program model remains intact. CSIDD's inclusion in OPWDD's waiver agreement resulted in the program becoming eligible to receive federal financial support.

Recent Statutory Changes of Interest to the Autism Spectrum Disorders Advisory Board

Chapter 227 of the Laws of 2018 Expands Autism Advisory Board Duties

Expands the responsibilities of the Autism Advisory Board to include a requirement to identify strategies and methods of improving outreach and coordination of services for minority groups including African American, Latino, and Asian children.

Two changes of note were included in the New York State budget adopted April 2019, including:

Joint Licensure

Authorizes the delivery of integrated services by DOH, OMH, OPWDD and OASAS licensed or certified provider by allowing providers to deliver integrated outpatient services in one location, under the single licensure/certification.

Sensory Friendly Emergency Room Pilot

Provides \$30,000 for a pilot to study the impact of an emergency room that is designed to meet the needs of individuals with intellectual and developmental disabilities who may have trouble adapting to the visual and audio stimuli typical of hospital environments. The pilot will be carried out by Ellis Medicine in Schenectady, New York.

Chapter 329 of the Laws of 2019

Exempts ABLE Funds from Income Limitations

Exempts funds in a New York Achieving a Better Life Experience (NY ABLE) savings account from assets limit tests to qualify or recertify for public assistance.

Chapter 545 of the Laws of 2019 Ties ABLE Contributions to Federal Limits

Links the maximum account balance for the New York Achieving A Better Life Experience (NY ABLE) program to the federally authorized amount for the purposes of calculating the tax exemption.

Three changes of note were included in the New York State Budget adopted April 2020, including:

Transfers Autism Awareness and Research Fund to OPWDD

Transfers the responsibility for administering the New York State Autism Awareness and Research Fund from DOH to OPWDD, including the requirement to publish an annual report regarding the use of the funds deposited into the account. The law became effective April 1st, 2020.

Extends OPWDD's ABA Exception

Extends OPWDD's exemption from the law requiring that anyone who performs duties considered to be within the scope of applied behavior analysis have an ABA degree until July 1st, 2025.

Telehealth Expansion

Authorizes CCOs to utilize telehealth. Authorizes the OPWDD Commissioner to approve additional acceptable modalities to deliver telehealth including audio communications, online portals and survey applications.

**Chapter 124 of the Laws of 2020
Authorizes Audio only Telehealth**

Allows for telehealth modality for delivery of a needed and approved service to an individual through audio only. Applies only if there exists federal financial participation.

Appendix A

Autism Spectrum Disorders Advisory Board

Mental Hygiene Law § 13.42

§ 13.42 Autism spectrum disorders advisory board.

(a) There is hereby established within the office the autism spectrum disorders advisory board. Such board shall consist of nineteen members, ten of whom shall be appointed and nine of whom shall serve ex officio. Of the ten appointed members, two shall be appointed by the governor, two shall be appointed by the temporary president of the senate, two shall be appointed by the speaker of the assembly, two shall be appointed by the minority leader of the senate and two shall be appointed by the minority leader of the assembly. Of the two members appointed by each appointing authority, one member shall have expertise of work as a professional in the field of autism and one member shall be a family advocate or self-advocate in the community that such advocate resides. A representative from each of the following state agencies shall serve ex officio: the office for people with developmental disabilities; the department of education; the office of mental health; the office of children and family services; the department of health; the developmental disabilities planning council; the council on children and families; and the office of vocational and educational services for individuals with disabilities. The chair of the board shall be selected by the governor.

(b) Members of the board shall serve at the pleasure of the appointing authority. Vacancies on the board shall be filled in the same manner as the original appointment. Members of the board shall receive no compensation, but may be reimbursed for actual and necessary expenses incurred in the performance of their duties within amounts appropriated therefor.

(c) The board shall have the following tasks and duties:

- (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;
- (4) Identify strategies and methods of improving outreach and coordination of services associated with autism spectrum disorders for minority group members including, but not limited to, African American, Latino and Asian children; and
- (5) Such other matters as may be deemed appropriate by the members of the board. At the discretion of the chair, the board may consult with stakeholders for the purpose of carrying out its tasks and duties in accordance with this subdivision.

