



NYS Office For People With Developmental Disabilities

Putting People First



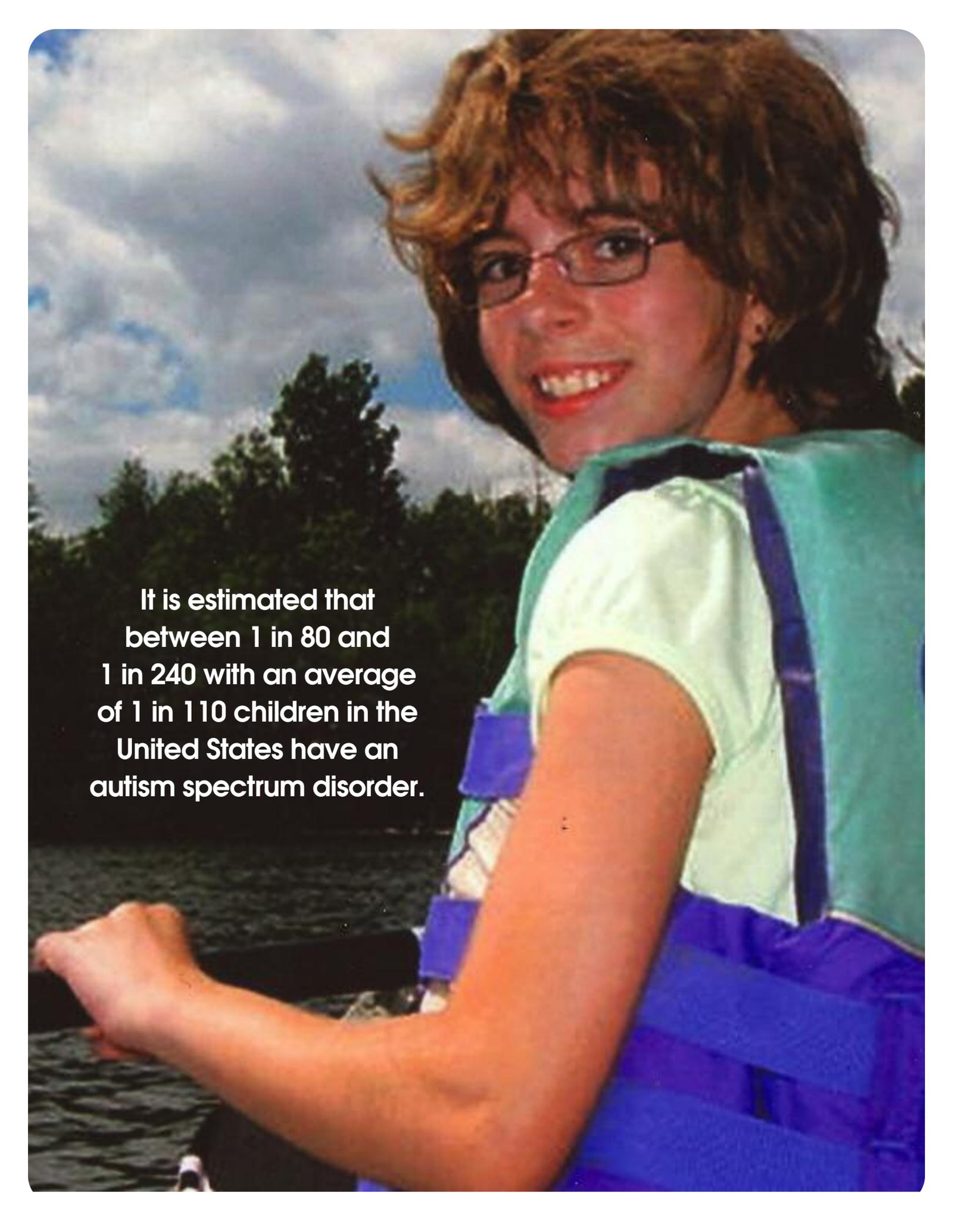
Autism Platform

November 2010



Andrew M. Cuomo
Governor

Courtney Burke
Commissioner

A young woman with short, wavy brown hair and glasses is smiling. She is wearing a light green short-sleeved shirt and a blue life vest. She is on a boat, with her hand on the edge. The background shows a body of water, trees, and a cloudy sky.

