New York State Interagency Task Force on Autism

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Table of Contents

I. Executive Summary ……..... 3

II. Task Force Members …….. 5

III. Introduction ……... 7

IV. Findings and Recommendations …….. 13

V. Appendices …… 41

VI. References …….. 95

I. Executive Summary

The number of Americans diagnosed with an Autism Spectrum Disorder (ASD) has risen dramatically in recent years. Estimates vary, but generally place the present incidence rate of ASD among children between one in every 91 - 150 individuals. In public forums held in 2007, New York State's service agencies heard about the tremendous needs facing people living with this diagnosis. In 2008, New York State Office of Mental Retardation and Developmental Disabilities (OMRDD) announced its Autism Platform, a comprehensive slate of initiatives for advancing OMRDD's system of supports and services to meet the needs of individuals with ASD. The Platform called for an Interagency Task Force on Autism that would examine how New York supports people diagnosed with ASD within service systems that exist to support individuals with many different needs. Based on these findings, the Task Force was charged with crafting a response that would improve inter-agency coordination of services, maximize the impact and effectiveness of services and agency functions, elevate New York's ASD competency, and identify opportunities for government to partner more effectively with private enterprise in support of individuals with ASD. New York State undertook this exercise at a time when the State's fiscal environment grew increasingly bleak. The Task Force was challenged to identify the needs faced by those with ASD and an appropriate response within the constraints of a monumental economic and budget crisis. The recommendations presented in this report will guide New York State to improve its support of individuals with ASD in the coming years. The short-term steps the Task Force has articulated embody immediate actions that will allow New York to embark on those improvements even now.

With assistance from the regional Centers for Autism and Related Disabilities (CARDs), the Task Force sponsored regional forums throughout the state to gather public input related to these needs. The agencies of the Task Force also posted a brief survey regarding the service needs of those with ASD on individual agency Web sites. The findings of both the regional forums and the online survey confirmed the five areas of focus that the Task Force chose to guide its year-long study:

- early identification of children with ASD
- better coordination of State services
- lifelong service delivery
- increased dissemination of ASD information
- coordinated ASD research

Respondents indicated that New York's top ASD priority should be providing services to individuals. They identified the provision of training for service providers, educators and families as the second most important activity to undertake.

Task Force workgroups assessed where and how New York's service agencies should be moving to address specific issues within each area of need. Their findings, contained in this report, document the following needs:

- increased ability of physicians and specialists to screen for, assess and competently diagnose young children with ASD,
- greater availability of accurate and reliable information about ASD and available services and supports,
- greater availability of evidence-based services and practices,
- specialized training for teachers,
- a continuum of residential supports to meet the full range of needs,

- greater support for families to avoid crises,
- additional assistance for individuals to prepare for post-school employment,
- improved provision of service coordination across the lifespan,
- improved coordination of service delivery across multiple systems,
- more information about the needs of those who don't now meet standards for service eligibility,
- overcoming language barriers in the provision of information and services, and
- a coordinated research agenda that can deliver improved ASD practices across the state.

The Task Force developed 27 distinct recommendations to guide New York service agencies in addressing these findings. To initiate real action during this difficult fiscal climate, the Task Force further articulated numerous short-term steps for agencies to take toward the accomplishment of each recommendation.

This report includes a discussion of the Task Force's findings. The Appendices represent the work products of several of the Task Force workgroups, including detailed summaries of the public outreach, an overview of New York State services for individuals with ASDs, the results of a Task Force survey of autism research underway in New York State, Task Force testimony delivered before the New York State Senate Committees on Health, Insurance, and Mental Health and Developmental Disabilities, and a detailed update on OMRDD's Autism Platform initiatives.

II. Task Force Members

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In addition, the Task Force acknowledges with gratitude the assistance provided by DDPC Staff member John McDonald in compiling, analyzing and reporting the results of the online survey and regional focus group questionnaires.

* Indicates Member Delegate also served on the Task Force Steering Committee.

III. Introduction

Autism spectrum disorders (ASDs) are a group of neurodevelopmental disorders that affect a person's social interaction, communication and behavior throughout their life. The "autism spectrum" refers to the continuum of symptom severity and expression that individuals with ASD can experience. The spectrum includes autistic disorder, Pervasive Developmental Disorder-Not Otherwise Specified and Asperger syndrome. These disorders are diagnosed by careful clinical observation. As the word "spectrum" implies, individuals diagnosed with ASD are each unique. They may be extremely verbal or entirely nonverbal. They may experience mild to severe difficulties in learning. Some experience challenging behaviors that endanger themselves or others. Others exhibit repetitive, self-stimulating behaviors such as hand flapping, rocking or twirling, or unusual interests and activities. Although the exact cause of ASD remains unknown, research is revealing there may be many factors that contribute to it and explain its variability. Scientists have uncovered a genetic basis that suggests a higher risk for ASD among siblings. At present, there is no cure for ASD, and many individuals with ASD will need lifelong supports and services.

The numbers of Americans diagnosed with an ASD have risen dramatically in recent years, although estimates vary greatly depending upon the survey methodology used. Data from the Autism and Developmental Disabilities Monitoring (ADDM) Network that looked at eight-year-olds in 15 regions reported ASD prevalence as one in every 150 children[1]. 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[2]. Odds for having an ASD were four times higher for boys than girls. Despite the range in estimates, there is general agreement that the numbers of individuals with ASDs are significantly higher than those reported ten years ago. At present, it is unclear how much of the reported increase in incidence of ASD is due to increased accuracy of diagnosis — identifying children with ASD who previously would have been diagnosed differently— or to a true increase in the incidence of ASD. While at least one recent study at the University of California, Davis indicates that only about a third of the increase in ASD incidence is due to earlier and better diagnosing, long term, population-based studies are needed to reveal the exact nature of the increase relative to the incidence of all developmental disabilities.

Costs and Context

The costs of assisting individuals with ASD in attaining their potential and living a productive life are significant and will be borne collectively by families, medical insurers and the government. In 2007, a study conducted by Harvard School of Public Health reported that each individual with ASD requires supports and care averaging approximately $3.2 million over his or her lifetime[3]. The costs of services for individuals with ASDs and the role of private insurance in meeting those costs is a current public health policy issue that is fast evolving and national in scope. Because of the ongoing dialogue around this topic, the Task Force did not seek to address the details of insurance mandates for ASD coverage.

Data contained in this report does document the increased resources dedicated by New York State to supporting individuals with ASD. Given the early and lifelong service needs of many individuals with

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[1] Center for Disease Control, Mortality and Morbidity Weekly Reports (MMWR) Surveillance Summaries, February 9, 2007 / Vol. 56 / No. SS—1

[2] Michael D. Kogan, et al. "Prevalence of Parent-Reported Diagnosis of Autism Spectrum Disorder Among Children in the US, 2007," *Pediatrics*, published online October 5, 2009

[3] Michael L Ganz, "The Lifetime Distribution of the Incremental Societal Costs of Autism," *Archives of Pediatric and Adolescent Medicine* 2007, 161(4):343-349.

ASD, the need to provide services and supports for these individuals is likely to continue to increase. New York State recognizes this trend, and the Task Force has sought to prepare New York's service systems to respond. New York has undertaken this most comprehensive and focused examination of the challenges of autism at a time when the State's fiscal environment has grown most bleak. The challenge before the Task Force was to identify the needs faced by those with ASD and identify a State government response that can occur within the constraints of an economic and budget crisis. The *findings and recommendations* within this report speak to what the State must do to address the needs of its citizens with ASDs. They are the horizon to keep in sight. The *short-term steps* direct meaningful and manageable actions State agencies can take today, even in the present fiscal crisis, to move New York's service systems toward greater effectiveness and efficiency and bring the horizon within reach.

The Task Force also recognized the service system context within which New York State agencies support individuals with ASDs and their families. None of the agencies participating in the Task Force exist to serve only people affected by ASD. Each has a broader mandate and has established programs of services that support a wide variety of people, *including* those with ASDs. The Task Force afforded these agencies the opportunity to examine what they do through the lens of a person or family living with autism so that the State can be assured it is working to serve this growing population effectively. The recommendations and short-term steps within this report will advance our agencies toward that goal. They will also bring many meaningful improvements to New York's service systems for the benefit of everyone who receive services. They do not represent a fracturing of service system focus, but rather an enhancement that supports greater effectiveness in fulfilling New York agencies' missions.

The Autism Platform and Interagency Task Force

In New York State, physicians, educators and State and voluntary agencies that provide services and supports have seen similar increases in ASD. In statewide public forums held in 2007, New York State's public service agencies[4] heard repeatedly about the tremendous needs facing the rising numbers of people living with this diagnosis, needs that often bring families to multiple State agencies for supports and services. In 2008, in response to these trends, New York State Office of Mental Retardation and Developmental Disabilities (OMRDD) put forth its Autism Platform. The Platform was and continues to be a comprehensive slate of key initiatives for advancing OMRDD's system of supports and services to meet the needs of individuals with ASD. Mindful of the need to rally a response to ASD that involves multiple State partners, OMRDD proposed within the Autism Platform development of an Interagency Task Force on Autism. The Task Force would engage the leaders of New York's various service systems, each of which plays a role in supporting individuals with ASD and their families. These leaders would examine how their respective parts of State government — in areas such as health, education, and disabilities services — together could provide lifelong support to New York citizens diagnosed with ASD as they seek to live meaningful and productive lives. In essence, the Task Force would examine how New York State services are meeting people's needs and where, working together, they can do a better job. With Governor David Paterson's support, 11 State agencies formed New York State's Interagency Task Force on Autism.

[4] The 2007 People First Forums were convened by the Commissioners of New York State OASAS, DOH, OMH and OMRDD in the spring and summer of 2007 at five locations around the state.

Charge of the Task Force

At its first meeting in November 2008, the members of the Task Force crafted a formal charge that would guide their work for the ensuing 12 months and culminate in a report to the New York State Governor, Legislature, Board of Regents and the Inter-Office Coordinating Council. Maintaining a focus on State service systems, Task Force members agreed that their greatest contribution as a State-level body would lie in examining the cross systems nature of the service needs of individuals with ASD and identifying ways the various State service systems can work together to better meet those needs across a lifespan. They agreed the Task Force should identify the greatest challenges in this regard, identify steps to address those challenges, and initiate interagency collaboration and momentum for taking those needed steps.

The charge for the New York State Interagency Task Force on Autism was:

- ***To examine*** how New York State government can prepare for a future in which it coordinates a comprehensive system of lifelong supports that assists a significantly increased number of families and individuals living with ASD to create the opportunities they desire for their lives;

- ***To gather input*** from the range of stakeholders (families, individuals with ASD, advocates, service providers, and others) on the needs and desires of those living with an ASD; and

- ***To make recommendations*** for:

  - ***improving the inter-agency coordination*** of services for individuals with ASD that put the needs of the person and their families first;

  - ***maximizing the impact and effectiveness*** of services and related agency functions;

  - ***elevating New York State's competency*** in understanding and responding to individuals with autism (from physicians and first responders to state and local service system workers and others); and

  - ***identifying and pursuing opportunities for government to partner with private enterprise*** in support of individuals with ASD and their families.

The Task Force members agreed their work would articulate a comprehensive State response to the needs of those living with ASD. For that response to be lasting and effective, the Task Force members also identified the following principles that should guide New York State's ongoing response to ASD:

- New York State should seek to support individuals with ASD and their families in identifying and pursuing their own goals for their lives;

- New York State services and supports for individuals with ASD should be informed by continuous and regular stakeholder input;

- New York State's response to ASD should be evaluated regularly for effectiveness with a focus on continuous improvement; and

- New York State supports and services for individuals with ASD and their families should be delivered by public and private entities working together in a coordinated manner.

Task Force Process

To carry out the work of the Task Force, each member agency designated staff persons to a Steering Committee that would plan the activities and meetings of the Task Force and serve as the communications hub for the 11 State agencies involved. The Steering Committee met frequently in person and via conference calls and became the forum for very frank cross system discussion and sharing of information about the different State systems engaged in addressing ASD. This elevation of systems knowledge between agencies cannot be underestimated in its value to New York's future ASD initiatives and services. It may defy measurement, but it informs the recommendations of this report and in many specific issue areas has resulted in collaborative "first steps" that a year ago would not have been suggested. This kind of cross agency collaboration and appreciation for agencies' shared responsibility to support individuals with ASD must continue. New York State government must advance what has begun with the Task Force process. It must continue to examine its service systems from the perspective of the citizens it supports and spur improvements in how those different systems each contribute to comprehensive and lifelong support for individuals.

Identifying Needs and Current New York State Initiatives

To begin its work, the Task Force recognized that it needed to understand two things: the types of issues and needs experienced by individuals with ASD and their families and the breadth of current New York State initiatives, services and supports. The Task Force examined the many distinct State services and initiatives recently completed or in progress within member agencies. The results of this initial Task Force exercise revealed a wide range of activities underway in New York State government related to addressing the needs of individuals with ASD.

The Task Force also created a two-part plan for assessing the many challenges experienced by individuals with ASD and their families. First, the Steering Committee examined existing reports documenting statements from service providers, professionals, parents and individuals about the needs and challenges facing people diagnosed with ASD and their families. New York's human services agencies had recently completed public forums around the state inviting comment and suggestions related to service needs. Similarly, much work had already been done by member agencies in fulfillment of their distinct missions. In many cases, agencies were engaged in specific projects that relate to ASD and had worked with respective stakeholders to gather input regarding their needs. The Task Force recognized that this up-to-date, existing knowledge would provide a good foundation for its work. The Task Force reviewed 16 documents that ranged from reports of statewide public forums and local ASD advisory group meeting minutes to reports from national disabilities organizations and distinct State agency reports related to ASD and other disability policy issues. This review provided an understanding of the needs and functioning of individuals with ASDs, their families, and local and State agency services and initiatives.

The Task Force also recognized the need to reach out to New York citizens to confirm the information it gleaned from recent reports and ensure that it did not overlook any newly emerging issues. For the second part of its information gathering, therefore, the Task Force would seek additional input from families, individuals and professionals. The outreach efforts would not be exhaustive and statistically conclusive, but rather, confirmation of a reasonable understanding of present needs related to ASD. With a time limited endeavor before the Task Force, this plan was both a manageable and meaningful way to accomplish its goals.

Five Areas of Need

The review of existing documentation of ASD related issues and the inventory of State activities led the Task Force to identify five pressing needs related to ASD:

- The need for early identification of children with ASD

  It is critical that New York State improve the ability of its health care providers to identify and accurately diagnose young children with ASD. Intensive treatment at the earliest ages has the greatest potential to improve the outcomes for children.

- The need for coordination of State services

  Individuals with ASD frequently require supports from more than one State service system during different stages of their lives or even at any particular point in time. New York's state government must improve transitions as individuals with ASD move from one service system to another and coordinate services for those receiving services from more than one system.

- The need for lifelong service delivery

  People with ASD often require lifelong supports. As the incidence of ASD is increasing, New York State must prepare to address the specific needs of individuals with the most appropriate, evidence-based treatments and support services.

- The need for increased dissemination of ASD information

  The need for State government to provide accurate information about ASD and services and supports to many different segments within the state is mounting. New York State must mobilize a coordinated effort to provide all parties with user-friendly means to access the information they need.

- The need for New York State to coordinate ASD research efforts

  New York State must marshal its greatest scientific talent and professional expertise to engage collaboratively in expansive scientific and applied research, research that makes the best use of public and private funding and takes us further faster in understanding ASD and how to respond to the needs it presents.

The Task Force organized its ensuing work according to these needs and established five staff level workgroups to examine more closely State activities related to each.

Outreach

To pursue the second phase of stakeholder input gathering, the Task Force undertook two specific outreach activities. With assistance from the six regional Centers for Autism and Related Disabilities (CARDs) throughout New York State, the Task Force sponsored regional forums throughout the state wherein service providers, teachers and other professionals, parents, family members and individuals with ASD provided direct input related to the five areas of need. Eight regional forums occurred within the months of September and October 2009. They engaged 117 stakeholders from diverse backgrounds in completing detailed questionnaires and group discussions.

The Task Force also developed a brief survey to obtain public input on the needs of those with ASD. The survey instruments inquired about the most important service needs for individuals with ASDs, the top ASD priorities for New York State, and the needs related to the workgroups' five areas of focus. The agencies of the Task Force posted this online survey on their Web sites and invited wide participation.

More than 3,000 responses were received. Appendix B contains a listing of the documents that were reviewed, the questionnaire and online survey, and their results.

The responses to the online survey and the focus group questionnaires confirmed many of the trends and issues Task Force agency staff expected and affirmed the appropriateness of the Task Force's five selected areas of concern (Early Identification, Adequacy and Capacity of Services, Coordination of Services, Information Dissemination, and ASD Research). They also provided new information regarding the most pressing priorities related to improving services for individuals with ASD and their families and future ASD research needs. Respondents told the Task Force that the most important ASD priority for New York State should be providing services to individuals. Respondents listed providing training for service providers, educators and families as the second most important activity to undertake.

The most important service need was for special education services, followed by behavior management training, access to clinical specialists with ASD expertise, transition services to assist students as they leave school, and respite opportunities. Respondents ranked the lack of insurance coverage and the cost of services as a significant obstacle to service delivery. They also said the availability of trained educators, clinicians, and direct support professionals and the availability of needed services were also obstacles. Crisis intervention services and job training or post secondary services were reported to be insufficiently available, and differences in the services available from different systems contributed to delays in receiving services.

With respect to informational needs, focus group participants reported that people most need information on behavior management, evidence-based treatments, accessing New York State services, and local resources and connections. They said information must be available in multiple languages and through means other than Web sites. In addition, the Task Force learned that not just parents, but all parties — teachers, physicians, direct support staff, emergency responders — need access to better information.

Finally, the focus group participants reported that research into ASD needed to focus first on early identification of ASD. Second, researchers should study the development of new treatment methods, and third, the development of educational methods.

IV. Task Force Findings and Recommendations

Finding 1:
There is limited use of ASD screening tools by primary care providers such as pediatricians.

Recommendation 1-1:
Increase the utilization of screening for ASD in young children by pediatricians and other primary health care providers and referral of children with potential ASD for early intervention services.

The New York State Department of Health (DOH) Early Intervention Program (EIP) in its 2007-08 program year served 3,922 infants and toddlers with ASD, nearly double the number that was served five years ago. DOH estimates that the EIP reaches approximately 70 percent of the children in New York State with ASD. While this figure represents a tremendous effort to reach young children with intervention services, nearly a third of all children who may be diagnosed with ASD are not receiving services under age three, unless parents obtain it privately. Research now shows that toddlers can be identified as having ASD as early as 18 months of age. DOH data indicate that the average age of reported diagnosis of ASD among children in the EIP is 23 months.

Evidence indicates that the earlier children are diagnosed with ASD and begin intervention services, the better their chances for minimizing the symptoms and impact on their lives. The American Academy of Pediatrics has recommended that pediatricians conduct early childhood screening as part of well child visits at both 18 and 24 months of age. Such screening involves the use of a questionnaire or an interview with the child's caregiver regarding the child's development and behavior. Screening is intended to identify children experiencing delayed development in key areas that might indicate an ASD. A positive screening result detects children who are at risk of having an ASD. By itself, a screening result does not constitute a diagnosis. Physicians should refer children whose screenings are positive to specialists with expertise in ASD to conduct more extensive evaluations prior to making a diagnosis.

Data from a 2004 survey of pediatricians indicate that many primary care providers are not using screening tools to conduct early screening of young children, revealing that only eight percent of pediatricians routinely screen for ASD[5]. The input the Task Force gathered from public stakeholders confirmed that these findings are still valid. Lack of training regarding the use of appropriate screening tools and lack of guidance regarding reimbursement for these screening services have been reported as primary reasons for the limited use of screening tools.