(d) Such board shall meet at least quarterly. Special meetings may be called by the chair. The agenda and meeting place of all regular or special meetings shall be made available to the public in advance of such meetings.

(e) The advisory board shall submit a written report to the governor, the temporary president of the senate and the speaker of the assembly by no later than October first of the year next succeeding the effective date of this section and annually thereafter, setting forth the recommendations and activities of the council on matters within the scope of its duties as set forth in this section.

Appendix B Regional Family Support Groups

The New York State Autism Spectrum Disorders Board does not endorse any of the organization’s linked websites and does endorse the views expressed or the products/services they offer. Additionally, the Board does not control or guarantee the accuracy, relevance, or completeness of information contained on a linked website.

Regional Family Support Groups

Organization	Address	Phone #	Website
Downstate			
Atlas Foundation for Autism	252 West 29 th St New York, NY 10001	212-256-0846	http://www.atlasforautism.org
Autism Society of America – North Central Bronx	3424 Kossuth Avenue, Room 151A11 Bronx, NY, 10467	718-519-4797	https://www.k12academics.com/national-directories/organization/autism-society-america-bronx-chapter
The Grace Foundation of New York	460 Brielle Ave Staten Island, NY 10314	718-983-3800	https://www.graceofny.org/
My Time, Inc.	1312 East 84 th Street Brooklyn, NY 11236	917 933-9875	https://www.mytimeinc.org/
Include NYC	116 East 16th Street 5th floor Gramercy Park NY	212-677-4660	https://www.includenyc.org/
Parent to Parent of New York State	25 Beaver Street New York, New York	800-405-8818	http://parenttoparentnys.org
Long Island Advocacy Center, Inc. - Nassau County	999 Herricks Rd. New Hyde Park, NY 11040	(516) 248-2222	https://theliac.org/
Autism society - Nassau Suffolk	N/A	(516) 404-2306	http://www.nsasa.org/
Center for Family Support	333 7 th Avenue, # 901 New York, NY 10001	888-813-5014	https://www.cfsny.org/

Care for Special Children Foundation	Coney Island Avenue 1977 Brooklyn, 11223	718-975-7171	https://www.careforspecial.org
Community Assistance Resources and Extended Services, Inc.	465 Grand St, New York, NY 10002	212-420-1970 ext. 142	https://www.caresnyc.org/
New Alternatives for Children, Inc.	Multiple Locations Check Link	646-367-8468	https://www.nackidscan.org/home/index.php
Pesach Tikvah - Hope Development, Inc.	18 Middleton Street Brooklyn, NY 11206	718.875.6900	https://www.pesachtikvah.org/
Shorefront	3300 Coney Island Avenue Brooklyn, NY 11235	718-646-1444	https://www.shorefrontny.org/
University Settlement	184 Eldridge Street New York, NY 10002	212-941-9090	https://www.universitysettlement.org/us/?
Asperger/Autism Network	303 Fifth Avenue, Suite 1003, New York, NY 10016	(617) 393-3824	https://www.aane.org/
Stony Brook Autism Spectrum Disorders	Stony Brook Medicine 101 Nicolls Road Stony Brook, NY 11794	(631) 689-8333	https://www.stonybrookmedicine.edu/node/1986
Upstate			
Westchester Jewish Community Services	845 North Broadway White Plains, Ny 10603	914-761-0600	http://www.wjcs.com
Parent Network of Western New York	1000 Main Street Buffalo, NY 14202	716- 332-4170	https://parentnetworkwny.org/
Autism Spectrum Disorder Family Support Group in St. Lawrence County	N/A	716-523-3325	N/A
Families Together in New York State	737 Madison Avenue Albany, NY 12208	518-432-0333	https://www.ftnys.org/