**It is estimated that
between 1 in 80 and
1 in 240 with an average
of 1 in 110 children in the
United States have an
autism spectrum disorder.**



The Office For People With Developmental Disabilities' Autism Platform sets the course for this agency to assure that its statewide system of supports and services is responding to the needs of those diagnosed with autism spectrum disorders (ASDs). It is an important part of OPWDD's commitment to helping not only people on the autism spectrum, but people with the full range of developmental disabilities, live richer lives.

OPWDD issued its first Autism Platform in 2008. However, as research rapidly reveals more about the disabilities we call the autism spectrum, practice and policy related to autism are rapidly evolving. The New York State Interagency Task Force on Autism conducted a year-long assessment of New York State's past and future response to the needs of individuals with ASDs, and in January 2010 issued a report containing numerous findings and recommendations for New York State.

The 2010 Autism Platform reflects these recent developments, and asserts an ambitious yet vital agenda for OPWDD. It describes numerous activities and projects related to four distinct areas of focus: training, sharing information, enhancing the OPWDD service system, and promoting collaborative research. Taken together, these areas of focus will allow OPWDD to promote increased ASD competency among the public, clinicians, families, service providers and the staff who assist individuals.

ASDs pay no heed to the economy, and despite the difficult fiscal climate, OPWDD's updated Autism Platform identifies positive steps the agency will take to effectively serve individuals with ASDs and their families. I look forward to bringing you news of our accomplishments in the months ahead.

Best Regards,

Courtney Burke, Commissioner

Autism Platform

August 2010

In the two years since the New York State Office For People With Developmental Disabilities (OPWDD) announced its original Autism Platform, a lot has happened. New York State government has experienced unprecedented collaboration around issues related to autism. New York's Interagency Task Force on Autism facilitated the development of a collective State focus on the challenges facing New York's families and crafted a clear set of recommended actions for State government to take in response to those challenges. At the same time, scientists have pushed further ahead in identifying the many possible causal factors contributing to autism. These advances, along with a State, national and even global fiscal crisis and the rapidly rising rates of autism spectrum disorders (ASDs) confirmed in new statistics from the national Centers for Disease Control and Prevention, have brought an increased sense of urgency and focus to New York State's actions. New York State's new autism landscape is reflected in this updated edition of The Autism Platform, providing a new baseline from which to focus and gauge our forward progress.



OPWDD's Autism Platform:

There is a clear and ongoing need to elevate New York's autism competency – the ability of our service system staff and administrators, educators, physicians, families, and communities to appropriately and effectively support individuals on the autism spectrum. Accordingly, the Autism Platform commits OPWDD clinicians and staff to working with other State agencies and external partners in projects that will:

- Develop ASD related training for a variety of parties;
- Promote the sharing of critical information about ASDs, available services and supports;
- Enhance the service system to more effectively support individuals and families; and
- Advance our scientific understanding of ASDs and the evidence base supporting best practices in the identification, assessment, diagnosis, education and treatment of ASDs.



The 2010 Snapshot

OPWDD exists to help people with developmental disabilities lead richer lives. That simple mission statement belies the agency's extensive system of individualized supports and services now supporting 126,000 people with developmental disabilities including ASD, epilepsy, down syndrome, cerebral palsy, traumatic brain injury and other conditions. While the numbers of individuals receiving OPWDD services has grown each year, the numbers of those who are diagnosed with ASD has and continues to climb steeply. By March 2010, more than 21,000 individuals, representing a full 17 percent of those receiving OPWDD services, had been diagnosed with ASD.