Because of the wide variability of the presence and intensity of the features of ASD, it is important that pediatric providers are aware of the signs and symptoms of ASD and use a standardized screening tool to identify early those children that need to be referred for further evaluation. To increase the ability of New York's pediatricians and family practitioners to competently screen for ASD such that children can be diagnosed as early as possible, New York State must increase training and information dissemination to promote awareness and use of appropriate ASD screening tools by physicians.

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[5] Susan Dosreis et al., "Autism Spectrum Disorder Screening and Management Practices Among General Pediatric Providers," *Journal of Developmental & Behavioral Pediatrics*: April 2006 - Volume 27 - Issue 2 - pp S88-S94

Short Term Steps

The Task Force recommends New York State agencies undertake the following short-term steps toward implementation of this recommendation:

Public Awareness Campaign

The Autism Summit Public Awareness Workgroup, a cross-systems workgroup created by the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs, is developing a coordinated public awareness campaign to promote early recognition and screening of children with ASD. New York State agencies should commit to active participation in this statewide campaign. (This short-term step will also help New York State implement Recommendation 3-2.)

Develop Best Practice Protocols for Early Childhood Screening

Governor Paterson signed legislation in 2008 that requires DOH to issue best practice protocols for universal screening of children at 18- and 24-month primary pediatric care visits, including standards and guidelines recommended by the American Academy of Pediatrics (AAP). The protocols are required to include the use of the Modified Checklist for Autism in Toddlers (M-CHAT) tool as a component of the screening.

Promote Best Practices in Screening and Referral

As part of the New York State Partners for Healthy Futures for Children and Youth with ASD funded by the US Health Resource Services Administration under the federal Combating Autism Act, DOH will collaborate with the State's three American Academy of Pediatrics (AAP) chapters to promote use of the best practice protocols and ensure appropriate referrals of children with ASD to EIP for evaluation and intervention and promote appropriate care of children with ASD by community pediatric providers.

Examine Fiscal Barriers to Early Screening

Together, DOH and the New York State Insurance Department should review current reimbursement for autism screening by primary care providers and provide clarifying guidance if indicated. This review should include an assessment of existing statute that defines what is required to be reimbursed as part of routine well child visits, an assessment of the extent that health insurers are currently providing reimbursement for ASD screening in New York State, how insurers reimburse for the services provided during a well child visit, i.e. whether providers are reimbursed according to each service performed or a global amount for the visit regardless of the services provided during the visit, and any differences in reimbursement methods for participating providers versus non-participating providers.

Early Identification

Finding 2:
Throughout much of New York State, it is difficult for families to find and get appointments with professionals with the experience and expertise needed to evaluate and diagnose ASD. These difficulties delay early identification and treatment.

Recommendation 2-1:
Provide information and training on assessment and diagnosis of ASD to physicians, mental health professionals, and families throughout the state to expand their understanding of and capacity for appropriate and early diagnoses of ASD.

Stakeholder response to the Task Force's regional forums revealed that access to thorough assessments conducted by primary care physicians and other specialists using instruments designed to assess for autism is a significant barrier to accurate and timely diagnoses. Many respondents reported that lack of knowledge on the part of practitioners is common and presents a challenge to accessing early intervention. Forum participants suggested that physicians lacked awareness of proper assessment tools and reported experiencing an apparent reluctance on the part of physicians to diagnose individuals with ASD. Many respondents also suggested that New York State institute training for physicians and others regarding ASD, including its identification.

A survey conducted in July and August 2009 on behalf of the Task Force by Parent-to-Parent of New York State revealed that many parents are finding it difficult to obtain information about specialists who are trained to conduct diagnostic evaluations for ASD and, once experienced specialists are located, families report lengthy waiting times prior to receiving an initial evaluation. The lengthy delays mean children remain undiagnosed. In some cases these delays may delay referral of a child to the EIP, although most children with ASD initially qualify for the EIP based upon quantified developmental delays in the communication and social emotional domains previous to obtaining a diagnosis of ASD.

A diagnosis of ASD is determined by careful observation and assessment using appropriate assessment tools designed to uncover an individual's unique strengths and challenges and make sure symptoms are not caused by another medical or psychological disorder. The types of professionals who conduct these assessments and diagnose ASD include pediatricians, psychologists, psychiatrists, and specialists such as pediatric neurologists and others who have experience with ASD. To help them in making a diagnosis, they may call upon other professionals such as speech-language pathologists, occupational therapists, special educators and audiologists to assess specific areas of a child's development and functioning. Therefore, professionals in many distinct areas of practice need preparation specific to ASD to ensure that New York families have access to needed diagnostic services.

To increase the ability of New York's specialists to conduct diagnostic evaluations for ASD such that children can be diagnosed as early as possible, New York State must develop clinical practice guidelines, promote their use, and make training and information available.

Short Term Steps

The Task Force recommends New York State agencies undertake the following short-term steps toward implementation of this recommendation:

Update Clinical Practice Guidelines for Assessment and Intervention for Young Children

New York State DOH should update and disseminate widely the Autism/Pervasive Developmental Disorders Clinical Practice Guidelines for Young Children after completing an assessment of the medical literature that has been published since the guidelines were first released in 1999.

Develop Clinical Practice Guidelines for Assessment and Diagnosis for all Ages

The New York State Office of Mental Retardation and Developmental Disabilities (OMRDD) should develop clinical practice guidelines for assessing and diagnosing ASD in people ranging in age from birth to adulthood, providing a "clinical best practice" model and recommendations that will be accessible and useful for New York State service system clinicians, service providers and private practice professionals, and will inform parents and care givers about appropriate assessment tools.

Enhance Primary Care Physicians' Training in Disabilities Assessment

The New York State Developmental Disabilities Planning Council's (DDPC) Parent Partners and Health Education grants provide primary care medical residents training to increase their skills in screening and assessing children for developmental disabilities, including ASD. DDPC should continue working with the Council on Graduate Medical Education to infuse the Parent Partners in Health Education curriculum into all New York State primary care medical residency and other medical training programs (such as nurses, nurse practitioners and physician assistants.) (This short term step will also help New York State to implement Recommendation 1-1.)

Update and Re-issue Information for Physicians on Identifying Children with ASD

SED should update and re-issue the brochure titled "Identifying Children with Autism Spectrum Disorders: Information for Physicians and Primary Health Care Providers." This brochure provides diagnostic information to support the early identification of children with ASD and contact information and other resources to assist physicians in ensuring these children have access to appropriate educational programs and services.

Information Dissemination

Finding 3:
There is no centralized resource providing families, individuals and others access to accurate, up-to-date information regarding autism and New York State initiatives and services.

Recommendation 3-1:
Develop and regularly update a New York State Web site on autism that provides basic information on ASD and New York State's many autism initiatives and services.

Recommendation 3-2:
Use effective, alternative (non-Internet dependent) mechanisms to inform New York citizens about ASD, the importance of early detection, and New York State supports and services for individuals with ASD and their families.

The Task Force heard numerous statements from a variety of stakeholders regarding the need for easily accessible, easy-to-understand information for families and others about ASD and New York State services. Parents, in particular, described their journey in learning about ASD and finding services for their loved one as a quest for information too often marked by delays and misinformation. The Task Force learned there is still a need to educate parents and physicians about developmental milestones and the needs of individuals with ASD. Families and individuals need information about available New York State support services as well as help understanding how to determine the quality of services. Educators, parents and service providers need information about effective, evidence-based treatments and interventions. In short, the comments and suggestions stakeholders provided made it clear that getting accurate, current information to those who need it — essentially all the parties involved in interacting with and supporting someone with ASD — must be a priority for the State.

Hearing this call for information, the Task Force initiated development of a New York State Web site on ASD that will provide a central hub of up-to-date information on ASD and program initiatives. The site also is expected to provide clear guidance on available State services and supports. The Task Force was an ideal mechanism to enlist the collaborative efforts of multiple State agencies in developing such a needed resource.

In its regional stakeholder forums and its online survey to gather additional public input, the Task Force invited comment regarding the best use of New York ACTS to meet informational needs related to autism. Comments received voiced strong support for New York ACTS and suggested numerous types of informational content that would address current informational needs. Most importantly, they said, New York ACTS needs to provide: clear information about how to access New York State services for individuals with ASD, information to help families and professionals understand how to effectively and positively manage behavior, information about evidence-based interventions, and connection to other families of individuals with ASD. Respondents also suggested that New York ACTS provide information on local resources for families and information specifically intended for pediatricians, teachers and school personnel, emergency responders and direct support professionals.

The Task Force developed plans to launch New York ACTS – an online initiative for Adults and Children on The Spectrum – early in 2010.

Short Term Steps

The Task Force recommends New York State agencies undertake the following short-term steps toward implementation of this recommendation:

Develop, maintain and continue to expand a New York State Web site on Autism

The Interagency Task Force on Autism has developed New York ACTS (www.nyacts.com), an official New York State online resource providing up-to-date and easy-to-understand information about ASD and New York State support services for individuals with ASD and their families. The Web site is designed to be the first stop for a family or individual that has recently received a diagnosis of ASD. It connects users directly to appropriate New York State agencies – and the specific offices within those agencies – to address their needs. While this new centralized resources is a major step forward in meeting informational needs related to ASD, maintenance is essential, and the Web site should continue to grow in its usefulness. Member agencies of the Task Force should identify agency liaisons to participate in an interagency committee that will meet quarterly to review and update Web site content and ensure the Web site remains responsive to informational needs related to ASD.

New York State service agencies should use New York ACTS to disseminate information regarding activities undertaken in response to the recommendations of the Interagency Task Force on Autism contained in this report.

In response to the repeated call for initiatives to inform and educate a range of parties regarding particular aspects of supporting individuals with ASD, several Task Force recommendations call for disseminating information. In each of these instances, New York State should make full use of New York ACTS as an effective means for providing needed information. As New York's State agencies maintain New York ACTS as a public resource, they should explore the potential for the Web site to bring additional types of information to additional parties.

Task Force agencies should develop a shared public information strategy to bring key information related to ASD and State services to New York citizens via effective, non-Internet dependent means.

While the Internet is an essential element in New York State's efforts to address this finding, New York State should not rely solely on the Internet to bring information about ASD to those who need it. Many New York residents do not have access to the Internet. In addition, it is important for New York State to make its outreach efforts as broad, visible and successful as possible by pursuing other effective means of informing citizens about ASDs and New York State's services. The Task Force agencies should collaborate to make sure this informational initiative is comprehensive and continue to execute New York's cross agency commitment to support those with ASD. Agencies should examine and, if appropriate, make use of the materials available from the National Center for Disease Control's "Learn the Signs, Act Early" campaign. New York State's public information endeavor must also recognize and support the activities of the ongoing Autism Summit Public Awareness Workgroup now operating under the leadership of New York's Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Programs.

Adequacy and Capacity of Services

Finding 4:
Individuals with ASD need greater availability of evidence-based services and interventions to support them throughout the stages of their lives.

Recommendation 4-1:
Further promote the delivery of and access to evidence-based services for individuals with ASD through development of guidelines and training programs regarding these practices.

As New York State responds to the increasing diagnoses of ASD with increased information dissemination and appropriate services and supports for individuals, it is imperative that it do so with the highest levels of integrity and responsibility. New York State agencies, in delivering and funding services and supports to address people's needs, must ensure that those services and supports are based on thoroughly examined methods, specifically, methods for which evidence is research-based and has been carefully documented and peer reviewed. To promote unstudied treatments and interventions would be irresponsible. Therefore, New York's agency staff must carefully review scientific evidence demonstrating the effectiveness of various types of interventions and promote those that clearly indicate safety for the individual and support for positive outcomes.

In addition to ensuring a high standard of quality and safety in services, New York State must also advance a widespread understanding of ASDs and the most effective means to support individuals with an ASD, help them learn, and help them find success in their lives. Each year carefully designed studies reveal new information that can improve outcomes for individuals. New York State must assist in translating these research findings into improved practices in screening, assessment, diagnosis, education, and in vocational, clinical and habilitative services. These improved practices will in turn lead to better outcomes for children and adults with ASD. Doing so will advance the use of state-of-the-art, evidence-based methods by private professionals and public service providers, elevating ASD competency throughout many professional disciplines and ensuring that New York's citizens with ASD receive the greatest opportunities for success.

Short Term Steps

The Task Force recommends New York State agencies undertake the following short-term steps toward implementation of this recommendation:

Develop Training Curriculum on Behavioral and Educational Interventions for Early Childhood

DOH, as part of the "Partners for Healthy Futures Initiative" should collaborate with other State partners to develop and implement a training curriculum for EI service providers on Applied Behavior Analysis and other evidence-based behavioral interventions for young children, with input from an expert advisory group. Other State agencies should explore the applicability of this curriculum to other service settings and age groups.

Develop Evidence-Based Practices for Delivering Behavioral Intervention Services in School Settings

In October 2009, the "Short-Term Intensive Behavioral Assessment and Intervention Program" in New York City began providing intensive clinical support to school personnel working with children with some of the most severe self-injurious/aggressive behaviors. OMRDD and SED should study the effectiveness of this program and disseminate information on the lessons learned through this project to

OMRDD service providers and school districts throughout the state. (This short-term step will also help New York State implement Recommendation 5-1.)

Develop an Updated Training Curriculum in Positive Behavior Management

OMRDD should develop and implement an updated curriculum of best practices in positive behavior management training for State and voluntary service provider staff. This curriculum should assure the health and safety of individuals and staff and emphasize the use of physical interventions as a last resort when individuals present an immediate health and safety risk to themselves or others. The curriculum should increase staff understanding of the impact of positive and functional relationships, environments, communication and respect on behavior.

Develop an ASD Training Curriculum for OMRDD Staff throughout the State

OMRDD should develop an ASD training curriculum for OMRDD staff involved in delivering services and service coordination throughout New York State to educate them about ASD, the needs of individuals with ASD, and effective methods of supporting individuals with ASDs. Once the curriculum is available for all OMRDD employees, the agency should explore opportunities to make the curriculum more widely available to staff in voluntary service providing agencies and others. (The second phase of this short-term step will also help New York State implement Recommendation 12-2.)

Develop a Training Curriculum for OMRDD Residential Services

OMRDD should draw upon its collaboration with the SUNY Binghamton Institute for Child Development in developing state-of-the-art residences for young adults and developing and implementing training for the delivery of such residential services throughout the state.

Disseminate Effective Educational Practices for Students with ASD

SED should re-issue and disseminate the Autism Program Quality Indicators Guide which is a research-based self review and quality improvement guide for schools and programs serving children ages three - 21 with ASDs.

Adequacy and Capacity of Services

Finding 5:
Teachers need specialized training and expertise to meet the unique educational needs of pre-school and school aged students with ASD.

Recommendation 5-1:
Identify and disseminate information on evidence-based practices that support improved educational outcomes for students with ASD.

Recommendation 5-2:
Promote the availability of pre-service and in-service educational opportunities related to ASD for teachers, administrators and related service personnel.

Throughout the reports reviewed by the Task Force and, based on comments received through its public outreach, parents and professionals repeatedly called for improved educational services to meet the needs of students with ASDs. Respondents to the online survey and the focus groups ranked providing ASD training for educators among the top three most important activities for New York State to undertake.

Data over the past five years shows significant increases in the number of students in New York State classified with autism. For example, in 2003, there were 10,617 students with autism reported in New York State between the ages of four and 21, compared to 19,132 reported as of October 1, 2008. It is anticipated that there will be an even increasing number of students classified with autism given that 14,046 of those students in 2008 were between ages four and 13[6]. There are likely many other students with ASD that may be classified under other disability categories, such as "preschool student with a disability" and "multiple disabilities" and "learning disabled." These students, enrolled in public and private schools throughout the state, receive special education and related services such as speech and language therapy, occupational therapy, physical therapy and counseling in the least restrictive environment possible for each individual student.

Section 3004 of New York State Education Law establishes training requirements for special education teachers and administrators regarding the needs of individuals with ASD. All persons applying for a teaching certificate or license after September 2, 2009 as a special education teacher and all school administrators and supervisors assigned after September 2, 2009 to serve as special education administrators must complete training in the needs of children with autism. The coursework must be obtained from a provider approved by the New York SED.

To ensure a supportive, quality educational environment for the many students with ASD, however, the teachers, administrators, and other school staff assigned prior to these training requirements also need increased awareness and understanding of ASDs and the most effective ways to educate and support students with this diagnosis. From classroom teachers and school psychologists to lunchroom staff, bus drivers, and other students without disabilities, everyone involved in public education needs current

[6] Data available on-line at http://www.vesid.nysed.gov/sedcar/goal2data.htm

information regarding ASD. Informed staff and teachers will be more effective at engaging families as partners in providing consistent quality support for students with ASD to learn and succeed at school, at home and in the community.

Short Term Steps

The Task Force recommends New York State agencies undertake the following short-term steps toward implementation of these recommendations:

Disseminate Information on Evidence-Based Practices to School Districts and Service Providers

SED should disseminate information on the following topics to school districts; voluntary providers of special education and related services; and private and specialized alternative schools for students with disabilities:

- Identification of schools with effective instructional practices for children with ASD
- SED's Autism Program Quality Indicators
- Research-based educational practices
- Effective behavioral practices

Disseminate Information on Regional Training Resources Available to School Districts and Service Providers

OMRDD and SED should collaborate in disseminating information on trainings available from New York's Centers for Autism and Related Disabilities (CARDs) and other available trainings to New York State school districts and voluntary providers of special education and related services. In addition, SED should widely disseminate information on ASD coursework requirements and the list of training providers for individuals seeking certification as special education teachers or school administrators and supervisors assigned to serve as special education administrators.

Adequacy and Capacity of Services

Finding 6:
There is a need for a continuum of residential supports ranging from minimal supports for individuals who can live with relative independence to 24-hour specialized supports.

Recommendation 6-1:
Continue New York State's investment in residential services that support individuals living in their own home, their family homes or in provider-managed housing.

Recommendation 6-2:
Develop a state-of-the-art residential model for young adults and adults and evaluate the effectiveness of these services to support continuous improvement of the model.

Recommendation 6-3:
Develop a sufficient number of in-state Children's Residential Program (CRP) opportunities for children whose needs require specialized residential settings.

Recommendation 6-4:
Establish mechanisms to support collaboration between State service agencies and school districts to facilitate transition planning for students in residential and nonresidential programs.

Individuals on the autism spectrum vary widely in the severity of symptoms they experience and the extent of supports and services they require throughout their lives. Some individuals are faced with tremendous needs, while others, with appropriate supports and services, can enjoy an independent life that includes higher education, living in their own home or apartment, and employment. The need for residential services to meet a range of needs was identified as a top priority for participants in both the CARD-sponsored forums and the on-line survey. Forum and survey participants placed a high priority on both 'supervised' residential services (staffing available at all times) and less intensive "supportive" residential supports for individuals who do not need 24-hour supports.

In addition to these supportive and supervised residential opportunities, some individuals with developmental disabilities, including individuals with autism require specialized residential services. For children who cannot be served in their home school district, placement in a residential school may be necessary. Approximately 715 children have left New York State and live in out-of-State private residential schools in order to receive this level of services. Billy's Law, passed in 2005, seeks to return children who are placed into private residential schools outside of New York State and to create in-State opportunities to address the future needs of children. In response to the passage of this law, OMRDD and SED initiated a series of joint development projects to create new in-State opportunities for children (Children's Residential Programs or CRPs). There are a total of 255 CRP opportunities under development, 69 of which are being developed particularly for school age children with ASDs.