Center for Autism and Related Disabilities (CARD)	1534 Western Avenue Albany, NY 12203	518-422-2574	https://www.albany.edu/autism
Autism Society of Western New York	19 Limestone Drive, Suite 1, Buffalo, New York 14221	716-633-2275	https://autismwny.org/
Autism Society of the Greater Capital Region	433 State Street 4 th Floor Schenectady, NY 12305	518-355-2191	https://www.asgcr.org/
AutismUp Headquarters	50 Science Parkway Rochester, NY 14620	585-248-9011	https://autismup.org/
Autism Council of Rochester	Check link various locations	(585) 413-1681	https://www.theautismcouncil.org/
St. Rose Friday Knights Program	432 Western Avenue, Albany NY 12203	800-637-8556	https://www.strose.edu/academics/schools/school-of-education/campus-based-professional-groups/friday-knights-program/
DDAWNY Family Committee		(716) 877-7007	http://www.ddawny.org/committees/family-committee/
Golisano Autism Center	Golisano Autism Center 50 Science Parkway Rochester, NY 14620	(585) 685-8300	https://www.golisanoautismcenter.org/

Appendix C

Self-Advocate Technology Recommendations

On November 13, 2019, the Autism Spectrum Disorders Advisory Board self-advocate workgroup convened to provide input on assistive technology, an issue which reflects one of the Board's recommendations to expand the use of technology in service delivery.

Below is a summary of their feedback.

When considering the types of technology used, and types of challenges assistive technology can help overcome, the most prominent sentiment was that this varies by individual. Autism is a spectrum, and a variety of technologies respond to a variety of needs. Technology should be personalized to each individual based on an assessment of skills, (personal and related to the community) as well as their needs and goals.

The technology used by people with autism is often the same as that used by people without disabilities. One example is the use of smart phones, and many standard features that may be of benefit to people on the spectrum (e.g. calendars and alarms for reminders).

Automated reminders may assist some people on the spectrum with memory and cues. Smart phones may also help provide a distraction for people when they may otherwise stim or exhibit (socially unacceptable) behavior that most people would not understand.

There are also technologies designed specifically for people with ASD. Many are designed for children (e.g. to assist with social skills). There is a hope that such technology could be adapted for use by adults as well, as such needs may continue through adulthood.

It appears there are more options specifically geared toward helping those with higher support needs (e.g. speech generation), while people with lower support needs typically adapt more generic technologies for their use.

It is important that information on technological service and support options be made available to those who create service plans including care managers, school districts/special education departments and staff members. This is complicated by the fact that technology is always changing. Parents will likely depend on staff and care managers to gain an understanding of the options available with smart phones.

In terms of newer technologies that self-advocates found promising, the *smart tower* was noted. This device uses sensors and reminders to provide prompts for the person using it and can also provide crucial information to the person's guardian (e.g. parent, support staff). For example, if a front door to the person's apartment opens at an unusual time (e.g. the middle of the night), a motion sensor will register the movement and send a text message to their parent or guardian. This allows greater personal independence for people

with support needs, as the smart tower helps maintain constant contact and provides for safety assurances to the parent and the person with the need.

Types of Technology Suggested/Commonly Used by Self-Advocates

- Apps
 - Calendar Alerts
 - Geo-tracking
 - Social Skills
- Disability robots
- Motion sensors
- Smart phones
- Smart tower
- Speech and communication augmentative technology
- Virtual assistants
- Voice to text on smartphone

Appendix D

Listing of Autism Research Resources

The New York State Autism Spectrum Disorders Board does not endorse any of the organizations' linked websites and does not endorse the views expressed or the products or services they offer. Additionally, the Board does not control or guarantee the accuracy, relevance, or completeness of information contained on a linked website.

Federal and State Government

Clinical Trials (search with keywords)	https://clinicaltrials.gov/
New Jersey Government Agencies	https://www.autismnj.org/information-services/government-agencies/
National Institute of Mental Health	https://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd/index.shtml
Eunice Kennedy Shriver, NICHD	https://www.nichd.nih.gov/health/topics/autism
Interagency Autism Coordinating Committee	https://iacc.hhs.gov/
National Human Genome Research Institute	https://www.genome.gov/Genetic-Disorders/Autism
National Institute of Neurological Disorders and Stroke	http://www.ninds.nih.gov/disorders/autism/autism.htm
National Institute on Deafness and Other Communication Disorders	https://www.nidcd.nih.gov/health/autism-spectrum-disorder-communication-problems-children
U.S. National Library of Medicine Medline Plus	https://medlineplus.gov/autismspectrumdisorder.html
Centers for Autism and Developmental Disabilities Research and Epidemiology	https://www.cdc.gov/ncbddd/autism/caddre.html