In response, OPWDD continues to examine the readiness of its system to effectively meet the range of needs of these individuals – and those to come. It also continues its commitment to meeting the needs of individuals with ASD within a comprehensive system that provides effective supports and services to eligible individuals regardless of diagnosis. The agency's system of supports and services remains one that is dedicated to helping people with developmental disabilities – including ASD – lead richer lives. The Autism Platform provides a tool with which OPWDD can examine its system from the perspective of one particularly fast-growing segment of its service population. The initiatives that result will improve the supports and services available throughout the OPWDD system for the benefit of the full range of individuals served.

A snapshot of the significant developments influencing autism policy today is, without doubt, characterized by the increasing incidence of ASDs, the changes in the diagnostic categories of ASDs that are proposed, and the many strides researchers are making in revealing the biology of ASDs and bringing us closer to effective, new interventions.

Increasing Incidence

In October 2009, the journal *Pediatrics* published a study of a 2007 national telephone survey of parents, which showed a parent-reported prevalence of ASD of approximately one in 91 children in the United States. Odds for having an ASD were four times higher for boys than girls. Although some questioned the accuracy of the parental reporting method that resulted in this estimate, another study, reported in December 2009 by the Autism and Developmental Disabilities Monitoring (ADDM) Network found on average, approximately one child in every 110 in the 11 ADDM sites was classified as having an ASD. This new prevalence of ASDs among children represented a 57 percent increase in prevalence in 10 sites from the 2002 data.

While many factors may be contributing to this increasing prevalence rate, research is indicating that at least part of the higher estimates reflects a true increase in the incidence of these disorders. Researchers at the University of California, Davis found just 33 percent of the increased diagnoses in California were the result of physicians using broader definitions of autism and diagnosing younger children, leaving 67 percent of the increase unexplained. The December 2009 ADDM Network study states "Although some of these increases can be accounted for by improved identification and awareness, the steady increase in ASD symptoms in the population possibly reflects increased risk, particularly among males."

A Changing Diagnosis

The American Psychiatric Association (APA) is currently revising its Diagnostic and Statistical Manual of Mental Disorders (DSM), the reference document used by clinicians such as psychiatrists, physicians, and psychologists to diagnose mental illness, and ASDs. The process of revising these criteria is a lengthy one, and the final DSM-5 is scheduled for publication in May 2013. The APA issued its draft diagnostic criteria in February 2010 for review and comment by clinicians and researchers in the field.

The new edition of this diagnostic manual is expected to place a greater emphasis on the severity of patients' symptoms and on the existence of symptoms that crosscut different disorders. This new emphasis is apparent in the proposed changes to the criteria for diagnosing ASDs. For the first time, the manual will group ASDs together into a single diagnostic category "Autism Spectrum Disorder" that will include the current diagnoses of autistic disorder, Asperger's disorder, childhood disintegrative disorder, and pervasive developmental disorder (not otherwise specified). APA has also proposed consolidating the three domains of social impairment, communication impairment and restrictive and repetitive behavior into two categories: social interaction and communication and repetitive behaviors and fixated interests and behaviors. These changes, if implemented, will have implications for diagnostic labels and the growing societal understanding of autism as a spectrum disorder in which individuals experience a wide range of impairments within common domains rather than distinct diagnoses.



Advances in Science

As the incidence of ASDs continues to rise, the quest to understand the biologic causes within the human genome and brain, and to develop effective means of combating the symptoms and supporting individuals with ASDs to live full and productive lives intensifies. Each year scientists and researchers report exciting findings that explain more of the puzzle, bringing new insight into the complex genetic and environmental interplay that is thought to lead to autism. In recent years, researchers have: expanded our understanding of how variations in the human genome are connected to the behavioral and social impairments seen in individuals with ASDs, improved our ability to effectively screen and diagnose children at an early age, increased our understanding of risk factors that contribute to ASDs, and better identified how individuals with ASDs process the world and respond to various treatments.