The need for services to be provided in the person's own or family home was echoed throughout the public input received by the Autism Task Force. Needed in-home supports can range from the assistance of a direct support professional to more specialized clinical supports to address behavioral needs. New York State must continue to examine its provision of residential services to individuals with ASD to ensure the highest quality and sufficient capacity of services while continually ensuring the availability and provision of in-home services to support those who wish to remain in their family home.

Short Term Steps

The Task Force recommends New York State agencies undertake the following short-term steps toward implementation of these recommendations:

Provide in-home Intensive Behavioral Supports for Individuals to Remain in their Home

OMRDD should pursue development of its Intensive Behavioral Services for individuals enrolled in the Home and Community Based Services waiver who live at home. These services will be short-term, outcome-oriented services focused on developing effective behavioral management strategies to ensure health and safety and/or to improve quality of life. They will provide in-home behavioral intervention intended to help families understand and respond to challenging behaviors, and thereby avoid crises and remain intact in the family home. Intensive Behavior Supports will be provided by appropriately trained and credentialed clinicians under the guidance of a licensed psychologist or licensed clinical social worker. (This short-term step will also help New York State implement Recommendation 7-2.)

Develop and Evaluate an Evidence-Based Residential Model for Adults with ASD

OMRDD should carefully evaluate the model residences for adults with ASD and apply the lessons learned to the agency's development of residential services throughout the state. OMRDD should continue this evaluation of new residences for individuals with ASD as they are developed and make the enhanced understanding of residential needs for individuals with ASD widely available to voluntary service providers throughout the state.

Develop an ASD Training Curriculum for Direct Support Personnel and Supervisors

OMRDD should package the ASD residential staff training curriculum it is currently developing in partnership with SUNY Binghamton's Institute for Child Development and make that curriculum broadly available throughout the State and voluntary segments of the OMRDD system.

Develop Additional CRP Capacity within New York State

OMRDD and SED should continue to develop the projected 255 in-state Children's Residential Program opportunities, identifying an appropriate number of opportunities to be made available to children with a diagnosis of ASD.

Improve Data Sharing between State Service Systems to Facilitate Improved Planning for the Residential Needs of Graduating Students.

OMRDD, SED and OMH should examine and improve their agency data-sharing practices to ensure that service agencies and school districts are aware of all students in residential and nonresidential schools and can initiate early service planning for post-school residential services.

Adequacy and Capacity of Services

Finding 7:
There is a need for greater availability of information and services that assist families, schools and individuals to avoid crises and to respond to crises when they occur.

Recommendation 7-1:
Identify effective crisis avoidance and response practices and promote such practices throughout New York State's service systems**.**

Recommendation 7-2:
Provide information to parents of children with ASD regarding reliable, evidence-based practices to address behavior issues in the home, classroom and community.

The Task Force's review of existing documents describing the needs of individuals with ASD and their families and the comments and responses received during the Task Force regional forums and online survey attest to the significant need for families to receive assistance in responding to and managing the behavior of their family member with ASD. Respondents ranked training for families, as well as for service providers and educators, as the highest priority activities for New York State to undertake. In particular, respondents to the online survey ranked training and education in behavior management as the second most important service need. Families want information and education so that they can provide the most effective support in their homes.

Being better equipped to support their loved one in positive behaviors can reduce stress on all family members and allow families to be proactive in avoiding crisis and retaining family unity. Respondents reported that, when crisis or near crisis occurs, families need psychologists, behavioral therapists and paraprofessionals to be available for intensive intervention, and they need those parties to teach those skills to the family so that the professionals are not continuously needed. Because many individuals identified with ASD in New York State are children, OMRDD, SED and local school districts all have a role in assisting these individuals with behavior management and supporting them for success. These agencies have recognized the importance of supporting families in their roles as caretakers and advocates for their family members with ASDs. Appendix B of this report describes current program initiatives that are supported by SED, OMRDD and DOH.

Unfortunately, crises sometimes occur despite these family supports. When this happens, New York's service agencies must have mechanisms in place for ensuring that individuals receive the intensive intervention services needed and, if they must leave their home for a time, are able to return to their community, friends and family with needed supports in place to assure greater success.

Short Term Steps

The Task Force recommends New York State agencies undertake the following short-term steps toward implementation of these recommendations:

Assist Families to Address Behavior Needs with Specialized Services designed to Prevent Crisis

The initiation of Intensive Behavior Services will support families to address behavior needs. (See short-term step under Recommendation 6-1.)

Assist Schools to Provide Consistency of Behavioral Support between School Settings and Home

On a case-by-case basis, OMRDD and SED should provide general information to school districts that will assist the school districts in interacting and sharing information with clinicians who provide Intensive Behavioral Services to students in their homes so that behavior support plans developed for the home setting are congruent with behavior support plans being implemented in school settings.

Develop Evidence-based Practices for Delivering Behavioral Intervention Services in School Settings

OMRDD and SED should implement, study and disseminate the results of the "Short-Term Intensive Behavioral Assessment and Intervention Program" in New York City. (See short-term step under Recommendation 4-1.) This information should be made available to families and schools districts.

Develop and Implement a Pilot Program using "The Promise Zone" Framework to Support Student Success and Identify and Access Needed Services for Children and their Families

The Promise Zone is an initiative of the New York State Children's Plan to achieve New York State's goals of student engagement, academic achievement, dropout prevention, social and emotional competence, positive school culture and school safety. It is a testable model that maximizes current resources and can be replicated in urban and high need schools and communities statewide. New York's service providing agencies should demonstrate and document the usefulness of The Promise Zone framework in promoting positive outcomes for students, including students with ASDs, and, when necessary, help students with ASDs receive the services they need from the most appropriate service systems. (This short-term step will also help New York State implement Recommendation 9-3.)

Using New York ACTS and other means, Provide Information to Help Families Avoid Crisis

OMRDD should expand its provision of parent information and training opportunities related to supporting positive behavior in individuals with ASD. It should review existing resources, develop materials in a variety of formats, and explore cost-effective options for delivering the information effectively to families.

Develop and Implement a Statewide Training Program on Emergency Preparedness

OMRDD, in partnership with the Westchester Institute for Human Development, has developed and implemented training for service coordinators and others in preparing individuals with developmental disabilities, including ASD, for emergencies. Preparing individuals, families and communities for potential emergency situations involving individuals with developmental disabilities can help keep small emergencies from becoming or contributing to larger crises. OMRDD should develop this training into a wider reaching train-the-trainer curriculum and implement it throughout New York State.

Develop and Implement Statewide Training Program on First Response

DDPC should pursue development of a Train-the-Trainer Program to increase the awareness and competence of first responders (fire fighters, police and emergency medical professionals) throughout New York State to provide services to individuals with developmental disabilities, including ASD.

Develop a Statewide ASD Intensive Treatment Center for Adults with Severe Behavioral Challenges

OMRDD should continue to evolve its Consaul Road intensive intervention Program for Adults with ASD into a statewide center available to meet the intensive treatment requirements for adults with ASD from throughout New York State who are experiencing severe behavioral challenges. The Consaul Road Program should become a transition program that can assist individuals' behavior through intensive behavioral and clinical/medical monitoring and intervention and ensure those individuals are able to return to their home communities with ongoing behavioral supports in place to promote greater success.

Adequacy and Capacity of Services

Finding 8:
Individuals with ASD need additional supports and services to prepare them for post-school employment.

Recommendation 8-1:
New York State should monitor ongoing national studies related to addressing the barriers to employment for young adults with ASD and effective practices for supporting individuals with ASD in employment, and initiate improved New York State services for adults with ASD seeking employment.

Recommendation 8-2:
New York State should disseminate information on best practices related to supported employment services and fostering successful school-to-work transition and training for students with disabilities, including ASD.

Individuals with ASD experience a wide range of challenges and strengths; each one is unique from every other. As with anyone else, as each child with ASD grows and develops, their dreams and plans for their life take shape. Many are capable of and desire the opportunity to learn skills, gain an education, find a job and be responsible for themselves and their lives. Nonetheless, researchers report that individuals with ASD are among the least likely to be employed, even within the disability community. Current data indicate that only 15 percent of people with ASD are employed. We also know that when supports are in place to help individuals address specific behaviors, employment outcomes can be improved. With appropriate supports to help them prepare for and maintain employment, many individuals with ASD will become contributing members of the workforce.

The Task Force received numerous comments from a variety of stakeholders regarding the need for additional vocational training and employment supports for individuals with ASD. Students transitioning out of school into adult life, in particular, need assistance preparing for and identifying appropriate job opportunities. In New York State, the demand for this assistance is increasing. Although individuals with an ASD diagnosis represent less than two percent of all the individuals receiving vocational rehabilitation services in New York State, the number of individuals with ASD who receive those services has doubled between 2006 and 2008.

Moving from school to job training and education to employment is an expected right of passage for most young adults and a critical time in their personal development. So it should be for individuals with ASD. The fulfillment of personal goals and the sense of accomplishment and personal responsibility that result will contribute to successful, meaningful lives and healthy communities. New York State agencies have several initiatives underway that should be carefully studied and used to advance a better understanding of how best to support individuals with ASD to obtain and be successful in employment. National organizations are currently undertaking extensive research to identify effective practices and translate these practices into improved employment outcomes.

Short Term Steps

The Task Force recommends New York State agencies undertake the following short-term steps toward implementation of these recommendations:

Evaluate Supported Employment Demonstration for Individuals with ASD

In 2009, OMRDD established 106 contracts with voluntary providers to provide enhanced supported employment services to approximately 700 individuals with developmental disabilities, including those with ASD. These contracts provide ample opportunities to study effective program designs that promote employment outcomes for individuals with disabilities who have significant support needs. OMRDD will report to the Inter-Office Coordinating Council (IOCC) the status of this initiative, the employment outcomes of supported individuals with ASD, and lessons learned. OMRDD should also make the information learned from these projects available to providers of supported employment services throughout New York State and to SED's Vocational Rehabilitation Division.

Identify Best Transition Practices in New York Schools

In 2008, SED established the Model Transition Projects (MTP) to improve access for students with disabilities to educational, vocational and community supports as they transition from school to employment or to post-secondary training. Funding was provided for 60 projects in more than 180 private and public high schools. To assist in meeting the objectives of the MTP projects, the State University of New York (SUNY) at Buffalo provided training in key areas in support of these activities. Using data provided by the projects, Cornell University is working with SED to identify effective practices which should be shared with high schools throughout the state.

Increase Vocational Counselors' Knowledge about Autism and Effective Strategies for Supporting Vocational Outcomes for Individuals with Autism

SED's Office of Vocational Rehabilitation Division should share resource information regarding ASD with vocational counselors throughout New York State and work with SUNY Buffalo's Region 2 Technical Assistance and Continuing Education Center to develop and implement autism related training for vocational counselors statewide. (This short-term step will also help New York State implement Recommendation 4-1.)

Evaluate DDPC's Employment Demonstration projects and Disseminate Lessons Learned/Best Practice Information to Providers of Supported Employment Services, SED's Office of Vocational Rehabilitation, Parents of Individuals with ASD, Individuals with ASD, and School Districts

DDPC has funded two recent grants that will demonstrate employment sector/industry immersion approaches to school-to-work transition and training, education and job preparation for 200 students with disabilities, including those with ASDs. DDPC should evaluate the experience of these projects and document and disseminate best practice information to parties involved in providing or seeking services related to vocational training or employment preparation and support.

Coordination of Services

Finding 9:
Many families report they find themselves without adequate guidance and direction regarding available services and where and how to access them.

Recommendation 9-1:
Develop and implement training programs throughout New York State to help service coordinators work in multiple service systems.

Recommendation 9-2:
Explore the creation and funding of demonstration projects to test innovative forms of primary care delivery which can provide medical care, social and educational service coordination and possible alternative funding mechanisms.

Recommendation 9-3:
Identify ways for ensuring that families and individuals are provided access to service coordination.

Recommendation 9-4:
Examine the need for guidance regarding payment or reimbursement by private insurers for medical and mental health services often associated with ASD.

The New York State service systems that support individuals with ASD and their families are distinct. Each provides supports and services to individuals either at a particular stage in their life or to meet particular needs. Because each service agency has been created by and operates to carry out the purposes of different statutes, each one uses unique language to describe its programs and operations. Moreover, the statutory definitions of the individuals each one serves differ as well. As individuals move from one service system to another throughout the course of their lives or as they access services from more than one service system to meet different needs at a single point in time, these system differences can cause confusion and delay the delivery of needed services.

One type of service that is especially critical to individuals with ASD is service coordination or case management which assists individuals and families to identify and access needed services. Each of New York's service systems approaches coordination and case management very differently. In the comments received from stakeholders, the Task Force heard repeatedly how essential it is for individuals with ASD and their families to be assisted by knowledgeable service coordinators who can advise them about the supports that are available from New York's different service providing systems.

Finding service coordinators with this kind of "cross system" knowledge, however, is a challenge. Service coordination or case management is typically provided according to system-specific program requirements and service options. When it comes time for individuals to transition to another system for services due to their age, the current service coordinator many times is not informed about the services available from the next service system the person will be entering. In addition, in the special education system the service coordination provided by schools is generally focused on services provided by the school to address a student's educational needs. Families may require the support of a service coordinator for assistance accessing supports and services outside of school. Service coordination addressing a range of needs is provided for all children eligible for Early Intervention services. Coordination of preschool and school-age services generally focuses on educational needs. If eligible, families can access service coordination for non-educational needs through the OMRDD or OMH service

systems. Because many students only receive services from their school districts, their families cannot access the guidance and assistance that might help them access services beyond those the school district provides. Obtaining accurate information about vocational preparation and adult services is also critical as youth prepare to leave high school.

System transitions aside, service coordination is also critical to families of individuals with ASDs because of the complex nature of individuals' needs. Increasingly, experts are indicating that ASD is a diagnosis that crosses several different realms in service provision: medical, educational, psychological and social. As such, individuals with ASD frequently access services from professionals in each of these areas and need guidance in how to navigate these multiple systems from someone who is well informed about all four. The wide range of treatment modalities used to support individuals with ASDs is beyond the current expertise of any one discipline. As they seek to help their loved one with ASD, families bear the responsibility of being the only party with a complete picture of that person and his or her full range of challenges and needs.

New York State must take steps to ensure that its service systems are equipped to usher individuals and families from one system to the next with well informed planning and without disruptive delays in services. It must also help families better understand the services available to support individuals with ASD, and it must explore possible service delivery models that will better meet the varied service needs related to ASD.

Short Term Steps

The Task Force recommends New York State agencies undertake the following short-term steps toward implementation of these recommendations:

Disseminate Information on Available Services

New York's service agencies should enlist the assistance of consumer organizations such as Special Education Parent-Teachers Associations, Parent-to-Parent of New York State, Inc. and Families Together of New York State to disseminate information on available services and how to access those services to families of individuals with ASDs. This activity should be included in the cross systems public information initiative recommended to initiate Recommendation 3-2.

Develop and Implement ASD Training for Service Coordinators and Others

To elevate the competency of OMRDD service coordinators, parents of individuals with ASD and other service provider staff, OMRDD should develop and implement training in ASD for these parties. In the past, OMRDD has developed and delivered ASD trainings at various locations. OMRDD will review and update these training materials as needed and evaluate the cost-effectiveness of making this updated training available to the widest possible staff population. (This short-term step will also help New York State implement Recommendation 12-2.)

Expand the adult-focused training program "One Person, Two Systems: Optimizing Services for Individuals with Dual Diagnosis (MH/DD)" to include Children and Families needing services from Multiple Service Systems

DDPC, OMRDD and OMH should create and implement a child and family version of the "One Person, Two Systems: Optimizing Services for Individuals with Dual Diagnosis (MH/DD)" training to address the service coordination needs of children and families whose needs cross multiple service systems. (This short-term step will also help New York State implement Recommendation 10-2.)

Evaluate the Adirondack Region Medical Home Pilot Project

DOH should evaluate its Adirondack Medical Home Pilot Project with respect to how it addresses the needs of individuals with ASD to determine if successful methods for coordinating care can be implemented in other systems. In January 2009, this project began providing enhanced reimbursement to health care providers in northern New York who are implementing a new standard of care with increased emphasis on primary and preventive care, improved coordination of care and management of chronic diseases, improved communications with patients, the use of electronic health records and electronic prescribing, and adherence to quality and safety standards. Such an expanded model of primary care could have significant potential to meet the varied service needs of individuals with ASD and their families.

Assist New York families to understand what ASD Related Services should be Covered by Private Insurance

Using New York ACTS and other means, the New York State Insurance Department should provide information to the public regarding the types of services which, based on New York State law, should be accessible to those with ASD through their private health insurance. The Department should also provide guidance regarding how one may proceed if coverage for these services is denied.

Coordination of Services

Finding 10:
Eligibility criteria, assessments, services and practices vary considerably across State agencies, making it difficult for families to obtain comprehensive care when needed services are not available within a single service system.

Recommendation 10-1:
Publish clear, concise information regarding the eligibility criteria for services provided by the different New York State service agencies.

Recommendation 10-2:
Explore options for clarifying and streamlining the eligibility and intake processes for New York State's numerous service systems.

The Task Force found service eligibility to be a significant concern for individuals with ASD. The fact that individuals usually move from system to system as they mature means that they are subject to different eligibility standards at different times in their lives. As such, individuals and families must understand multiple eligibility structures and determination procedures.

Different service system eligibility criteria also present challenges to families when their loved one requires services from more than one system, for instance someone with ASD who also has a co-occurring mental health disorder such as depression or bi-polar disorder. The Center for Autism and Related Disabilities at the University of Southern Florida cites rates of co-occurring diagnoses in individuals with ASD between 67 and 70.8 percent[7]. In these situations, individuals may need to meet eligibility for two separate systems, but more importantly, they may need services from two systems. It is often difficult to provide services to someone who is physically located in another system's facility. For others, a primary diagnosis places them in one system that may be unable to address their secondary diagnosis. In these instances, their secondary diagnosis may simply go untreated. New York State OMH reports that approximately 2.5 percent of the children receiving mental health services in OMH residential facilities have a primary or secondary diagnosis of ASD that may not be sufficiently addressed by OMH services. Among adults, approximately .16 percent of those receiving OMH residential services have a diagnosis of ASD.

The multiple service systems involved in supporting individuals with ASD and their families reflect the wide range of needs of individuals with ASD. However, their distinct administrative structures and eligibility also make it daunting for families to understand and access the services that exist to support their loved one. New York State's service agencies must continue to fulfill their separate missions and their distinct statutory obligations and authorizations. Nonetheless, to truly be agents of support, these agencies must recognize the impact of system differences on those they serve and take steps to help families and individuals with ASD and other cross system needs understand and navigate those differences.

[7] Center for Autism and Related Disorders University of South Florida, "Autism and Mental Health Issues: A guidebook on mental health issues with Autism Spectrum Disorder," http://card-usf.fmhi.usf.edu/ cardpubs/ CARD_ASDMH_ Brochure092109.pdf

Short Term Steps

The Task Force recommends New York State agencies undertake the following short-term steps toward implementation of these recommendations:

Update and Disseminate Information regarding Service Eligibility

Despite the difficulties in coordinating service eligibility between separately mandated and uniquely described systems of service, New York's service providing agencies (OMRDD, SED, DOH, and OMH) can and should provide families and individuals easy access to clear, up-to-date, and easy-to-understand descriptions of their particular service eligibility criteria, standards and determination processes. They should use the New York ACTS Web site to provide centralized information and other methods to make sure information is available broadly.