University Center for Excellence in Developmental Disabilities

Rose F. Kennedy University Center for Excellence in Developmental Disabilities Education, Research and Service	http://www.einstein.yu.edu/cerc/
Westchester Institute for Human Development UCEDD in affiliation with New York Medical College	http://www.wihd.org
Strong Center for Developmental Disabilities, University of Rochester	http://www.urmc.rochester.edu

Research Database

PubMed (search with keywords)	https://www.ncbi.nlm.nih.gov/pubmed/
Clinical Trials (search with keywords)	https://clinicaltrials.gov/
Center Watch	https://www.centerwatch.com/clinical-trials/listings/condition/612/autism/
Interactive Autism Network	https://iancommunity.org/cs/research_studies/overview
National Institute of Child Health and Human Development Clinical Trials	https://www.nichd.nih.gov/health/topics/autism/clinicaltrials

University Centers

Association of University Centers on Disabilities	https://www.aucd.org/
Albany Center for Autism and Related Disabilities	https://www.albany.edu/autism/
Stony Brook	https://neuro.stonybrookmedicine.edu/centers/autism/team
SUNY Binghamton Institute for Child Development	https://icd.binghamton.edu/
University of Rochester Strong Center for Developmental Disabilities	https://www.urmc.rochester.edu/strong-center-developmental-disabilities/programs/rochester-regional-ctr-autism-spectrum-disorder.aspx
Golisano Autism Center	https://www.golisanoautismcenter.org/
Mount Sinai Seaver Autism Research Center	https://icahn.mssm.edu/research/seaver
Columbia University Center for Autism and Developing Brain	https://childadolescentpsych.cumc.columbia.edu/locations/center-autism-developing-brain-cadb
NYU Langone Child Study Center	https://nyulangone.org/locations/child-study-center/autism-spectrum-disorder-service
Weill Cornell Autism Research Program	https://pediatrics.weill.cornell.edu/research/weill-cornell-autism-research-program-wcarp
Hofstra University	https://www.hofstra.edu/community/slzctr/slzctr_institute_asd.html
Montefiore-Einstein Center for Autism	https://www.montefiore.org/cacd
Children's Hospital at Montefiore	https://www.cham.org/specialties-and-programs/neurology/conditions/autism-diagnosis-and-treatment
Maimonides Children's Hospital	https://www.maimonidesmed.org/maimonides-infants-and-childrens-hospital/pediatric-medical-services/development-and-behavioral-medicine
Rutgers Douglass Developmental Disabilities Center	https://gsapp.rutgers.edu/centers-clinical-services/douglass-developmental-disabilities-center
Children's Hospital of Philadelphia Center for Autism Research	https://www.centerforautismresearch.org/
Kennedy Krieger Institute, Johns Hopkins University	https://www.kennedykrieger.org/
Waisman Center, University of Wisconsin	https://www.waisman.wisc.edu/
Nisonger Center, Ohio State University	https://nisonger.osu.edu/
Marcus Center, Emory University	https://www.marcus.org/

Academic Associations

International Society for Autism Research	https://www.autism-insar.org/
Council for Exceptional Children	https://www.cec.sped.org/

Council for Exceptional Children Division of Autism	http://www.daddcec.com/
American Academy of Pediatrics Autism Initiatives	https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Pages/autism-initiatives.aspx
American Academy of Neurology Policy & Guidelines	https://www.aan.com/Guidelines/home/GuidelineDetail/33
American Academy of Child and Adolescent Psychiatry	https://www.aacap.org/aacap/families_and_youth/resource_centers/autism_resource_center/home.aspx
Association for Behavior Analysis, International	https://www.abainternational.org
Association of Professional Behavior Analysts	https://www.apbahome.net/
Cambridge Center for Behavioral Studies	https://behavior.org/help-centers/autism/