OPWDD's research arm, the New York State Institute for Basic Research in Developmental Disabilities (IBR) is engaged in studies related to each of these areas. Its scientists are actively seeking ways to identify children at very young ages who may later develop an ASD. They are testing drugs that may target the core symptoms of fragile X syndrome and autism. And they are finding effective ways to deliver intensive behavioral services to students whose behaviors are threatening their placement in public school. IBR continues to advance an extensive slate of autism related initiatives and to partner with other research organizations.

Each study, whether at IBR or elsewhere, contributes to our rapidly growing understanding of ASDs and brings us closer to identifying new, effective treatments. Still, understanding of this extremely complex neurological condition cannot come soon enough. Rigorous study must continue, and government must play a role in promoting and applying the growing body of knowledge that results.

The Interagency Task Force on Autism

Throughout 2009, the Commissioners of OPWDD and the State Education Department (SED), as co-chairs of the Interagency Task Force on Autism, engaged the leadership of nine other State agencies in a comprehensive examination of the needs and issues facing New Yorkers with ASDs and ways to provide supports and services more directly, efficiently and effectively. The Task Force reviewed recent documents describing public testimony regarding families' needs and conducted focus groups around the state and an online survey. It also examined all New York State initiatives related to autism, taking the first comprehensive look at all that New York State has been doing to respond to the needs of those diagnosed with ASDs.

In January 2010, the Task Force submitted a report of its findings and recommendations to Governor Paterson, the New York State Board of Regents, the leadership of the New York State Legislature and the Inter-Office Coordinating Council. The report contains 13 findings related to the needs of New York citizens living with ASDs and numerous recommendations that will guide New York State to improve its support for these individuals. Perhaps most importantly, the Task Force broke each recommendation down into smaller, achievable short term steps that State agencies can pursue even now, within the current fiscal climate. The Task Force recommendations are focused around five areas of need:

- Early Identification of Children with ASDs
- Adequacy and Capacity of New York State services
- Coordination of Services between different State Systems
- Providing Information
- Coordination of ASD Research





www.nyacts.com

In addition to providing New York State with a carefully considered and comprehensive plan of action, the Task Force created a State information resource on ASDs in the form of a new State Web site: New York’s Initiative for Adults and Children on the Autism Spectrum (www.nyacts.com). The Web site was created in direct response to the expressed need for a single point of reliable information on autism and the services and supports New York State agencies provide to individuals diagnosed with ASDs and their families. NYACTS represents a State-wide collaboration to make the information the public needs available in one place, in easy-to-understand language and to provide direct links to the programs and agencies that can start families and individuals on their way to receiving the support they need. While the Task Force has completed its work, each agency participant has pledged to continue contributing to the maintenance and expansion of the NYACTS Web site.

The report of the New York State Interagency Task Force on Autism can be found at http://www.omr.state.ny.us/autism/images/hp_autism_interagencyreport.pdf.

A Focused Platform of Response

From these developments and trends, several themes have emerged, each of which speak to the clear and ongoing need to elevate New York’s competency – the ability of our service system staff and administrators, educators, physicians, families, and communities to appropriately and effectively support individuals on the autism spectrum. As OPWDD continues to pursue the initiatives within its original Autism Platform, and add to them the steps identified by the Interagency Task Force, it will organize its work according to these themes and keep before the agency the overarching goal of increasing ASD competency. Each project within the Platform contributes to one of these four themes and ultimately, to that overall goal.

The Autism Platform commits OPWDD clinicians and staff to working with staff of other State agencies and external partners in projects that will focus on:

- Developing ASD related training for a variety of parties,
- Sharing critical information about ASDs, available services and supports,
- Enhancing the service system to more effectively support individuals and families, and
- Advancing our scientific understanding of ASDs and the evidence base supporting best practices in the identification, assessment, diagnosis, education and treatment of ASDs.