Undertake a Cross Systems Eligibility Initiative

New York State's Inter-Office Coordinating Council should undertake an examination of issues surrounding service eligibility for individuals with disabilities, including ASDs. As part of this initiative, the service agencies should explore options for coordinating intake and sharing information across the service systems such that individuals with needs that cross systems are able to receive appropriate services from multiple systems.

Coordination of Services

Finding 11:
Families report that individuals diagnosed with ASD who need support may not meet service agency eligibility standards and are unable to access publicly funded supports.

Recommendation 11-1:
Conduct a multi-agency collaborative review to identify the numbers of individuals in New York State who fail to meet service eligibility criteria and their unmet service needs.

No discussion of the needs of individuals with ASD fails to reveal the need for services for those individuals on the autism spectrum who do not meet current service eligibility standards. Families and advocates report that, in some instances, these individuals do not demonstrate the level of disability that New York's service systems require to access services. In other cases, individuals may fail to demonstrate the potential for success needed to access services. Individuals may find that their ASD diagnosis impacts their lives such that they are unable to be sufficiently independent to succeed, yet they are too adept at many aspects of life to get the help they need. As ASD diagnoses increase, the numbers of individuals in this situation is likely to increase. If the needs of these individuals fail to meet service eligibility standards, these individuals could, at some point in their lifetime, find they are unable to access needed supports and services, experience poorer outcomes — reflected in unsustainable employment or problems such as substance abuse or health concerns — and ultimately require public support.

New York State currently has little data to characterize the needs of individuals with ASD who fail to meet service eligibility criteria. Greater understanding of how the needs of these individuals do and do not align with New York State's service programs is needed. Fortunately, the State's best interest is the best interest of its citizens; an examination of the possible service options that will support these individuals to make their fullest contribution to society would serve both New York State and the many individuals on the higher end of the autism spectrum.

Short Term Steps

The Task Force recommends New York State agencies undertake the following short-term steps toward implementation of these recommendations:

New York State's Inter-Office Coordinating Council (IOCC) should undertake an Eligibility Initiative

In addition to examining eligibility and system intake processes, New York State's service agencies represented in the IOCC should examine system differences in eligibility and the impact of those differences on families of individuals with ASDs and recommend policy solutions that will allow New York State to better support those whose service needs currently remain unaddressed.

Information Dissemination

Finding 12:
Effective Coordination and delivery of services and supports to individuals and families within the non-English speaking community is often impeded because of a language barrier and/or a lack of cultural awareness.

Recommendation 12-1:
Increase translation services, promote awareness of translation services, and, where possible, provide priority information in Spanish.

Recommendation 12-2:
Implement training programs to increase the cultural awareness and cultural competence of service coordinators and case managers.

Recommendation 12-3:
Increase support and technical assistance for agencies serving non-English speaking communities.

The Task Force heard numerous comments regarding the difficulties non-English speaking families encounter in learning about and accessing supports and services for their loved one with ASD due to the unavailability of information in languages other than English. According to SED's 2009 data, there are 272,046 students in New York State who meet the definition of Limited English Proficiency/English Language Learner[8]. According to the 2000 US census, in New York State a language other than English is spoken in 28 percent of households with children more than five years old[9].

New York State must recognize the increasing cultural diversity of its citizens and respond with information and services that reach everyone who needs them. When people are unable to find information they can understand – because of a language issue, a readability issue, or an access issue – they are unable to receive needed services. New York State's service providing agencies must ensure that information is available in the languages people speak and that those service providers who serve non-English speaking populations are fully prepared to do so. Investing in human services that are available to all New York State citizens in need has always been essential to good stewardship of our public dollars, fulfillment of agency missions, and sustaining the public trust. Cultural competency is at the core of good government today.

[8] NYSED data available on-line at http://www.emsc.nysed.gov/biling/docs/NYSLEP-ELLData7-09Final.pdf

[9] US Census Bureau, "Language Use and English Speaking Ability: 2000," (October 2003): 5.

Short Term Steps

The Task Force recommends New York State agencies undertake the following short-term steps toward implementation of these recommendations:

Make key information contained on the New York ACTS Web site and other agency Web sites available in Spanish

While an important goal is to make the information contained on the New York ACTS Web site understandable by all, an interim step should be to make key information available online in Spanish. Similarly, agency-specific web content, brochures and guidelines related to ASD should be made available in Spanish as soon as possible. In addition, agencies providing information (through New York ACTS and other means) must make every effort to reach the widest audience possible by using easily understood language to communicate complex clinical information.

Promote the availability of New York State Telephone Interpreter Services that can convey Information about New York State Services in Native Languages

Using mechanisms including Web sites, stakeholder distribution lists and service providing agency networks, New York State agencies should widely promote the availability of telephone interpreter services that can make information about services available to members of the public in their native language.

Support OMRDD's Multicultural Service Providers by Expanding the Technical Assistance Provided to Multicultural and Emerging Providers through OMRDD's Technical Assistance and Consultation Unit.

OMRDD provides ongoing assistance in support of emerging and multicultural agencies that provide services to individuals with developmental disabilities, including ASDs. The agency should continue to expand the training it provides these important service providers so that they may continue to effectively reach and assist all of the communities they serve.

Coordination of Research

Finding 13:
New York State needs to coordinate public and private research efforts so that resources are effectively used and the advancements in understanding achieved are made more broadly available across the state.

Recommendation 13-1:
New York State should further develop a State Autism Consortium as a mechanism through which New York's most accomplished ASD experts in all disciplines can unite in the shared pursuit of greater understanding of ASDs and advancements in treatment and services for citizens with ASD throughout the state.

Recommendation 13-2:
The New York State Autism Consortium should make the translation of research results into improved practices and the study of treatment methods priority activities.

The Task Force's review of existing documents as well as the comments it received through its regional forums and online survey indicate that New Yorkers concerned about ASD want research efforts to focus on improving the early identification of children with ASD, developing new effective treatments for ASD, and finding the best ways to educate individuals. Discovering the exact prevalence of ASD and causation were a somewhat lower priority for respondents. Some specific comments called for researchers to generate information on best practices in behavior supports and cited the need for that information to be made available to and understandable for families. Others called for research into effective health services for individuals with ASD.

Currently, in New York State, numerous private entities are engaged in a variety of ASD research initiatives. These projects range from exploring the basic sciences (including genetics and animal models) to clinical research involving medications and educational interventions to service delivery research. In addition, New York State's Institute for Basic Research conducts extensive research related to the causation and expression of ASD. To date, however, New York State has not coordinated these public and private efforts so that they are able to share resources. Research projects have been limited in scope simply because of their separate nature.

New York State has tremendous ASD resources within its borders. Doctors, teachers, service providers and families constitute a statewide, multi-disciplined and passionate group of people who can make even greater strides working together than they have individually to date. New York State's Institute for Basic Research on Staten Island is an emerging international leader in the field of autism research and is becoming a training center for neuropathologists working in the field of autism. Projects are underway with funding from the U.S. Department of Defense, the National Institutes of Health and others. Groundbreaking research done at Cold Spring Harbor Laboratories has resulted in a new genetic perspective on autism, suggesting that autism is often caused by spontaneous mutations rather than inherited genetic abnormalities. In addition, research done at Mt. Sinai related to the use of oxytocin to treat the social deficits of autism was the first of its kind. Scientists at IBR were the first to recognize that premature infants who will later go on to become autistic show abnormal traits differentiating them from other premies as early as one month of age. Clearly, research potential is not the issue. Rather, the challenge today is to harness these resources under the shared yoke of advancing our understanding of ASDs and translating research findings into practice and easily understood public information materials.

With diagnoses of ASD rising rapidly, New York State must act now to unite its most accomplished experts and lead them to bring their collective abilities to bear on the challenges of ASD.

Short Term Steps

The Task Force recommends New York State agencies undertake the following short-term steps toward implementation of these recommendations:

Develop Research Agendas in Key Issue Areas

The New York State Autism Consortium now underway should include the following priority areas for ASD related research within New York State: training and education, treatment, early identification and intervention, and translational research. The Consortium should develop research agendas in each of these areas and pursue the development of related projects, engaging public, private and nonprofit organizations with expertise in ASD and ultimately enhancing New York State's ability to meet the needs of citizens with ASD.

Ensure ASD Research Informs State Service Systems and Information

As the New York State Autism Consortium undertakes projects to advance our understanding of ASDs and ASD treatment and services, it must convey the findings and implications of those projects and studies to State service system administrators, including the educational, health and disabilities agencies, to ensure that State services are informed by the most current understanding and best practices. This translation of research results into practice fulfills the fundamental purpose of research and will benefit the New Yorkers who rely on State services to meet the challenges of ASD. It must be an essential component to each Consortium project.

V. Appendices

A. Stakeholder Input

B. Current State Services and Supports for Individuals with ASD and their Families

C. ASD Research Survey Results

D. Task Force Testimony to New York State Senate Committees

E. Autism Platform Status Report

A. Stakeholder Input

1. Documents Reviewed by Task Force

(Listed according to date of publication)

- Summaries of OMRDD's 2009 5.07 Plan Public Forums. "Statewide Comprehensive Plan 2009-2013" New York State Office of Mental Retardation and Developmental Disabilities, October 1, 2009.
- *Connecting the Dots: A Platform for Sustaining Pockets of Innovation and Development in Individualized Supports, Work Plan Ideas for the NYSACRA Learning Institute*. January 2009.
- The Interagency Autism Coordinating Committee Strategic Plan for Autism Spectrum Disorder Research. January 26, 2009.
- Summary Notes from meetings of the Taconic Developmental Disabilities Service Office's Autism Advisory Group. 10/21/08, 4/22/09.
- Summary Notes from Developmental Disabilities Planning Council Focus Groups on ASD. November 2008 Summary Report.
- Proposed Amendment to the Regulations of the NYS Commissioner of Education Relating to Requirements for Course Work or Training in the Needs of Students with Autism. August 20, 2008.
- "Annual Performance Report for the NYS Early Intervention Program, 2006-2007" NYS Department of Health, Division of Family Health, Bureau of Early Intervention. April 2008.
- "Planning for the April 2008 Board of Regents Regional Meeting on Students with Autism." NYS Office of Vocational and Educational Services for Individuals with Disabilities (VESID) Memo. March 4, 2008.
- 2008 Autism Policy Conference Summary Report, Pennsylvania Department of Public Welfare.
- "*Living with Autism Study*" Easter Seals Report. 2008.
- 2007 Autism Policy Conference Summary Report, Pennsylvania Department of Public Welfare.
- "Education Programs and Services for Students with Autism, Including Asperger Syndrome" NYS VESID Memo. November 16, 2007.
- "Vision, Priorities & Progress – An Update to the OMRDD Five Year Comprehensive Plan: 2006-2007" NYS OMRDD. October 2007.
- Report on the New York State People First Coordinated Care Listening Forums. OMRDD. October 24, 2007.
- "A Comparison of Health Care Utilization and Costs of Children With and Without Autism Spectrum Disorders in a Large Group-Model Health Plan" by Lisa A. Crowen, Daniel V. Najjar, G. Thomas Ray, Linda Lotspeich, and Pilar Bernal. PEDIATRICS Vol. 118 No. 4. October 2006, pp. e1203-e1211.
- "The Availability and Effectiveness of Programs for Preschool Children with Autism" A Report to the Board of Regents, The Governor, and The New York State Legislature by NYS Education Department, VESID, Special Education Policy, Planning and Partnerships. March 2004.

2. Focus Group Questionnaire and Results Summary

Presented to Eight Focus Groups by New York's Regional Centers for Autism and Related Disabilities, October 2009

Note: The averages contained in this survey represent the mean response which is calculated by adding the value of all responses to a particular question across all Centers for Autism and Related Disabilities (CARDs) and then dividing by the total number of responses.

I. Early Identification

The Task Force recognizes that intensive treatment at the earliest ages has the greatest potential to improve outcomes for children diagnosed with Autism Spectrum Disorders (ASD). To make that possible, doctors and other practitioners must be able to identify and accurately diagnose young children who have autism spectrum disorders using the most up-to-date and appropriate screening tools. With this in mind:

1. The following are potential issues/barriers to obtaining accurate and timely diagnoses of ASD for young children in New York State. Please indicate the degree to which each issue/barrier is a challenge for children with ASDs. (Rank each on a scale of 1-5, with 1 being "not a challenge" and 5 being "a significant challenge.")

a.) Access to specialists (psychologists, developmental pediatricians, child psychiatrists) to obtain a diagnosis

Average: 4.19

b.) Timely screening of children for developmental delay or autism at well baby visits

Average: 4.15

c.) Access to thorough assessments conducted by primary care physicians and other specialists using instruments specifically designed to assess for autism.

Average: 4.33

d.) Other (Please list briefly any other barriers you have encountered or understand to be a challenge to early identification.)

Summary: Many respondents suggested that knowledge barriers are common and are often a challenge to early intervention. Multiple individuals cited a "lack of knowledge" on the part of specialists, doctors, and parents as being a barrier to early identification. Respondents also suggested that a lack of proper assessment tools may be a barrier to early identification along with doctor reluctance to diagnose individuals as having ASD even when signs are exhibited; many individuals suggested that doctors often tell them to "just wait" and that their child's delay is "temporary."

2. It is recommended by the American Academy of Pediatrics that pediatric health care providers universally screen all children for ASD at 18 and 24 months of age. What actions could New York State take to ensure this practice occurs regularly for all children?

Summary: A large number of participants suggested that the best way for New York State to ensure that screening for ASD occurs is to make screenings mandatory. Individuals suggested that screenings should be done in-line with early vaccination schedules in children younger than 18 months. Some individuals suggested that proof of screening should be required before children can

enter school (similar to proof of vaccination). Respondents also suggested that insurance companies should be required to cover comprehensive ASD screenings.

II. Coordination of Services

Individuals with ASDs often require supports from more than one State service system, during different stages of their lives or even at any particular point in time. The Task Force recognizes that in these situations, regulatory or other requirements of the different service systems can become barriers to receiving the services that are needed. When that happens, individuals can be left without services for a time or without all the services they need.

1. If you have encountered challenges for individuals with ASDs as they move from one service delivery system to another, at which point did difficulties occur?

a.) Early Intervention to Pre-School

Count: 30

b.) Pre-School to School

Count: 52

c.) School to Adult services or Employment

Count: 49

Summary: Respondents suggested that a lack of communication/cooperation during transition between stages leads to a more difficult transition for individuals with ASD and their families. Multiple respondents suggested that the adult service system lacks proper support for individuals with ASD to have a high quality of life.

2. The following are potential issues that individuals with ASDs may encounter when transitioning from one service system to another or coordinating services from various agencies. Please indicate the degree to which each issue is a barrier to the timely access to services? (Please rank each on a scale of 1 to 5, with 1 being "not a barrier" and 5 being "a significant barrier.")

a.) Access to assistance from a case worker or service coordinator to learn about and get started receiving services from a new system

Average: 3.67

b.) Types of services offered differed from services available in previous system

Average: 3.94

c.) The new system had a different standard of eligibility for services.

Average: 3.66

d.) Administrative and scheduling processes

Average: 3.59

e.) Access to information about the parent/caregiver role in the new system

Average: 3.71

f.) Clarity regarding which service delivery system should be providing the service(s).

Average: 3.76

g.) Ability to receive services from multiple systems when multiple needs/diagnoses are present.

Average: 3.99

3. Briefly list assistance you have you experienced or heard of that has worked well during system transitions and accessing services from multiple agencies?

Summary: Individuals suggested that having knowledgeable and helpful service coordinators is a large factor in easing the difficulties sometimes associated with transition. On a broader scale, communication between the bodies through which the individual with ASD is transitioning was mentioned multiple times as helpful.

III. Adequacy and Capacity of Services and Supports

People with ASD often require lifelong services to live to their fullest potential. Because the incidence of ASD is increasing at a significant rate, New York State must prepare to address this growing need and to provide the most appropriate, evidence-based treatments and services.

1. To what extent have the following services been available for individuals with ASDs? (Please rank each on a scale of 1 to 5, with 1 being "sufficiently available" and 5 being "significant shortage of this needed service.")

a.) Crisis Intervention

Average: 4.15

b.) Behavior Management

Average: 3.93

c.) Respite Services

Average: 4.03

d.) Special education programs with expertise in autism and ASD

Average: 3.83

e.)Clinical Services such as Psychological (not psychiatry) Services, Occupational Therapy, Speech and Language Therapy

Average: 3.51

f.) Psychiatry

Average: 4.21

g.) Nutritional Services

Average: 3.58

h.)Socialization Training and Opportunities

Average: 4.04

i.) Family Support Groups

Average: 3.55

j.) Supported Employment

Average: 3.97

k.) Transportation

Average: 3.67

l.) Residential Services – Supervised (24/7) Homes in the Community

Average: 4.22

m.) Residential Services – Supported (less than 24/7) Homes in the Community

Average: 4.17

n.) Other (Please list briefly one or two other services that are needed by individuals with ASD and/or their families and have not been sufficiently available to you.)

Summary: Participants suggested that the use of Applied Behavior Analysis, literature in varied languages, and job training/post-secondary services have not been sufficiently available to them. Additionally, multiple individuals suggested a need for more after-school supports and sibling (and parent) training and support services.

2. How have the following issues affected service delivery to individuals with ASDs and/or families? (Please rank each on a scale of 1 to 5, with 1 being "not an obstacle" and 5 being "a significant obstacle.")

a.) Numbers of trained *educational* professionals available to deliver needed services.

Average: 4.01

b.) Numbers of trained *clinicians* available to deliver needed services

Average: 4.11

c.) Numbers of trained *direct care professionals* available to deliver needed services (e.g., respite workers)

Average: 4.33

d.) Availability of the needed service

Average: 4.26

e.) Lack of insurance coverage or cost of the service

Average: 4.14

f.) Eligibility criteria or standards

Average: 3.58

g.) Other (Please list briefly one or two other issues that affected service delivery for individuals with ASD and/or their families)

Summary: Multiple respondents cited "long waitlists" as a major issue that has affected delivery of services for themselves or an individual with ASD in their family. Individuals also suggested that monetary issues often lead to a delay or inability to obtain services and supports (this includes a lack of personal funds, reimbursement, and program money in the current economic climate).

IV. Information Dissemination

As more New Yorkers are diagnosed with an ASD, the need for State government to provide accurate information about autism and related services to different segments within the state is mounting. Information can help doctors to accurately screen and diagnose a child, parents to find services for their children, and a community to accept and serve individuals throughout their life. The Task Force is working to mobilize a coordinated effort to provide all parties with user-friendly means to access the information they need. To this end, it is launching a New York State Web site on autism that will provide basic information and link families directly to the State service systems that can help them.

1. What types of information should the website provide? (Please rank the following types of information on a scale of 1 to 5, with 1 being "not important to provide" and 5 being "essential to provide.")

a.) Information on accessing services from New York State.

Average: 4.81

b.) Basic information about ASD.

Average: 4.21

c.) Information about what New York State is doing to address autism.

Average: 4.10

d.) Information about New York State and federal laws related to autism.

Average: 4.20

e.) Information about research findings.

Average: 3.99

f.) News and Events listings.

Average: 4.06

g.) Profiles of individuals living with ASD.

Average: 3.47

h.) Resources to connect families to each other.

Average: 4.44

i.) Information on managing behaviors at home.

Average: 4.59

j.) Information about evidence-based treatments

Average: 4.46

k.) Other (Please list briefly one or two other types of information that the New York State website should provide.)