Autism Journals

List of Major Journals on Autism	https://www.omicsonline.org/autism-journals-conferences-list.php
<i>Journal of Autism and Developmental Disorders</i>	https://link.springer.com/journal/10803
Journal of Applied Behavior Analysis	https://onlinelibrary.wiley.com/journal/19383703
Behavior Analysis in Practice Autism	https://link.springer.com/journal/40617
Autism Research	https://journals.sagepub.com/home/aut
Autism Research and Treatment	http://onlinelibrary.wiley.com/journal
Research in Autism Spectrum Disorders	https://www.hindawi.com/journals/aurt/contents/
Focus on Autism and Other Developmental Disabilities	https://www.elsevier.com/research-in-autism-spectrum-disorders
Education and Training in Autism and Developmental Disabilities Journal	https://journals.sagepub.com/home/foa
Behavioral Interventions	http://daddcec.org/Publications/ETADDJournal.aspx
	https://onlinelibrary.wiley.com/journal/1099078x

Newsletters

Spectrum Autism Research News	https://www.spectrumnews.org/
Disability Scoop	https://www.disabilityscoop.com
Autism Research Podcasts	https://journals.sagepub.com/page/aut/podcasts
Autism Parenting Magazine	https://www.autismparentingmagazine.com/

Foundations

Organization for Autism Research	https://researchautism.org/
National Autism Center	https://www.nationalautismcenter.org/
Autism Speaks	https://www.autismspeaks.org/
Autism Science Foundation	https://autismsciencefoundation.org/

Autism Research Institute	https://www.autism.org/
Autism Society of America	https://www.autism-society.org/
Simons Foundation for Autism Research	https://www.sfari.org/

Advocacy Groups

Autism New Jersey	https://www.autismnj.org/
Autistic Self Advocacy Network	https://autisticadvocacy.org/
National Autism Association	http://nationalautismassociation.org/
Central NY Chapter of Autism Society of America	https://www.cnyasa.org/
Upstate NY Autism Alliance	http://www.upstatenyautism.org/
Parent to Parent of New York State	http://parenttoparentnys.org/
Autism Society of the Greater Capital Region	https://www.asgcr.org/
Autism Council of Rochester	https://www.theautismcouncil.org/
Autism Up	https://autismup.org/
Asperger Autism Network	https://www.aane.org/
Autism Society of Western New York	https://autismwny.org/
NEXT for Autism	https://www.nextforautism.org/
Specialized Autism Support and Information	https://sasiny.org/
Autism Beacon	http://autismbeacon.com/home
American Autism Association	https://www.myautism.org/

Staff Training

Interdisciplinary Technical Assistance Center on Autism and Developmental Disabilities	https://www.aucd.org/itac/template/training_toolbox.cfm
Ohio Center for Autism and Low Incidence	https://www.ocali.org/

Directory of Individual Providers

Behavior Analysts	http://www.BACB.com
Psychologists, therapists, social workers	https://www.psychologytoday.com/

Diagnosis

CDC	https://www.cdc.gov/ncbddd/autism/screening.html
Autism Speaks Learn the Signs	https://www.autismspeaks.org/learn-signs
Well Child Lens	https://www.wellchildlens.com/video_room/section/process-and-diagnosis
Adult Diagnosis	https://www.autismspeaks.org/expert-opinion/getting-evaluated-autism-adult-where-go-who-see

Early Intervention

NYS Department of Health	http://www1.nyc.gov/site/doh/health/health-topics/early-intervention.page
Early Childhood Direction Centers	http://www.p12.nysed.gov/specialed/techassist/ecdc/home.html
Early Intervention Provider List	http://www.p12.nysed.gov/specialed/techassist/ecdc/home.html

Tool Kits

Autism Speaks Tool Kits by Topic	https://www.autismspeaks.org/adults-22
Organization for Autism Research Tool Kits by Topic	https://researchautism.org/how-we-help/families/resources/

Education

Special Education	http://www.p12.nysed.gov/specialed/autism/
Approved Schools	http://www.p12.nysed.gov/specialed/appschools.html
Transition from Early Intervention to SED (age 3-5 yrs)	https://www.health.ny.gov/community/infants_children/early_intervention/transition/
NYC ASD NEST & Horizon Programs	https://steinhardt.nyu.edu/asdnest/