Reshaping its Autism Platform around these four objectives allows OPWDD to respond to current developments and understanding and continue as a leader in New York State’s comprehensive response to autism.

In nyacts, individuals with autism spectrum disorders and their families now have a single comprehensive resource to go to for important information on autism and the State services available to address the needs of these individuals and their families.



ASD Training

Many recommendations of New York State’s Interagency Task Force on Autism called for the State to provide appropriate training related to ASDs for a wide variety of parties. The Task Force found that New York’s teachers, physicians, families, service system staff, and first responders – to name a few – all need access to training to improve how they support and serve individuals with ASDs. These parties interact with individuals in different ways, but each group is in need of more specific information to help them interact more effectively and lead to better outcomes.

This Autism Platform commits OPWDD to implementing an extensive slate of ASD training initiatives. The projects will build on efforts that are currently underway and add new instructional initiatives intended to respond to specific, identified needs. The autism training initiative includes developing and implementing the following training programs:

- A staff and supervisory curriculum for delivering residential habilitation services;
- A statewide Train-the-Trainer program for instructing parents and caregivers in behavior modification and teaching related to targeted challenges;
- A statewide First-Responders Train-the-Trainer program for preparing fire fighters, police and emergency medical personnel to effectively serve individuals with developmental disabilities, including ASDs;
- Expansion of the joint OPWDD and Office of Mental Health “One-Person/Two-Systems” training to a “One-Person/Multiple Systems” curriculum that is relevant to multiple service systems serving both children and adults;
- A basic ASD Curriculum for OPWDD staff (Service Coordinators and others);
- A positive behavior management curriculum for OPWDD and voluntary service provider staff; and
- An emergency preparedness curriculum for OPWDD staff.

As OPWDD develops each of these trainings, it will review existing resources and best training practices and work with partners both within and external to State government to ensure the efficient use of State resources and the widest reach for the new materials. As it develops and implements new trainings, OPWDD will seek ways to provide them to both State staff (within multiple systems if appropriate) and voluntary providers of OPWDD services, paying particular attention to providing training opportunities for emerging and multi-cultural providers.

Sharing Information

OPWDD’s provision of information related to ASDs and the services and supports available to individuals with ASDs and their families is a second area of focus within this Autism Platform. Short of needing structured training, many people simply need ready access to information, information that can lead a family to understand child development and have confidence in approaching their pediatrician or seeking out a professional evaluation, or information that can guide them to the services their loved one needs. Some people know what information they seek and are savvy with informational technologies such as the Internet. Others do not realize they need information, and many do not have access to the Internet. For others, finding information in their own language is the largest challenge.

The Interagency Task Force on Autism recommended numerous activities that contain an important public education component or that relate directly to information dissemination. Fulfilling these recommendations and bringing information about ASDs to the State’s citizens is now engaging OPWDD fully in the realm of public awareness: describing and disseminating

broadly and strategically critical information related to ASDs and doing so in ways that address language and technology barriers.

The Autism Platform commits OPWDD to significant activity in ASD communications:

- Participation in a multi-agency ASD Public Awareness Campaign;
- Publicizing, maintaining and expanding NYACTS to provide additional information;
- Maintaining and expanding OPWDD’s Autism page;
- Disseminating information on ASD trainings, available New York State services, service system eligibility standards, and behavior management; and
- Finding ways to make information accessible to non-English speaking individuals.

OPWDD has already begun and will continue working with other State agencies to pursue these activities. The partnerships formed through the work of the Task Force provide unprecedented opportunities to achieve broad and effective information dissemination, and ultimately, improve the ASD competency of our service systems and the public.

Improving the Service System

When the Interagency Task Force on Autism asked focus group participants and survey respondents to rank the most important activities for New York State to undertake, providing services to individuals and families was the first on the list. OPWDD is committed to providing the highest quality, most effective services and supports to individuals with developmental disabilities. It is essential to fulfillment of the agency mission, and many administrative structures are in place to allow the agency to continually assess and improve the delivery of services. As OPWDD takes steps to improve its ability to meet the needs of individuals with ASDs in particular, it enhances the services that are available to any qualifying individual, with or without an ASD diagnosis.