Summary: Respondents suggested that the NYS website should provide a means by which families and individuals can communicate (socially) in order to coordinate events and meetings as well as to

share information. This type of central "gathering place" could help individuals become more involved with the community and know what is going on in their geographic region. Other individuals suggested that information in a variety of languages should be available for non-English speaking individuals and families. Information on where individuals can find schools, programs, and colleges with experience in ASD was also requested on this particular question.

2. Beyond a State Web site on autism and autism services, what can New York State do to get information to people who need it?

Summary: Many respondents listed the following as effective ways New York State could disseminate information about ASDs: subway and bus advertisements, posters in physician offices, and TV Public Service Announcements. A few individuals also suggested using agencies and services such as Developmental Disabilities Service Office, CARDs, and BOCES to reach more rural areas and individuals without access to technology.

3. Aside from families, which of the following parties do you think need better access to information? (Please rank each on a scale of 1 to 5, with 1 being "doesn't need additional information" and 5 being "a significant need for additional information.")

a.) Pediatricians and adult physicians

Average: 4.65

b.) Teachers

Average: 4.59

c.) Emergency responders (fire fighters, police officers, emergency medical technicians, paramedics)

Average: 4.43

d.) The general public

Average: 4.10

e.) Direct support professionals providing daily care and services to individuals

Average: 4.49

f.) Other (Please list briefly <u>one or two</u> other parties that require additional information about ASD.)

Summary: Multiple respondents suggested that school personnel/staff should receive more information on ASD. It was also discussed that children (who presumably may have classmates on the spectrum) should receive information on ASDs in order to increase knowledge in the classroom.

V. <u>Coordination of Research</u>

Much research has focused on ASD in recent years. As rates of incidence climb, our society must come to understand the causes of ASD and their earliest signs in order to begin the treatment process early. The Task Force will recommend steps New York State can take to expand scientific and applied research in these areas.

1. Which of the following topics do you think should be New York's top research priorities related to ASD? (Please rank each on a scale of 1 to 5, with 1 being "not important" and 5 being "very important.")

a.) Prevalence research

Average: 3.38

b.) Causation of ASD

Average: 3.94

c.) Research into the development of new treatments

Average: 4.41

d.) Research to improve early identification and intervention

Average: 4.49

e.) Educational Research

Average: 4.22

f.) Other (Please list briefly one or two other topics that should be research priorities.)

Summary: Respondents suggested that health services and models should be considered a research priority. Multiple respondents suggested there should be more research focused on outcomes for individuals with ASD post-high school (adult outcomes). A few individuals suggested that more research should be focused on the social characteristics of individuals on the spectrum.

2. When fiscal and human resources are limited, it is often necessary to prioritize the State's work. Please rank each of the following priorities in order of importance from 1 to 8, with 1 being "least important" and 8 being "most important".)

a.) Providing Services

Average: 6.13

b.) Conducting Research into Causes

Average: 3.92

c.) Conducting Research into Effective Treatments

Average: 4.56

d.) Conducting Prevalence Research

Average: 3.19

e.) Training for Service Providers, Educators

Average: 5.70

f.) Training for Families

Average: 5.37

g.) Training for Clinicians

Average: 4.90

h.) Other (Please specify an alternative priority)

Average: 2.71

Rank (most important to least)

- **Providing Services**
- **Training for Service Providers, Educators**
- **Training for Families**
- **Training for Clinicians**
- **Conducting Research into Effective Treatments**
- **Conducting research into Causes**
- **Conducting Prevalence Research**
- **Other**

***Note:** Queens College and the Western New York Autism Center were the only two groups where the average rating did not place "providing services" in the "most important" position (they ranked "Training for Service Providers, and Educators" and "Training for Families" as most important respectively.

Summary: Multiple participants suggested that trainings enabling families to advocate for individuals with ASDs are another important area of focus.

3. Focus Group Discussion Summary

This information is the result of consensus found among members of each individual CARD focus group. This consensus was then examined to identify commonalities between the focus groups. These points of consensus were raised during a facilitated discussion where survey participants discussed points of concern/interest in each of the five topic areas outlined in the long form survey.

I. Early Intervention

a.) Universal Screening – Most focus groups, except Lake Placid and Westchester Institute for Human Development, suggested that a form of Universal Screening should be implemented and mandated by New York State. In Albany, individuals suggested that proof of ASD screening should be required for children to enter school, similar to requirements in place related to immunizations. Individuals at the Western New York Autism Center suggested that pediatricians be required to complete a "checklist" looking for signs of ASD before a child turns 18 months old. In addition to the completion of the checklist, it was suggested that an electronic/billing record be required to accompany this checklist to ensure that all pediatricians are screening.

b.) Mandatory Training – Lake Placid, Hunter College, Albany, Queens College, and the Western New York Autism Center all suggested that mandatory training for pediatricians, nurse practitioners, and school personnel be instituted. Training recommendations covered a range of areas including identification of ASD, interacting with individuals with ASD, sensitivity to the needs of families with an individual with ASD, etc. Individuals in Lake Placid suggested training for foster parents. Respondents at Queens College suggested that parents become involved in the delivery of in-service training.

c.) Connecting with non-English speaking Individuals/Families – Individuals in Rochester and at Hunter College suggested that non-English speaking families are at a distinct disadvantage when it comes to obtaining screenings and services. Individuals at Hunter College suggested there is a large need for more non-English competency in the New York City area.

II. Coordination of Services

a.) Transition – All eight focus groups suggested that there should be more focus on easing the difficulties associated with transitioning in-and-out of service systems and between systems. Participants at Queens College suggested that New York State look into developing a manual on transition for families similar to one already being used in New Jersey. The Western New York Autism Center focus group participants suggested that New York State develop/adopt a set of policies/guidelines to smooth transition planning for families and individuals with ASD. Individuals at Westchester Institute for Human Development pointed to a huge gap in services for adults that exists due to poor transition preparation for aging individuals.

b.) School age vs. Adult – Most focus groups reported that families and individuals believe that the level of care/services available to them in school is much different than those available post-secondary and beyond. This may be a transitional issue, but respondents suggested that there is a definite lack of services to transition into for individuals with ASD post-secondary. The Western New York Autism Center suggested that individuals with ASD should have a "consistent, well-trained, and knowledgeable service coordinator throughout the lifespan." With this in place, individuals may be able to obtain services and care during all stages of their lives.

III. Adequacy and Capacity of Services and Supports

a.) Training for Professionals – Many of the focus groups suggested that there should be more training for various professionals and service providers. Some examples of the individuals who would benefit from the training—according to respondents in Lake Placid—were educational professionals, bus drivers, teachers, and cafeteria workers. Respondents in Albany cited teachers and dentists as individuals who could benefit from training on ASDs.

b.) Lack of Programs – Almost all Focus groups cited a lack of programs in their geographic area as a hindrance to families' ability to obtain all the services required for a higher quality of life. Respondents in Albany and Lake Placid suggested that there is a need for more crisis intervention services for individuals with ASD along with a strong need for more residential options. Respondents in Lake Placid suggested that there is a need for overnight respite services for individuals with ASD. Rochester cited a need for expanded options in all areas for individuals with ASD and a need for better supports and services for individuals with a developmental disability (not necessarily Autism). Individuals at the Westchester Institute for Human Development focus group suggested that rural areas in their geographic region are put at a distinct disadvantage in regards to obtaining services and supports.

IV. Information Dissemination

a.) Respondents suggested that information should be easily accessible and in a parent-to-parent style of language so that it is easy for all to understand. Additionally, individuals at Hunter College suggested that information should be provided in a variety of languages for non-English speaking individuals/parents/families/etc. Respondents in both Rochester and Lake Placid suggested the use of streamlined Web sites sponsored by New York State which would provide information on local and statewide parent groups, job opportunities for individuals with ASD, positive outcome information, and a listing of evidence-based services based on geographic location. Focus groups in Albany, Lake Placid, and Queens College reported that while websites are a helpful tool, information should always be made available in other formats so that individuals without internet access can still learn about services and supports in their area. Some suggested methods of disseminating information included PSAs, brochures, mailings, commercials, segments before movie previews in local theaters, and radio announcements.

V. Coordination of Research

a.) Considering the answers provided by all eight focus groups, there was little common ground among responses. The commonalities present suggest that individuals would like to see more research done in the areas of treatment issues/models (Hunter College and Rochester), interventions that families could use (Lake Placid and Rochester), and a focus on health services (Westchester Institute for Human Development and Rochester). Respondents at Queens College suggested that more research should be done on best practices and positive behavior supports and how they can be implemented. Albany was the only focus group to suggest more research on the discrepancies in gender differences related to ASD and diagnosis. The Western New York Autism Center focus group suggested that New York State should create a "system for collecting epidemiological information leading to improved incidence and prevalence data."

4. Online Survey Results

Survey

The Interagency Task Force on Autism is a group of representatives from ten state agencies charged with examining the needs of New Yorkers diagnosed with Autism Spectrum Disorder and developing ways to improve the State's response to those needs. To do so, the Task Force needs your help identifying the most pressing needs facing these individuals and families. Thank you for taking the time to participate in this electronic survey

Question 1:

I describe myself as a ….(please select no more than two responses.)

- Almost half (47.86%) of respondents identified themselves as a "Family member of a person with a developmental disability." This was the most frequent response.
- The next most frequent response was individuals identifying themselves as an "educator or educational assistant" (23.57%).
- Primary Care Physicians are either taking the survey the least (only 0.20% of respondents) or they are identifying themselves as other options before identifying themselves as a "Primary Care Physician."

Answers for how individuals identified themselves in the survey ranked from highest frequency to least were as follows:

- Family member of a person with a developmental disability
- Educator or educational assistant
- Advocate
- Clinician (e.g., psychiatrist, psychologist, therapist, etc.)
- Voluntary agency employee (other than direct support staff)
- Other Answers (302 individuals selected this option and detailed responses can be found in the attached appendices)
- Member of the general public
- OMRDD employee (other than direct support staff)
- County or local government official or staff
- Other governmental employee
- Voluntary agency employee (direct support staff)
- Person with a developmental disability
- OMRDD employee (direct support staff)
- Primary care physician

Question 2:

Please choose your county of residence (NY State only)

The top ten (10) responses ranked from highest frequency to lowest frequency were as follows:

- Suffolk – 323
- Nassau – 251
- Erie – 242
- Monroe – 186
- Westchester – 157

- Onondaga – 123
- Queens – 119
- Albany – 98
- Kings – 97
- Broome – 97

Most other counties reported 50 or less responses.

Question 3:

Please identify the FIVE most important service needs of people with Autism Spectrum Disorders that New York State agencies should be addressing.

The five most frequent selections (from highest frequency to least) are listed below. Each of these five responses was selected over 1,200 times.

- Special education programs for children with ASD,
- Behavior management training and education,
- Access to clinical specialists with ASD expertise (psychiatrists, psychologists, neurologists, etc.),
- Transition services from high school to adult services, and
- Respite opportunities.

Options receiving less than 1,200 responses, from most frequently to least frequently chosen are:

- Employment opportunities
- Informed primary care physicians
- Residential opportunities for adults
- Service coordination
- Day services
- Crisis intervention
- Other Answers (615 individuals selected this option and detailed accounts of these can be found in the attached appendices)
- Transition services from Early Intervention to Pre-School
- Transportation

Question 4

In this period of fiscal challenge, it is important for New York State to get your feedback on where to invest resources and focus our efforts. Please rank the importance of each of the following priorities on a scale of 1-5, with 1 being "not important at all" and 5 being "most important."

Providing services and trainings ranked high, while other selections were more evenly chosen. Findings are consistent with the prioritized responses for Question 3. On a scale of 1 to 5 (5 being most important and 1 being least important) respondents most commonly ranked the options as follows:

Option	Rank	Percent
Providing Services	5	86.77%
Training for Service Providers/Educators	5	78.39%
Training for Families	5	75.06%

• Training for Clinicians	5	69.44%
• Conducting Research into Effective Treatment	5	61.92%
• Conducting research into causes	5	35.66%
• Conducting Prevalence Research	3	30.87%

Question 5

Are there other priority activities New York State should engage in to meet the needs of individuals with ASD and their families? Please list a maximum of two activities.

This question received 1,723 responses while 1,785 individuals opted to not answer this question. It should be noted that on the data sheets some responses are entered identically multiple times.

- More than 250 respondents suggested that training should be a priority activity.

- Over 100 individuals suggested a need to focus more on providing residential services for individuals with ASD.

- About 31 respondents suggested that support for Early Intervention services for individuals with ASD should be made a higher priority in order to benefit families and individuals in New York State.

- At least 26 respondents suggested that financial support for families/individuals and agencies should be a priority. A few of these individuals suggested that financial training/support should be a priority.

B. Current New York State Services and Supports for Individuals with ASD and their Families

Background

This report is the product of the Adequacy and Capacity Workgroup of the New York State Interagency Task Force on Autism. The charge of the workgroup is to examine the needs, challenges or obstacles facing those with Autism Spectrum Disorders (ASDs) and their families and the services currently available in New York State to address those needs. This appendix presents data on the numbers of individuals with ASDs who are served by member agencies and data on the services these individuals receive.

One of the early tasks of the Adequacy and Capacity Workgroup was to collect and review existing sources of information regarding the service needs for individuals and families living with ASDs. Based on this review, the workgroup identified the following major themes that have emerged from current needs assessments:

- The need for Early Diagnosis and Screening
- The need for Clinic Services and Services that Support Educational Outcomes
- The need for Services Supporting School to Post School Transition and Employment Outcomes
- The need for Supports for Families
- The need for Residential Supports

This report evaluates existing service provision around each of these themes.

The data for this report was provided by the Office of Mental Retardation and Developmental Disabilities (OMRDD), the State Education Department's Office of Vocational and Educational Services for Individuals with Disabilities (VESID) Special Education and Vocational Rehabilitation Offices, the Office of Mental Health, and the New York State Early Intervention Program (EIP) (Department of Health). There are important differences among the agencies that contributed to this report regarding how data is collected and how individuals with ASDs are identified. An explanation of the data sources appears on the final section of this report. Note: the information presented in this report is purely descriptive and should not be used to draw conclusions about the incidence or prevalence of ASD in New York State.

Services for People with Autism in New York State

In calendar year 2007, The Early Intervention program provided $99.8 million in services for children under the age of three who have a diagnosis of ASDs or have developmental delays that meet the NYS definition of developmental delays Pervasive Developmental Disorders.

Once a child with an ASD diagnosis reaches the age of three, he or she may be eligible for preschool special education services provided through SED approved preschool programs. Children with autism receive the special education instructional and related services (such as speech and language therapy, occupational therapy, physical therapy, counseling and parent counseling and training) as recommended on their individualized education programs (IEPs) at no cost to the child's parents.

At the age of five, a child who continues to be a child with a disability is eligible to receive school age special education services, including, beginning at age 15, appropriate activities to prepare the student to transition from school to adult services. Most students with autism receive services in the education programs operated by public school districts or Boards of Cooperative Educational Services (BOCES). In addition, there are 62 day and 11 residential schools located in New York State that are SED approved to serve school age students with autism. While SED approves certain programs for children with autism, it does not directly operate any education program for this population of students.

Individuals with autism may be eligible beginning at age 16 for the vocational rehabilitation services of VESID and support from Independent Living Centers. OMRDD provides services to individuals with ASDs of all ages, who meet eligibility guidelines. On an annual basis, OMRDD provides $658 million in Medicaid-funded, community-based services to individuals with an ASD diagnosis (based on 06-07 data). The majority of these Medicaid-funded services ($490 million) are for residential supports provided in the person's own home or in homes that are operated by OMRDD or by not-for-profit providers.

Numbers of Individuals Served

The agencies represented in the Adequacy and Capacity workgroup have all reported increases in the number of individuals served who have an ASD diagnosis.

School district reporting for the period of 2001 to 2007 shows an increase of over 100 percent in the reported cases of ASDs among school age children (ages 4-21) who receive special education services (figure 1).

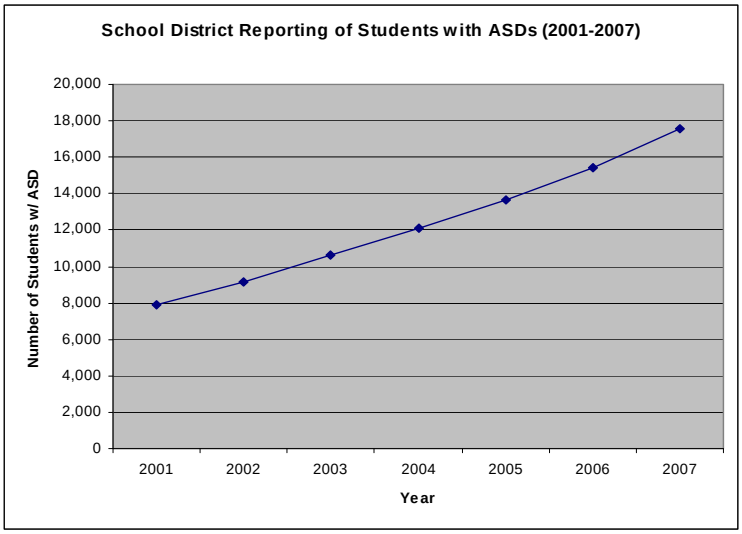

Figure 1

School districts do not identify preschool children (ages 3-4 year olds) by disability category and therefore a reported prevalence for preschool students with autism is not known, but is estimated based on a study[10] conducted in 2004, at approximately 3,150. There was significant regional variation in the estimated number and percentage of preschool children with autism throughout the State from 6 percent of preschool children with disabilities in the Western and Southern Tier regions to 20 percent in the Upper Hudson Valley region.

[10] State University of New York (SUNY) at Albany: *Report on the Availability and Effectiveness of Preschool Programs for Children with Autism in New York State*, 2004

OMRDD reports a 400 percent growth in the number of individuals served between the years 1989 and 2009 (figure 2). In 2009, OMRDD's Tracking and Billing System (TABS) identified over 20,000 individuals with an ASD Diagnosis (figure 2).

Data from the Office of Mental health, school districts and OMRDD indicate that the highest rates of ASD diagnosis are among younger individuals. Of the 17,599 students (ages 4-21) with autism identified by New York school districts in 2007, the largest group is between four and eleven years of age (a total of 10,740 students).

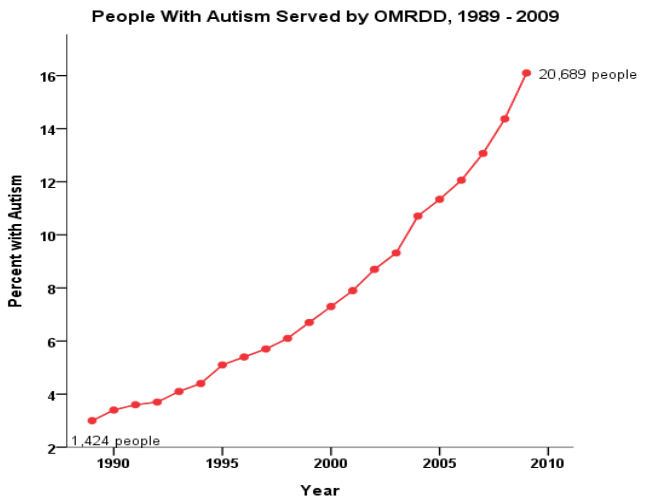

Figure 2

OMRDD's Tracking and Billing System (TABS) data shows that younger groups have the highest rates of ASD diagnosis (figure 3). The age groups between three and seventeen have rates of diagnosis over 25 percent. Similarly, the percentage of individuals under the age of 18 served by the Office of Mental Health in 2008 with an ASD primary or secondary diagnosis was 2.53 percent (159 out of 6277 individuals). For individuals age 18 and older served by OMH, the rate of ASD diagnosis is .16% (42 out of 25,950 individuals).