Treatment Options

Association for Science in Autism Treatment	https://asatonline.org/
Well Child Lens	https://www.wellchildlens.com/video_room/section/therapies
Autism Science Foundation: Beware of non-evidence based treatments	https://autismsciencefoundation.org/what-is-autism/beware-of-non-evidence-based-treatments/
Upstate Family Behavior Analysis Clinic	http://www.upstate.edu/healthcare/providers/location.php?clinicID=1138

Employment

Administration for Community Living	https://acl.gov/programs/youth-transitions/employment
US Department of Labor Office of Disability Employment Policy	https://www.dol.gov/odep/topics/Autism.htm
Integrate Autism Employment Advisors	https://www.integrateadvisors.org/for-employers
Spectrum Careers	https://www.thespectrumcareers.com/
Specialistern	https://specialisterneusa.com/
Career and Employment Options, Inc.	http://www.ceoincworks.com/
Job Path NYC	http://www.jobpathnyc.org/
NYS Adult Career	http://www.acces.nysed.gov/vr

Housing

Autism Speaks Housing Toolkit	https://www.autismspeaks.org/tool-kit/housing-and-residential-supports-tool-kit
OPWDD Housing Options	https://opwdd.ny.gov/opwdd_services_supports/residential_opportunities/housing_options

Special Needs Legal Counsel

Wrights Law	https://www.wrightslaw.com/
Disability Rights New York	https://www.drny.org/

Other

Association for Science in Autism Treatment	https://asatonline.org/for-parents/becoming-a-savvy-consumer/
Autism Watch (Watch Dog)	https://www.autism-watch.org/
US Department of Education on Research	https://www2.ed.gov/rschstat/research/pubs/rigorousvid/index.html
OAR A Parent's Guide to Research	https://researchautism.org/resources/a-parents-guide-to-research/
Interactive Autism Network	https://iancommunity.org/cs/understanding_research/overview
Autism Spectrum News	https://autismspectrumnews.org/
Autism Science Foundation	https://autismsciencefoundation.org/

Advocacy Groups

Autism New Jersey	https://www.autismnj.org/
Autistic Self Advocacy Network	https://autisticadvocacy.org/
National Autism Association	http://nationalautismassociation.org/
Central NY Chapter of Autism Society of America	https://www.cnyasa.org/
Upstate NY Autism Alliance	http://www.upstatenyaautism.org/
Parent to Parent of New York State	http://parenttoparentnys.org/
Autism Up	https://autismup.org/
Asperger Autism Network	https://www.aane.org/
NEXT for Autism	https://www.nextforautism.org/
Specialized Autism Support and Information	https://sasiny.org/
Autism Beacon	http://autismbeacon.com/home
American Autism Association	https://www.myautism.org/
Atlas Foundation for Autism	http://www.atlasforautism.org/
Autism Society of North America – North Central Bronx	
The Grace Foundation of New York	https://www.graceofny.org/
New York Families for Autistic Children	https://www.nyfac.org/
Child & Family Support Services, Inc.	https://www.nycfss.org/
My Time, Inc	https://www.mytimeinc.org/
Include NYC	

The Long Island Advocacy Center, Serving Nassau and Suffolk Counties	
Autism Society - Nassau Suffolk	http://www.nsasa.org/
Center for Family Support	https://www.cfsny.org/
Westchester Jewish Community Services	http://www.wjcs.com/
Starbridge	
Parent Network of Western New York	
Autism Spectrum Disorder Family Support Group in St. Lawrence County	
Families Together in New York State	https://www.ftnys.org/
Center for Autism and Related Disabilities (CARD)	https://www.albany.edu/autism
Autism Society of Western New York	https://autismwny.org/
Autism Society of the Greater Capital Region	https://www.asgcr.org/
Autism Council of Rochester	https://www.theautismcouncil.org/
GRASP (The Global and Regional Asperger Syndrome Partnership)	https://grasp.org/
Self-Advocacy New York State (SANYS)	https://sanys.org/