Within the Autism Platform, OPWDD is undertaking focused projects that will improve its ability to meet individuals’ needs and grow its understanding of best practices in doing so. As OPWDD evaluates each new service and initiative, it will apply the knowledge gained throughout its statewide system. OPWDD will continue to build the body of evidence demonstrating the effectiveness of its services and promote the use of evidence-based treatments and interventions for individuals with ASDs under the direction of qualified clinicians and professionals.

OPWDD will continue to pursue the following service system enhancements as part of its Autism Platform:

- Development of standardized guidelines for the assessment and diagnosis of ASDs;
- Development of a model for delivering clinical behavioral intervention services to students in public schools;
- Development and sustained operation of an effective short-term Intensive Treatment and Stabilization Center for adults with ASDs;
- Development of In-Home Intensive Behavioral Services;
- Development of a model for successful supported employment for individuals with ASDs; and
- Improved data sharing practices with other State agencies to facilitate smooth service system transitions for individuals.

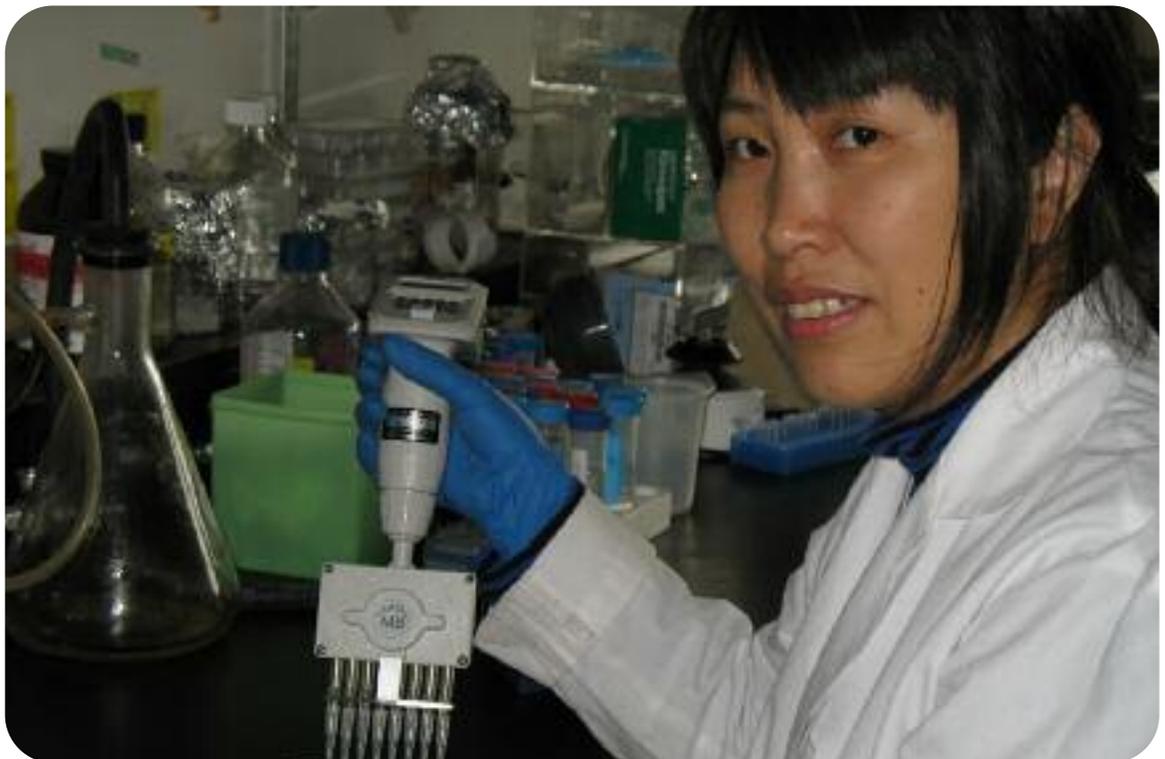


Advancing Research

OPWDD's commitment to research into the causes and prevention of developmental disabilities, including ASDs, is unwavering. The insights coming out of the work of the agency's Institute for Basic Research in Developmental Disabilities (IBR) on Staten Island support OPWDD's ability to improve the effectiveness of its services and relates directly to its mission of helping people with developmental disabilities live richer lives. IBR scientists and researchers continually pursue a comprehensive slate of basic and applied studies with significant implications for future treatment. In doing so, they forge partnerships with researchers throughout New York State and beyond, compounding knowledge and sharing in the quest for understanding and hope.

The Interagency Task Force on Autism noted the need for ASD research that connects and grows shared knowledge so that more expert minds can ask questions, form hypotheses, and make discoveries from a common, state-of-the-art understanding. It also noted the need to unite government and private sector resources to maximize impact and advancement. With these needs in mind, OPWDD's Autism Platform continues to pledge OPWDD's support for:

- Connecting IBR researchers to private sector researchers via shared ASD projects and studies;
- Pursuing a meaningful agenda of applied studies within OPWDD's Autism Treatment Laboratory at IBR and establishment of a clear channel for this research to support improved practice and service delivery statewide;
- Continued pursuit of a full slate of basic science research projects at IBR, drawing on federal and private research grant opportunities; and
- Continued scientific evaluation of ASD service delivery initiatives to "close the loop" and connect results to continuous system improvement.