Autism/ASD Prevalence by Age for OMRDD

(Source: TABS September 2009)

Age Group	Percent with Autism/ASD	Number with Autism/ASD	Total Number of People OMRDD
0-2	3.7	28	767
3-6	27.6	1,628	5,900
7-9	35.5	2,377	6,705
10-12	32.0	2,264	7,069
13-17	27.2	3,676	13,536
18-21	20.6	2,367	11,496
22-29	16.9	3,267	19,342
30-39	12.7	2,164	17,077
40-49	9.6	1,767	18,323
50-59	6.1	872	14,230
60-69	3.2	231	7,235
70+	1.2	48	3,888
Total	16.5	20,689	125,568

Figure 3

Early Diagnosis and Screening

New York's Early Intervention Program (EIP) provides services to children who are under 3 years of age and have a confirmed disability or established developmental delay, in one or more of the following areas of development: physical, cognitive, communication, social-emotional, and/or adaptive. All children referred to the Early Intervention Program receive a multidisciplinary evaluation to determine if they are eligible for the EIP.

EIP Annual Expenditure for Evaluation Services

(CY 07, Infants and Toddlers with a diagnosis of ASD or PDD/NOS)

Age	Individuals	Expenditure
0-11 months	54	40,598
12-23 months	771	680,953
24-35 months	1,014	757,488
36 months +	40	11,618
	1879	**1,490,657**

Figure 4

The multi-disciplinary evaluation must assess the child's developmental status and, if possible and appropriate, determine a diagnosis. Some children who are eventually diagnosed with autism are first found eligible for the Early Intervention Program because of developmental delays that meet the NYS definition of developmental delay.

In 2007, the EIP provided $1.5 million in evaluation services to 1, 879 infants and toddlers with an autism diagnosis[11] (Figure 4). As illustrated in Figure 5, the number of children identified with an autism diagnosis while participating in early intervention services has increased significantly, from 621 in the 1999-2000 program year (July 1-June 30), to 3,922 in the 2007-08 program year.

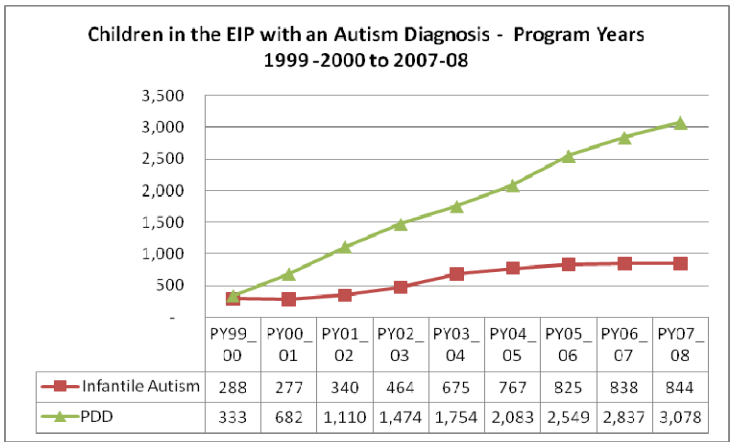

Figure 5 (CY 07, Infants and Toddlers with a diagnosis of ASD or PDD/NOS)

Several actions may have contributed to this trend. In 1999, the Department of Health issued its first in a series of six evidence-based clinical practice guidelines on assessment and intervention for young children with disabilities, *Clinical Practice Guideline on Autism/Pervasive Developmental Disorders: Assessment and Intervention for Young Children (Age 0-3)*. In 2007, the American Academy of Pediatrics published standards and guidelines recommending universal screening for ASDs for children at their 18- and 24-month well-child health care visits. Most recently, in 2008 Governor Paterson signed a law requiring the Department of Health to set up protocols or steps for the early screening of children for autism spectrum

[11] For children under three, appropriate ASD diagnoses are infantile autism and pervasive developmental disorders

disorders (ASDs). These steps must include the standards and guidelines recommended by the American Academy of Pediatrics (AAP). The steps must also include: routine use of ASD screening tools at regular times during important stages in a child's development; communication between the health provider and parents regarding the *Modified Checklist for Autism in Toddlers* (M-CHAT) (Robins, D., 2008; Robins, Fein, & Barton, 1999) screen so that parents become informed about ASDs; and, steps for referring children for further evaluation if the screen shows they are at risk for ASDs. The statute also required the Department to post the M-CHAT on its website (for more information, visit www. nyhealth.gov/community/infants_ children/early_intervention/autism/autism_screening_for_toddlers.htm)

Clinic Services and Services that Support Educational Outcomes

Many individuals with ASDs receive specialized services that assist in skill acquisition and learning. For preschool and school age children (3-21), special education services include instructional services and other "related" services, such as speech therapy and occupational therapy. The Early Intervention Program provides a similar array of services to children under the age of three, through its special instruction service and other clinic services. OMRDD Article 16 clinic services are available to eligible individuals of all ages.

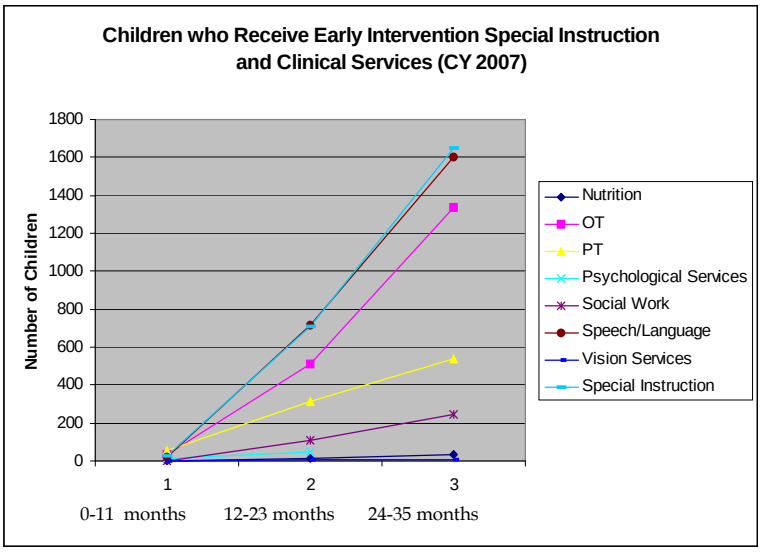

Figure 6

Early Intervention Services

In 2007, the Department of Health's Early Intervention Program (EIP) provided over $87 million in clinic and special instruction services to infants and children under the age of three with a diagnosis of ASD or Pervasive Developmental Disability/Not Otherwise Specified (PDD/NOS). These EIP services include: special instruction, speech/language therapy, occupational therapy, physical therapy, social work, psychological services, and vision and nutrition services. Of these services, special instruction has the highest level of utilization (Figure 6 and 7). Special instruction services

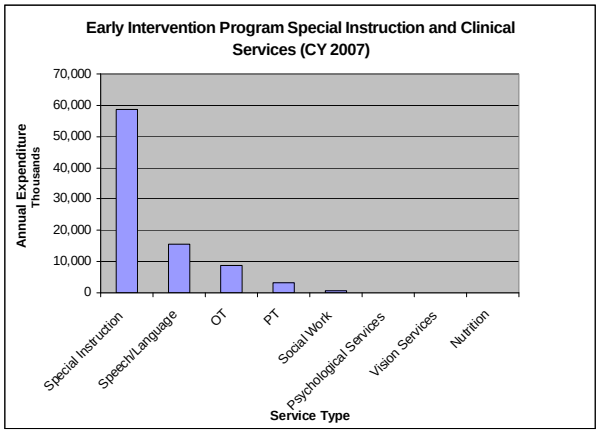

Figure 7

include the design of learning environments and activities that promote the child's acquisition of skills in a variety of developmental areas; curriculum planning; providing families and primary caregivers with information, skills, and support related to enhancing the skill development of the child; and, working with the child to enhance the child's development. As an example, intensive behavioral interventions would be identified as special instruction in the EIP data set.

Special Education Services

Special education services include instructional programs or services (such as special class or consultant teacher services) and related services such as speech and language therapy, occupational therapy, physical therapy, counseling and parent counseling and training.

Public school districts provide special education and related services for students who have disabilities who are ages three to 21. Special education services must be provided to a student in the least restrictive environment which could be in a public school or in a specialized school setting as appropriate to the individual student's needs. Special education and related services provided as recommended on a student's Individualized Education Program (IEP) are at no cost to the child's parents. As was described on page two of this report, New York school districts identified 17,599 students (ages 4-21) with autism who received special education services in 2007.

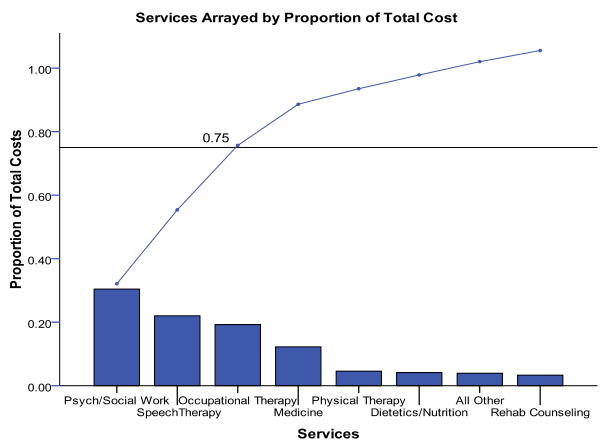

Figure 8

Clinic Services

OMRDD clinic services include behavioral health services which generally include psychology and/or social work, medical services, and therapy services such as speech, occupational and physical therapy. OMRDD provides clinic services for qualifying individuals of any age in certified clinic settings (known as Article 16 clinics), or in non-certified settings such as the family home.

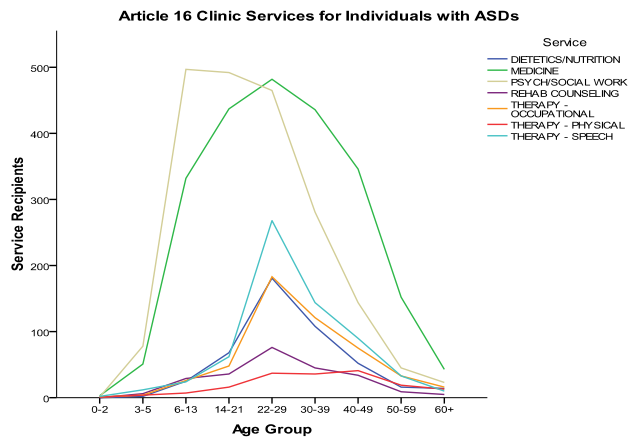

Figure 9

Preschool and school age children with ASDs may receive clinical services provided by OMRDD Article 16 clinics in addition to the special education services provided by the school district, although the utilization of Article 16 clinics for school age children is much lower than for adults.

For the period of July 2006 through June 2007, OMRDD provided over $7 million in clinic services to individuals with a primary or secondary diagnosis of ASD. Across all age groups, seventy five percent of Article 16 clinic expenditures for individuals with an ASD diagnosis are for psychology/social work, speech therapy and occupational therapy (Figure 8).

Article 16 clinics are a particularly important source of psychology/social work services for school age individuals with ASDs. Of the Article 16 clinic disciplines, psychology/social work has the largest number of school age recipients with ASDs (Figure 9). For adults (age 22 and older), medicine surpasses psychology/social work as the Article 16 service category with the largest group of recipients with ASDs.

Services Supporting School to Post School Transition and Employment Outcomes

Transition services are defined as a coordinated set of activities which prepare the student for adult life. Transition planning examines the student's opportunities for postsecondary education, employment, vocational training, adult education, adult services, independent living and community participation.

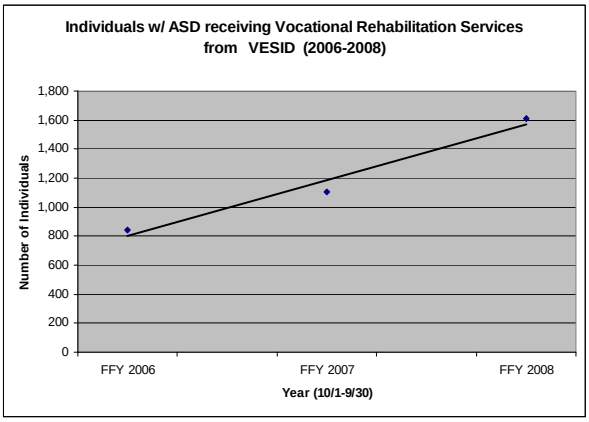

Figure 10

School districts are responsible for providing transition planning and services as part of the student's IEP (Individualized Education Program) beginning with the IEP that is in effect beginning with the year when the student turns age 15 and ending when the student graduates with a regular diploma, leaves school or at the end of the school year when the student turns 21. Although districts are responsible for providing transition planning, other community providers and State agencies play an important role while the student prepares to transition to adult life and during the first years following the completion of school services.

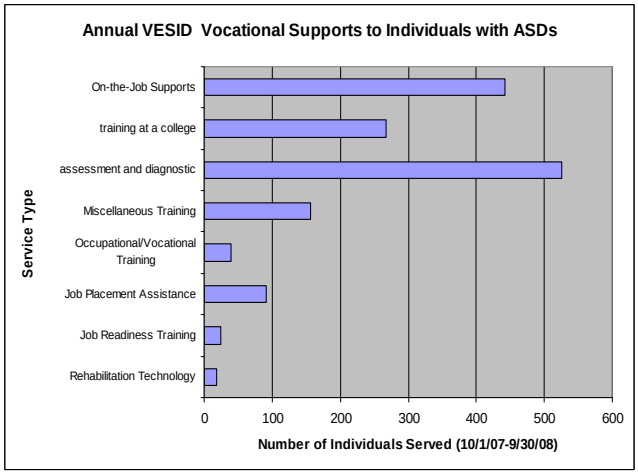

Figure 11

VESID also provides vocational rehabilitation (VR) services for individuals with physical or mental impairments who want to go to work. Students in the transition process who are nearing completion of high school may be eligible for VR services if they received special education services or other help because of a diagnosis of ASD. In 2008, VESID provided $3.8 million in vocational services to individuals with a primary or secondary diagnosis of ASD. The number of individuals served by VESID with an ASD

diagnosis has doubled between 2006 and 2008 to a total of 1,614 people (figure 10). The majority of these individuals were made eligible and began receiving vocational rehabilitation services with VESID prior to the age of 22. In 2008, over 80 percent of the individuals with ASDs who received vocational services from VESID (1,316 of 1,614 individuals) were between the ages of 16 and 22 when first applying for vocational assistance.

OMRDD also supports the transition of students to adult life. OMRDD's level of day service provision begins to increase for the 14 to 21 year old age group and the annual day service expenditure for 14 to 21 year olds with ASDs is $3.3 million. Of the OMR day services provided to this age group, vocational services (prevocational services and supported employment services) lag behind the provision of day habilitation (Figure 12).

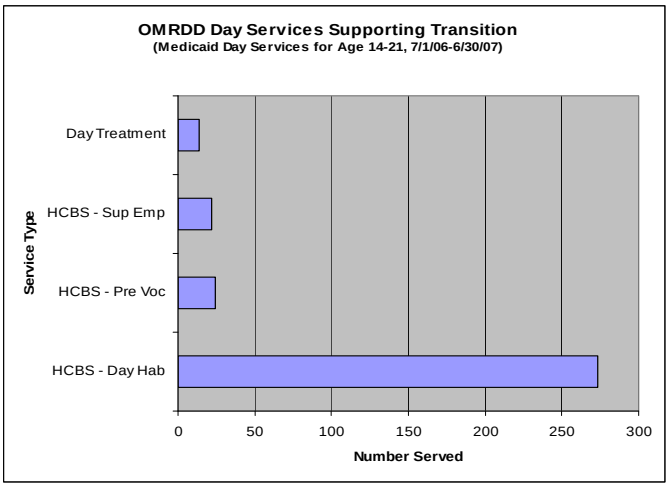

Figure 12

The day service that a young adult first enters after leaving school may have lasting repercussions throughout the person's adult life. OMRDD staff examined service enrollment data for 120 young adults with an ASD diagnosis who, during 2003, received a day service (day training, day treatment, day habilitation, prevocational services and supported employment). Of these individuals, 88 continued to receive some type of day services in June 2009. As of June 2009 only five of the 88 day service participants had moved into OMRDD Supported Employment services from one of the other day services.

Supports for Families

The need for additional services that support families who are living with ASDs is among the most frequently cited concerns raised at public hearings and forums. Services such as respite, recreational programs, counseling, and family training provide families with needed relief. At public forums, one of the often cited needs is for services that respond to the family in crisis. Service coordination, particularly for younger children with ASDs, is another important source of support to families.

Family Education and Respite

Both the OMRDD Home and Community Based Waiver and the Early Intervention Program (EIP) provide respite and family training programs to families of individuals with ASDs (Figure 13). Family

Early Intervention and OMR HCBS Waiver Supports to Families living with ASDs

(Early Intervention Respite, Early Intervention Family Training and Counseling, OMR HCBS Respite & OMR HCBS Family Educ. and Trng)

	Age 0-2	Age 3-5	Age 6-13	Age 14-21	Age 22- 55	Age 56+
Respite						
OMR/HCBS		$ 289,259	$ 3,659,395	$ 3,170,578	$ 1,947,885	$ 25,047
EIP	$ 9,212	$ 24,967				
Family Training/Counseling						
OMR HCBS	$ 100	$ 9,400	$ 34,050	$ 7,700		
EIP	$ 1,399,204	$ 3,350,643				
Total	**$ 1,408,516**	**$ 3,674,269**	**$ 3,693,445**	**$ 3,178,278**	**$ 1,947,885**	**$ 25,047**

Figure 13

training and education is among one of the most frequently provided services for the families of infants and toddlers with ASDs.

In school programs, many families of children with autism receive assistance in understanding the special needs of their child, as well as information about child development and help to acquire the necessary skills that will allow them to support the implementation of their child's IEP. When recommended on a student's IEP, these parent counseling and training services are at no cost to the parent.

For parents who are involved with the EIP, the *Family Initiative Coordination Services Project*, is an important source of parent education, support and training. The Department of Health's Bureau of Early Intervention supports this project as a means to collaborate with parents and promote parent involvement at all levels of the Early Intervention Program. One of the initiatives under this project is the delivery of Early Intervention Partners training for parents in the early intervention system. The EI Partners training project is designed to help parents of young children with disabilities develop partnership and leadership skills that will assist them and their families as they progress through the service delivery system. Hundreds of parents in NYS have participated in the EI Partners training, and the "Partners" parents have a strong presence on the State Early Intervention Coordinating Council and LEICCs across the state. In addition, many of these parents have used the skills they developed through EI Partners to improve and contribute to the service delivery system.

Crisis Intervention Services

In recent years OMRDD has experienced an increase in the requests for crisis intervention services through Family Support Services (FSS). These services, which include primarily respite, mobile crisis team response, and family training and intervention, are often required by families of individuals with ASD. In response, OMRDD began in 2006 to target significant portions of its annual FSS allocations to serve the families of individuals with challenging behaviors and/or ASD. In FY 2006-07, OMRDD targeted 75 percent of its FSS dollars to services for individuals with ASD or challenging behaviors. In FY2007-08, it allocated $7.9 million to FSS, 25 percent of which was targeted specifically to provide crisis intervention and services for those with challenging behaviors. Then, in FY2008-09, OMRDD allocated $5 million for FSS, with an additional $2 million targeted solely for services to individuals with a diagnosis of ASD. OMRDD estimates that the 08/09 targeted allocation will benefit approximately 1,300 individuals with ASD. Approximately 40 percent of all the children with ASD under the age of 22 who receive OMRDD services receive some type of Family Support Service. In 2008, OMRDD provided FSS services to 5,879 individuals with an ASD diagnosis (Figure 14).

Autism/ASD Prevalence by Groups of People Served by OMRDD

(9-30-2008)

Group	Percent with Autism /ASD Diagnosis	Number with Autism/ASD Diagnosis	Total Number of People
All individuals	15.0%	18,738	124,746
FSS Participants	13.5%	5,726	42,549
Individuals requesting a residence	15.7%	942	6,996
Residential participants	12.4%	4,690	37,922
Day participants (individuals)	10.3%	5,879	56,168

Note: Many individuals are served in more than one setting so the groups above aren't distinct.

Figure 14

Service Coordination

OMRDD, through Medicaid Service Coordination and Plan of Care Support Services, provides service coordination to over 6,000 children and young adults under the age of 22 with an ASD diagnosis. The EIP provides service coordination to 2,848 infants and toddlers with ASDs.

All children in the Early Intervention Program, including those children with an autism diagnosis, receive service coordination services. Upon referral to the EIP, an initial service coordinator is assigned to the child and the child's family by the local Early Intervention Official. The initial service coordinator has wide-ranging responsibilities related to assisting the family with the evaluation process and development of an individualized family service plan (IFSP). Families select an ongoing service coordinator at the time of their initial IFSP meeting, who acts as the single point of contact for the family in helping parents to obtain the services and/ or assistance they need, and coordinating services across agency lines. Service coordinators are responsible for providing assistance and services as necessary for the child and the child's family to receive the rights, procedural safeguards, and services authorized to be provided under the EIP.

Outreach and Information and Referral

Many Early Childhood Direction Center's funded by SED VESID provide direct assistance to parents of children with autism transitioning from early intervention to preschool special education centers. For example, the Rochester ECDC currently provides home visits to families in the Early Intervention System who have had a child recently diagnosed with an Autism Spectrum Disorder. The purpose of these visits is to provide the family with information on the diagnosis, and services available.

In addition, the Department of Health's Children with Special Health Care Needs (CYSHCN) Program identifies, reports, and responds to the needs of New York State's CYSHCN population, age birth to 21 years, and their families. The program contracts with county health departments to provide information and referral services for CYSHCN, including children and youth with ASD. Community CSHCN Programs link children, youth and young adults and their families to sources of health and dental insurance such as Child Health Plus, Medicaid, and Medicaid Waiver programs including the Home and Community-Based and Katie Beckett Waivers. In addition to insurance linkages, the CSHCN Program provides referrals to many other health-related and family support services such as respite, counseling, support groups, transportation, translation, and education. It also determines the need for a primary care physician for each child enrolled in the Program. If a child does not have a primary care physician, the program links the family with a primary care provider in the community who participates with their health insurance plan. The program also employs a Family Specialist to ensure family representation in systems development and systems change issues. The Department works collaboratively with family organizations, including Family Voices and Parent-to-Parent. The Family Specialist brings the family perspective to the CSHCN Program operations and serves on several state and national committees, including NYS Emergency Medical Services for Children Committee the Developmental Disabilities Planning Council Children's Issues Committee, and the Association of Maternal and Child Health Program's Board of Directors.

Residential Supports

OMRDD provides a wide range of residential supports; these include services provided in the person's own home and services provided in certified residences with varying degrees of staffing oversight. The types of residential opportunities include:

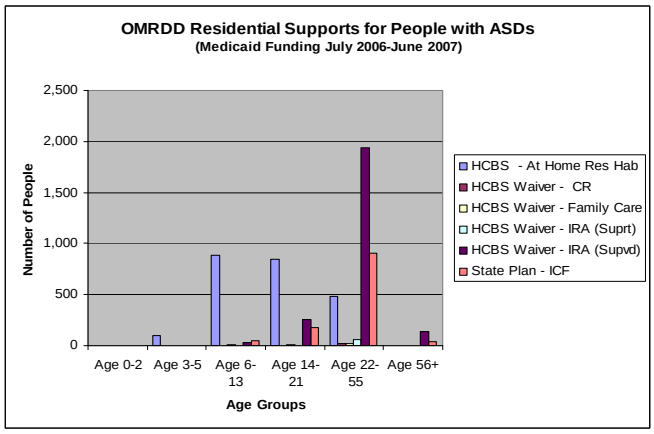

Figure 15

- **At Home Residential Habilitation**, an HCBS Waiver service that is available to individuals who live in their own or family home.
- **Family Care Homes**, community-based residential housing in certified private homes.
- **Supportive Residences,** community-based housing which includes Supportive Individualized Residential Alternatives (IRAs) and Supportive Community Residences (CRs). A supportive residence allows independent living with periodic staff supervision.

- **Supervised residences,** community-based housing, which includes Supervised IRAs and Supervised CRs. These residences provide 24-hour staffing.
- **Intermediate Care Facility (ICF/DD),** a facility that provides housing, 24 hour support and services including professionally developed and supervised activities and therapies planned for each resident by an interdisciplinary team.

Currently there are approximately 6,000 people with ASDs who receive community-based residential Supports from OMRDD. For children and young adults under the age of 21, At Home Residential Habilitation services are the most frequent source for residential supports (Figure 15). Among adults with ASDs who receive residential supports, most live in Supervised IRAs and ICFs. The recent trend in Supervised IRA development is toward homes with fewer beds (Figure 16).

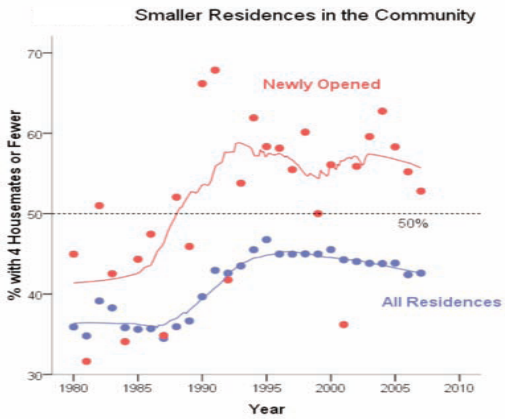

Figure 16

There are also a number of initiatives to develop specialized residential supports that address the particular needs of individuals with ASDs, including residences in the Capital District, the Binghamton area, Staten Island and in Long Island. OMRDD is also partnering with SED and voluntary service providers to develop additional children's residential program (CRP) opportunities to serve approximately 250 children age 21 or under with developmental disabilities, many of whom have challenging behaviors and who are currently being served outside of New York State.

Currently, OMRDD and SED certify or approve CRPs for 300 children with developmental disabilities, including children with autism, each serving 12 or fewer individuals and each affiliated with an approved private school developed to meet the specific educational needs of the children. Development of the additional CRPs will double the existing statewide capacity to serve children with intensive needs and allow hundreds of New York State children with developmental disabilities – approximately 150 with ASD – to be supported and educated at home in New York.

There are currently 11 residential school programs in New York State approved by the New York State Education Department to provide education programs to school age students with autism, four of which are CRP programs

Supporting Information

This section of the document includes descriptions of the data sources that are cited earlier in the appendix.

Data Sources

OMRDD Data

The source of the data included in this report is the OMRDD Tracking and Billing System (TABS) and DOH eMedNY Data Warehouse. Data from eMedNY was extracted on 10/30/09 and services were aggregated on date of service, not date of payment. All eMedNY data is for the period of July 1, 2006 through June 30, 2007. TABS is OMRDD's statewide database that is maintained by the 13 DDSOs and contains service and demographic data on individuals served by OMRDD. Age categorizations are based on the person's status as of 6/30/2007.

SEDCAR data source

Department of Health Data

Since the inception of the EIP, the Department has supplied the fifty-seven county and New York City agencies responsible for local administration of the EIP with a software application, known as the Kids Integrated Data System (KIDS), to use in the collection of data, local management of EIP activities, payment of bills submitted by providers, and processing of claims to commercial insurers, Medicaid, and the Department. Data are collected locally using the KIDS application and submitted to the Department on a quarterly basis. The Department maintains and regularly updates its state-level database on the EIP, using the quarterly data submitted by municipalities. In addition to the KIDS application, the Department maintains a Fiscal System application, which is used to process all claims submitted by municipalities for State reimbursement. In accordance with State law, municipalities must submit claims for payment within two years of the date of service. Data included in this report are derived from the KIDS and Fiscal Systems.

Office of Mental Health Data

The data is based on information maintained by OMH regarding individuals with a primary or secondary diagnoses of autism or pervasive developmental disorder, NOS (which would include ASDs and Asperger syndrome) who were served in 2008. The diagnoses are admission diagnoses, the numbers may be underestimated since many times our systems cannot capture secondary diagnoses.

C. ASD Research Survey Results

This document presents the results of a workgroup including Deborah Chapin from the New York State Developmental Disabilities Planning Council, Dr. Lawrence Sturman of New York State Wadsworth Center, and Dr. Eric London, from the New York State Institute for Basic Research in Developmental Disabilities. This workgroup set out to survey the ongoing autism research being done across New York State. After identifying 17 institutions which were likely to be conducting autism research, the workgroup sent a copy of a survey contained in this appendix to each institution. The expected result of this canvass was to obtain information from representatives at each institution about the projects and research they were conducting related to autism. Ten of the 17 institutions contacted by the workgroup responded with a completed survey.

1.) Wadsworth Center

The Wadsworth Center informed the workgroup that several projects studying the genetics of autism are ongoing. These projects are varied in nature and include the following:

- Studying the Genetics of Complex Behaviors in Mice – This research involves elucidating the genes responsible for autism-like social behaviors in mice.

- Studying the affect of genetic and environmental conditions on social behavior in Mice – This research involves manipulating the environment of the mice and is hoped to lead to advances in therapeutic interventions for individuals with ASD.

The Wadsworth Center recommends that research be conducted on the biomarkers used to identify autism.

2.) University of Rochester

The University of Rochester reported seven ongoing studies. Some of these studies are federally funded, while others are funded with the help of foundations.

- The Autism Treatment Network/AIRP Study – This project is funded to produce best practices for the medical treatments for individuals with autism and their families.

- Diet and Nutrition Study – This study will analyze what children with autism eat and will study excesses and deficiencies in the diet of individuals with autism.

- A Study on the use of Atomoxetine – Researchers will examine the effectiveness of Atomoxetine in comparison to parent training and a placebo to treat hyperactivity in children with autism.

- Taste and smell functions in children with autism

- Preschool parent training – This study is a collaboration with Yale University.

- A comparison of early interventions – This study is done with assistance from Johns Hopkins University and UCLA.

- A study of the mechanisms of audio/visual language using MRI and EEG technology

In addition to these ongoing studies, the University of Rochester has five grant proposals pending. These proposals include:

- A study of gastro-esophageal reflux and its relationship to sleep disturbance in individuals with autism

- A study of cross modal brain processing

- A study of audio/visual processing

- A study measuring outcomes for students who receive community based Applied Behavioral Analysis

- A study of the use of "social stories" as an intervention in autism

The University of Rochester recommended future studies related to ASDs that focus on:

- Community based practice research (health care systems, access to care, and cross system models).

- Evidence based assessment practices

- Behavioral interventions for individuals with ASD

- Psychiatric co-morbidity (assessment and treatment)

3.) North Shore/Feinstein Institute for Medical Research

The North Shore/Feinstein Institute for Medical research reported one study related to autism. This study involves investigating the genetic and immune system risk factors which may lead to autism and other neurodevelopmental disorders.

The Institute's recommendations for future research included studies exploring the effectiveness of different types of educational therapies and studies on the effectiveness of music in treating individuals with autism.

4.) Westchester Institute for Human Development

The Westchester Institute for Human Development (WIHD) along with the Westchester County Medical Center and New York Medical College reported three ongoing projects with funding from the

Leadership Education in Neurodevelopmental and related Disabilities program (LEND) of the federal Health Resources and Services Administration and the New York State Education Department:

- A study to document the benefits of individuals being diagnosed prior to three years of age and receiving early intervention services at such a young age. This particular project will study individuals who are just starting school.

- An examination of the use of early intervention charts as a tool in surveillance studies

- The impact of providing education and technical assistance to families and school personnel concerning evidence based practices

WIHD suggested two items for consideration in future research related to ASDs:

- Research focused on the behavioral assessment and treatment of challenging behaviors in the classroom

- Studies concerning the amount and types of intervention available across New York State

5.) New York University/Nathan Kline Institute

New York University (NYU) and the Nathan Kline Institute cited two programs which are continually funded by either a foundation or the federal government:

- The first program focuses on the early development of brain connectivity in autism. This program uses functional Magnetic Resonance Imaging (fMRI) to study spontaneous brain activity during sleep.

- The second program examines the connectivity of the anterior cingulate cortex networks in individuals with autism. Researchers are looking at two brain networks thought to be involved in social and cognitive functioning.

In addition, NYU and the Nathan Kline Institute reported one pending study which is a neural dissection of hyperactivity and inattention in individuals with autism. This study is intended to find whether hyperactivity and inattention use similar brain mechanisms in individuals with autism when compared to the brain mechanisms used in individuals with Attention Deficit Hyperactivity Disorder.

NYU and Nathan Kline Institute suggested that there should be more work to coordinate ASD registries in order to optimize clinical and research efforts in the future.

6.) Mount Sinai School of Medicine

The Mount Sinai School of Medicine reported 14 ongoing studies in the field of autism. These studies are funded by federal, pharmaceutical, or foundation grants. One of the foundations providing grant funds to Mount Sinai is the Seaver Foundation. The studies include:

- Evaluating the behavioral and neural effects of social skills intervention for school-age children with ASD

- Studying the mediators of motor functioning in adults with autism
- Creating an interactive video to educate pediatricians about the risk indicators for autism and information on assessing young children
- Studying the delineation of more homogeneous groups of individuals with autism and families for research on genetics
- Examining autism endophenotypes (hidden biological findings which can lead to other findings related to disease) and their association with oxytocin and cholesterol
- Researching the effectiveness of Risperidone in the treatment of children and adolescents with ASD
    - Studying the effects of Social Skills Treatment on neural and behavioral indicators of social cognition in children with autism
    - Exploring endophenotypes in families with autism
    - Examining the role of synaptic cell adhesion molecules in ASD
    - Examining anterior cingulated and fronto-insular related brain networks in autism
    - Advancing the Autism Genome Project, a large multi-site, international collaborative effort to pool subjects to support the search for genes connected to autism
    - Studying the role of SHANK3, a gene involved in synapse formation, in ASDs
    - Investigating the effects of intranasal oxytocin on social cognition in healthy humans to inform the experimental therapeutics in ASDs
    - Conducting a pilot multi-site randomized clinical trial to evaluate the effects of memantine on skill acquisition in children with ASD in their cognitive and motor functions

In addition to these ongoing projects, the Mount Sinai School of Medicine is also engaged in the following five projects:

- A study to elucidate the genetic architecture of autism by deep genomic sequencing
- A study of the reward and social interaction in individuals with ASD

- A study of the acute and sustained effects of social skills intervention on neural and behavioral outcomes in children with ASD

- A phase 3 randomized double blind study of the role of digestive enzyme Luminenz-AT in children with autism

- A study of Trichuris suis Ova and autism symptom domains in adults with autism

The Mount Sinai Medical College recommended the following two areas for future study:

- Multi-site study of behavioral intervention combined with psychopharmacology for targeting core deficits

- Research focused on disentangling the genetic heterogeneity of ASD

7.) Albert Einstein Medical College

The Albert Einstein Medical College informed the workgroup of three ongoing studies. However, none of these studies currently have funding.

- A study of stereotypy in autism and other developmental disorders

- Social skills training in schools to train teachers to develop social skills training in the classroom

- A study of the neuropathology of autism

Pending projects undertaken by the Albert Einstein Medical College include a comparison of stereotypy in high functioning children with ASD and tics in Tourette's syndrome.

Albert Einstein Medical College recommended the following two areas for future research on autism:

- Comparative effectiveness of interventions provided to children with autism

- Functional imaging/electrophysiologic studies of different types of language disorders in autism

8.) Hunter College

While Hunter College is not doing research, they do have grants to conduct program development, provide technical assistance, and train teachers. Their activities related to autism include:

- The Regional Center for Teacher Training at Hunter College (through the New York State Education Department)

- Summer institutes for up to 94 staff members (through the New York City Department of Education)

Hunter College has a pending project which is a subcontract with New York University for a grant to develop a comprehensive inclusion program for children with ASD.

When asked how future research should be focused, Hunter College recommended that more program development with research be performed to identify roadblocks to best practice within the public school system.

9.) New York State Institute for Basic Research in Developmental Disabilities

Through federal and foundation grants, the New York State Institute for Basic Research in Developmental Disabilities (IBR) has studies underway that examine:

- Markers of inflammation and oxidative damage in autism
- Oxidative stress and immune response
- Characterizations of the pathological and biochemical markers found in brain tissue and their correlation to the clinical signs of autism
- Mitochondrial abnormalities in the lymphoblasts of autism
- Person centered transition planning for people with ASDs
- Epigenetic regulation of autism associated genes by environmental insults—novel associations
- Clinicopathologic correlations in autism (The Autism Brain Atlas Project)

In addition to these projects, the IBR has 11 projects which are funded entirely through the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD):

- The development of a behavioral inventory (PDDBI) for people with Asperger syndrome
- The study of familial mood disorders genetics and outcomes in children with PDD
- Analysis of the behavioral characteristics associated with autism and Fragile X
- Proteomic analysis of individuals affected with autism
- mRNA analysis of lymphoid cells from families with multiple children affected with autism, their parents, and their unaffected siblings
- The study of brain protein abnormalities in autism (isolated from postmortem tissue)

- The study of the genetics of proapolipoprotein accumulation in the brain of individuals with autism

- The study of neuronal progenitor cells and their development when exposed to autism sera

- Development of laboratory biomarkers to aid in the diagnosis of autism

- The study of the frequency of autism in a sample of individuals with Fragile X

- The study of neuropeptides in autism

IBR has 21 projects with funding pending, but they were not listed in their response.

10.) Summit Educational Resources/ University at Buffalo

Summit Educational Resources and the University at Buffalo reported three studies which are funded through federal and foundation grants:

- A study of comprehensive school based intervention for students with high functioning ASDs

- A study of intensive social skills intervention for children with ASD

- A study of the Connections Summer treatment Program – a program for individuals with Asperger syndrome

Summit Educational resources and the University at Buffalo suggested two areas for focus in future research on autism:

- Studies examining variables thought to be associated with the best outcomes in early intensive behavioral interventions

- Studies examining social development in children with ASD

D. Task Force Testimony to New York State Senate Committees

Interagency Task Force on Autism

Testimony before NYS Senate

Committee on Health

Committee on Insurance

Committee on Mental Health and Developmental Disabilities

October 23, 2009

In May 2008, New York State Office of Mental Retardation and Developmental Disabilities (OMRDD) unveiled its Autism Platform, a comprehensive plan for confronting the increasing incidence of autism spectrum disorders (ASD). Within that multi-faceted campaign, the agency called for a collaboration of state agencies to work together to improve the State service agencies' ability to work together to provide a comprehensive system of lifelong supports. The goal was to ensure that State services are driven by what people truly need, not by what our systems currently allow. With the support of the office of the Governor, that collaboration took shape in the New York State Interagency Task Force on Autism, co-chaired by OMRDD and the State Education Department.