OPWDD recognizes the vital connection between the aggressive and relentless pursuit of knowledge and the power to more effectively help people. Services must be grounded in real understanding, understanding that has been tested by rigorous evaluation. For all those individuals yet to be diagnosed with ASD, and no doubt many who already live with ASD, research is the key that will unlock a better life in ways we are only beginning to imagine.

Putting People First and New York's Fiscal Challenges

Putting people first is a motto at OPWDD. It came from the 2007 "Putting People First" statewide listening forums held by OPWDD in partnership with the New York State Office of Mental Health and Office of Alcohol and Substance Abuse Services. The motto now captures OPWDD's fundamental guiding principle: to seek ways to allow the individual receiving services to shape how the agency supports his or her life.

"Putting people first" is particularly challenging and essential as New York State responds to the needs facing individuals with ASDs. Many State agencies, each with their prescribed systems of support, provide services to individuals with ASDs and their families. Yet, each system has structures and procedures that can conflict with the requirements of another system. State agencies are challenged to look outside the confines of their unique administrative structures for ways to ensure that the individual's needs are being addressed efficiently, that State bureaucracy is not hindering the assistance that is needed and available. To examine the adequacy and the ability of New York's numerous service systems to work together to meet the wide ranging needs of individuals with ASDs, New York State must take on the perspective of the one being served.

The current fiscal crisis has also made it necessary to examine government operations within and across New York State agencies. With reduced resources, OPWDD must identify and hone in on the most meaningful improvements it can make in its provision of services for individuals with developmental disabilities, including those with ASDs. The fiscal climate demands this selection and focus. The "person first" perspective will reveal the needed improvements.

As part of the Autism Platform, OPWDD is committed to continued collaboration with New York State's human service agencies in identifying the "person-first" perspective and finding ways to effectively support individuals with ASDs and their families with multiple systems.

For information on OPWDD's progress in implementing the initiatives of the Autism Platform, visit www.omr.state.ny.us and click on "Autism Platform".

To initiate real action during this difficult fiscal climate, the Autism Task Force articulated numerous short-term steps for agencies to take toward the accomplishment of its recommendations.





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For further information, please check the OPWDD Website:

www.opwdd.ny.gov

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