The Task Force held its first meeting in November 2008 involving leaders from 11 State agencies. These key agency representatives agreed that the Task Force would be a temporary body that would examine how New York State can provide effective, lifelong supports to a significantly increased number of individuals and families living with ASD. Together, they would look for ways to improve inter-agency coordination, maximize the impact and effectiveness of state services, elevate New York State's competency in understanding and responding to ASD, and pursue opportunities for partnering with private enterprise in these activities.

Over the ensuing months, the Task Force worked steadily to pursue this mission. Breaking its work into five priority areas of need related to autism, it assigned workgroups to examine New York State's:

- Early identification of children with ASD,
- Adequacy and capacity of services for those with ASD,
- Coordination of services across systems,
- Information dissemination, and
- Coordination of research.

The Task Force examined the current status of State services and programs as they relate to these areas of need and reviewed many documents and reports attesting to the needs of individuals with ASD in each of these areas. In addition, the Task Force solicited further information regarding the needs of individuals and families living with ASD through organized focus group forums conducted on behalf of the Task Force by the six regional New York State Centers for Autism and Related Disabilities (CARDs)

and through an online survey posted on Task Force agency Web sites. Together these outreach activities assured the Task Force of a current understanding of New York State's response to autism to date and the remaining areas of concern and need. The results of both will be summarized in the Task Force's final report to be released in December 2009.

Providing a Single Source of Information

Throughout this year-long examination, the Task Force has also been taking steps to immediately address one of the areas of need, that of greater dissemination of accurate, up-to-date information about ASD. NYACTS, a comprehensive New York State Web site on autism, will be up and running within the next few weeks. NYACTS stands for our State initiative for Adults and Children on the Spectrum. It will provide one-stop-shopping for families and professionals seeking current, evidence-based information related to ASDs, New York State services for individuals and families, recent laws related to autism, New York's autism platform, and New York citizens of all ages living with autism. It is designed to be family-friendly in its presentation of information and, using electronic links to all the agencies, will easily guide and connect a family to the service system they need to access for information or services for their loved one. NYACTS will provide a dynamic and family-friendly mechanism for continually expanding the kinds of information New York State can provide the public. Task Force member agencies have pledged to continue working together to maintain and expand this informational resource.

Pointing New York to the Next Steps

Finally, the Task Force is now assessing what steps New York State should take to better connect its separate service agencies in responding to the needs of those with ASD in ways that are on target, effective and efficient. It is sifting through all the information it collected about its service systems and the needs of individuals and families, and drafting recommendations and next steps toward this end. These recommendations will affirm the need to complete ongoing projects, but also identify new areas for collaboration. There is much we need to do. We must prepare physicians, direct care providers, professionals, vocational counselors and teachers to effectively serve individuals on the autism spectrum and prepare individuals with autism for and support them in gainful employment. These are challenging and complex needs to which the State must respond.
The Task Force will, in its final report, identify specific first steps that will allow New York to begin to address these issues and advance toward provision of comprehensive, lifelong supports that help individuals with ASD live lives of achievement and success.

Continuing what has Started

The Interagency Task Force on Autism provided an opportunity for separate State agencies to discuss their programs of services for individuals with ASD in relation to other State agency programs and services from the point of individuals with ASD and their families. In doing so, agencies have learned much and have taken important steps to align New York's service systems to address the needs of those with ASD in unison. That is not insignificant. In December 2009, the Task Force will submit its final report to both houses of the New York State legislature, Governor Paterson, and the Inter-Office Coordinating Council (IOCC). Each of the member agencies are committed to continuing the understanding and momentum that has begun. The recommendations within the final report, the IOCC, and the public, will ensure what has started will continue.

E. Autism Platform Status Report

In 2007, OMRDD participated with its sister service agencies in a series of "People First" listening forums across the state to gather public input regarding the service needs of New York citizens. Impassioned comments received at each forum made it clear that New York State needed to provide information and services to address the challenges faced by the growing number of people diagnosed with Autism Spectrum Disorders (ASD). In May 2008, OMRDD responded with publication of its Autism Platform, a comprehensive plan for strengthening New York State's service systems for effectively serving individuals diagnosed with ASD and their families.

The Platform described OMRDD's planned activities related to ASD within five areas of priority concern and called for unprecedented cross agency collaboration among New York State's human service agencies. Since that time OMRDD has made its Autism Platform a top agency priority, identifying and pursuing ten key Platform initiatives and dedicating substantial leadership and staff time to the Inter-Agency Task Force on Autism and its cross systems examination of the many issues surrounding ASD.

While the Platform represents OMRDD's examination of its readiness for the current surge in those diagnosed ASD, the initiatives it contains will improve the ways the agency supports and serves all individuals. The Platform initiatives are underway within a system that is broader in scope than any single diagnosis. The Platform exists to improve that broad system for those with ASD, but it does not do so in a vacuum. Staying true to its mission, OMRDD's Autism Platform and the initiatives it contains will improve the system for everyone the agency serves.

In a veto message signed in July 2008, Governor David A. Paterson described the Autism Platform as an important initiative aimed at addressing many of the needs surrounding autism and thereby foregoing the need for costly new mandates. He also directed the Commissioner of OMRDD to report to the legislature on the progress of the Autism Platform within 18 months. OMRDD staff has prepared this report in fulfillment of that directive.

The Autism Platform

The Autism Platform is designed to address ASD and improve the OMRDD system on multiple fronts immediately and in the years to come with initiatives dedicated to:

- Increasing Research – *to ensure that New York State is aggressively pursuing increased understanding of the causes, manifestations of, and most effective treatments for ASD;*
- Translating Research into Improved Practices – *to ensure that the most current, scientifically valid understanding of ASD informs the methods used to treat and support individuals and their families;*
- Putting People First by Coordinating Service Delivery from Multiple Systems – *to ensure that New York State service agencies find ways to evaluate their supports for individuals with ASD from the point of view of the person being served and work together to more effectively meet the challenges presented by ASD;*
- Uniting Public, Private and Nonprofit Interests – *to ensure that New York State taps into ASD expertise wherever it lies and leads ASD experts to work collaboratively for the greatest gains; and*
- Providing Information – *to ensure that New York State disseminates accurate information to support individuals with ASD and their families and to elevate ASD competency throughout the state's professional communities.*

OMRDD has undertaken initiatives in each of these areas and is working with many of its sister agencies to achieve significant enhancements in New York State's ability to meet the needs of New Yorkers with ASD.

Initiatives and Progress

Increasing ASD Research

OMRDD continues to support its Institute for Basic Research (IBR) on Staten Island in undertaking a wide range of studies that examine, among other things, genetic and environmental causation, brain morphology, and the potential to develop laboratory biomarkers for early detection of ASD. IBR has received approximately 1.7 million dollars for the coming year in federal grants to pursue autism studies. Approximately 25 percent of the scientific staff at IBR is working on autism research efforts.

Some of the most promising areas of ASD research at IBR include the following:

Finding a Gene that Predicts Autism Severity **-** Researchers at IBR have identified a gene that may predict the severity of autism. They found that this gene predicts which children will have low or high cognitive functioning and correlates highly with the severity of their autism. These are important observations because IQ and autism severity are both important predictors of later functioning. Identification of this gene may make it possible to predict response to drug treatment in autism. Since this gene affects cognitive functioning and severity, IBR scientists have hypothesized that it will also predict response to intensive Applied Behavior Analysis (ABA) intervention and have recently applied for funding to test this hypothesis.

Laboratory Biomarkers to aid in the Diagnosis of Autism - There is increasing evidence suggesting that abnormal regulation of gene expression contributes to the cause of autism. Researchers at IBR and others have identified various factors or biomarkers that may be observed in blood samples and thereby act as indicators of a person's possible autism. Scientists are now using these biomarkers to determine if gene expression is abnormally regulated following exposure to various environmental substances that have been hypothesized to cause autism. Specifically, the study will examine bisphenol A, fluoxetine, genistein and other compounds that affect brain chemistry, all of which children may encounter early in development. The results from this in-vitro system (test tube) will allow later studies using in vivo (animal model) systems to determine if these environmental factors may be involved in the development of autism. These studies may lead to the ability to modify or even prevent the development of autism.

Development of an Autism Brain Atlas - The autism brain bank at IBR, supported by the Autism Tissue Program, is undertaking the development of an Autism Brain Atlas using state-of-the-art stereological analysis of brain anatomy in autism. This is the first and only effort to document the anatomy of the autistic brain on this level. Important new findings are coming from this project demonstrating that neuron sizes differ from normal in many regions of the autistic brain.

Development of a Behavior Inventory to Assist in Evaluating Children with Asperger Syndrome - The PDD Behavior Inventory (PDDBI), an assessment tool developed by IBR for use with children with autism two to 12 years of age, was published in 2006. Based on the success of this instrument, IBR has begun developing a similar instrument for Asperger Disorder (the Asperger Disorder Behavior Inventory-ADBI) to provide quantitative, age-standardized scores based on a well-defined population of children with high functioning autism for a variety of behavioral domains relevant to autism and other developmental disabilities. No other Asperger Disorder assessment tool to provide this type of information is currently available. This project is in the development phase where IBR is gathering

information from parents and teachers. When all of the data have been collected, information will be gathered on a "normative" group of typically developing people which will make the ADBI a unique assessment tool for this population.

IBR Infant NICU Study - IBR's experts in the study of early high-risk infant development are studying potential precursors to ASD in infants assigned to a Neonatal Intensive Care Unit (NICU) at birth. These infants are statistically two times more likely to develop autism. Currently about 15 percent of all births get assigned to a NICU. This translates to approximately 20 percent of all ASD-diagnosed cases. For these reasons, NICU infants are an ideal group to study in order to identify and better understand the early markers for ASD, well before formal diagnoses are made. This work follows in IBR's tradition of research into infant development, whereby IBR scientists have studied arousal regulation, attention and motor development in high-risk NICU-assigned infants, following more than 3,000 infants intensely over their first few years of life. A group of these infants were recently identified to have ASD. These studies represent a new area of ASD research, providing a large amount of unique data including longitudinal video records of performance that will be further examined for potential precursors to ASD. Future detailed follow-up studies of NICU infants represent a new strategy for prospective research in ASD.

Fragile X Clinical and Research Consortium - The fragile X syndrome, the most common inherited cause of mental retardation and developmental disabilities, has a lot in common with autism, since more that half of subjects with this disorder also have ASD. IBR staff has had a long standing basic research interest in fragile X syndrome, as well as in running a fragile X clinic, the only one in the state. Recently, IBR was awarded a CDC-supported grant to coordinate the Fragile X Clinical and Research Consortium of 20 clinics nationwide. Development of this consortium will accelerate the clinical testing of targeted treatments. Basic research on a mouse model of fragile X syndrome has lead to the discovery that certain drugs that partially block some of the glutamate receptors in the brain produce dramatic improvements in the mice. Also drugs that stimulate the inhibitory GABA pathway can also create marked improvements in the mouse. Now IBR is participating in double blind trials in humans with fragile X and subjects with ASD using a purified form of the GABAergic drug Baclofen (see www.clinicaltrials.gov) sponsored by the Seaside Therapeutics Corporation. These drugs appear to have tremendous potential in both fragile X and autism.

Translating Research into Improved Practice

Ensuring that OMRDD's services for people with developmental disabilities are based on proven, scientific understanding is crucial to "putting people first" and fulfilling the agency mission of "helping people with developmental disabilities live richer lives." OMRDD is committed to providing services that are safe and based on current, demonstrated knowledge. Practices in ASD treatment and services are receiving tremendous attention and examination today. Researchers at IBR's Autism Treatment Research Laboratory are pursuing an agenda of applied research and program evaluation that will continuously inform and improve OMRDD's support for individuals with ASD. They are focusing on the study of the autonomic nervous system's role in autism and related developmental disorders. The parasympathetic system, which regulates most body functions such as eating and sleeping, is theorized to be deficient in autism while the opposing system, the sympathetic system (fight or flight) is overactive. Plans are underway to use non-medical treatments such as deep relaxation to improve that system's functioning. Improvements in this parameter may enable autistic people to be calmer, more attentive and more socially engaged. The long range goal is to extend treatment to the very youngest

subjects by developing ways of identifying babies at high risk to become autistic well prior to diagnosis. In order to do this, hospitals in the community are involved with planning a study of newborns.

In addition to this emphasis on applied research and service evaluation, OMRDD is currently pursuing six key initiatives that will improve its service system by bringing state-of-the-art understanding about ASD into practice:

- Developing best practice guidelines for assessment and diagnosis
- Developing regulations and curriculum for positive behavior support and management
- Bringing intensive behavioral intervention to students in New York City
- Developing behavior intervention instruction for parents
- Developing model, state-of-the-art residences for youth and adults
- Developing an adult intensive treatment stabilization center

Best Practice Guidelines for Assessment and Diagnosis - The focus and recommendations of the existing New York State guidelines for the assessment and diagnosis of ASDs are limited to young children between birth and age three. While these guidelines have supported the principles and practice of Early Intervention, there is no similar official guidance document for the assessment of school-age children and young adults. In addition, many of New York's pediatricians, general practitioners, non-medical assessment professionals, and other experts are not adequately informed and trained to assess for the presence of an ASD. As a group, they tend to rely on a broad range of different assessment methods. As a result of these factors, diagnostic reports are not always adequately supported by or consistent with officially identified diagnostic criteria. The scope of such assessments may be limited to the use of a single structured or semi-structured 'screening' procedure and/or general history-taking and fail to accurately identify qualifying developmental disorder(s) that demonstrate a person's eligibility for OMRDD services, or to provide an adequate basis for treatment recommendations.

Thus, physicians and other professionals who could provide ASD surveillance, screening, and diagnostic evaluation of children, may fail to do so because they lack clear expectations and have limited time, financial resources, and access to training and clear guidance in ASD assessment methods. These factors combine to leave New York's families without access to capable, well-prepared assessment professionals at a time when they are most needed.

To help address this situation, OMRDD's Bureau of Behavioral and Clinical Solutions has initiated a project that will produce a set of evidence-based clinical practice guidelines for the assessment and diagnosis of ASDs during the developmental years between birth and young adulthood. This document will offer reliable information about ASD and recommendations regarding appropriate, adequate, scientifically-supported methods of assessment that should be utilized to determine and support a valid diagnosis of ASD.

A volunteer expert panel includes nationally and regionally recognized ASD experts from academic (State University of New York-Binghamton, University of Rochester), clinical teaching (Mount Sinai-Seaver Center, American Association of Pediatrics), and private practice settings, representatives from State agencies (OMRDD and DOH clinicians and researchers), parents, and internationally-recognized expert reviewers. This expert panel has been engaged to review and provide feedback on the existing best practice assessment guidelines published since 1999, update the scientific research and information on which they are based, and create an accessible document that will inform and educate practicing clinicians, OMRDD eligibility review committee members, and parents throughout New York State. The resulting guidelines and recommendations will reflect current professional and scientific wisdom.

OMRDD will integrate the clinical best practice document into its Eligibility Guidelines advisory, provide training for OMRDD reviewers and clinicians, and disseminate it for reference and use by practitioners who assess and refer individuals for diagnostic evaluations and/or OMRDD services.

The expert panel began meeting in June 2009. The panel has researched and reviewed methodology for the creation and updating of best practice guidelines. The panel has also completed its review of all sets of existing guidelines, agreed on basic structural and conceptual elements and approaches, and is gathering updated information from the scientific literature for review. This literature review, and expert consensus on issues for which current scientific evidence is limited, will support the resulting recommendations on assessment methods and tools that OMRDD will establish for use in New York State. The panel expects to complete its work in late 2010 or early 2011 and issue clear guidelines that will assist New York's physicians to meet the demand for careful, state-of-the-art assessment and diagnostic procedures related to ASD, with competence and confidence.

Positive Behavior Support and Management - OMRDD is working to enhance its system of supports and services by establishing clear policies that articulate the importance of a comprehensive approach to behavior support and management that focuses on prevention and early intervention. This project will bring OMRDD practices in line with the "Recommendations for Coordinated Standards and Guiding Principles" put forth in 2007 by the Committee on Restraint and Crisis Intervention under the Council on Children and Families. It reflects the agency's commitment to increase the use of positive behavior supports, identify the most effective and least restrictive intervention techniques for modifying challenging behaviors and reduce reliance on the use of physical interventions, while also increasing monitoring, safeguarding and oversight of plans that include such interventions. As physical intervention is often necessary to protect individuals with ASD from harming themselves or others, OMRDD's efforts to inform all within its system of positive behavior management, and the proper, last resort use of restraint is expected to be particularly relevant to how it serves individuals with autism.

The project will result in promulgation of new behavior management regulations and development of an associated positive behavior management training curriculum for use throughout OMRDD's system of supports and services. OMRDD has engaged a team of staff representing a cross section of the agency's administration (Quality Management, Senior Staff, Regulatory Affairs, Psychology, and Behavioral and Clinical Solutions) to draft new behavior management regulations pertaining to how clinical and direct support staff develop and implement individuals' behavior management plans, the training required of those staff responsible for this planning, and ways in which staff promote positive behavior and respond to challenging behavior. Lead by OMRDD's Bureau of Clinical and Behavioral Solutions, this project is continuing to refine the draft regulations based on extensive comment.

In addition, the Bureau has developed Level 1 of a new 3-level training curriculum known as PROMOTE (Positive Relationships Offer More Opportunities for Everyone) and piloted that curriculum with Developmental Disabilities Service Office master trainers and external service providers in summer 2009. The Bureau is presently receiving extensive input from throughout the agency on the curriculum and has begun to engage additional external stakeholders in review of these materials as well. Feedback has been positive, and wider levels of review are planned.

These regulations and training curriculum are expected to impose significant fiscal demands with respect to clinical staffing requirements, time required for staff retraining in the new curriculum, new statewide reporting requirements for use of restrictive physical interventions and construction

requirements for any newly developed time-out rooms. OMRDD will prepare a fiscal impact statement when the draft regulations are ready for publication.

Intensive Behavioral Intervention in Schools – OMRDD, IBR, the New York State Education Department and New York City's Department of Education are partnering to provide behavioral assessment and intervention services to students in public school settings who present with severe behavioral challenges. The program will serve students with developmental disabilities, including autism, who display severe aggression and/or self-injurious behaviors that pose a significant health and safety risk. These severe problem behaviors often cause immeasurable stress and hardship to the students and their families and place the students at risk of losing their school placement and requiring out-of-home residential services.

In this program, clinical teams of experienced, doctoral-level behavioral psychologists and post-masters level certified behavior analysts are supplementing the expertise and resources within the schools to assess students and then develop and implement behavior intervention plans. Two clinical teams will serve two to three students at a time, with a total of 12-15 students served per year. The length of interventions will vary according to the intensity and duration required by each student, but is not likely to exceed 16 weeks. Teachers, staff and caregivers (e.g., parents, family members, legal guardians, and residential staff) are a vital part of the team and may receive direct behavioral support and training from the behavior analysts.

This program is based on the principles of Applied Behavior Analysis (ABA) which holds that human behavior can be accurately predicted and managed when the function of the behavior is identified. By identifying what motivates students to exhibit challenging behaviors, consultants can devise interventions that will lead the students to replace those behaviors with adaptive, functional behaviors and avert the need for more intensive service such as inpatient programs. All assessment and treatment occur in the school setting in collaboration with teachers, staff and caregivers.

This program, which began in September 2009, will be available in all five boroughs of New York City public schools. IBR staff is conducting a systematic evaluation of this program and will report on the clinical outcomes of the interventions as well as student, teacher and caregiver satisfaction with the program. OMRDD and SED will identify best practices in delivering behavioral interventions in school settings demonstrated through this program and disseminate relevant information to the public, New York's school districts and private practitioners across the state.

Behavior Instruction for Parents - Through its stakeholder advisory bodies, the Interagency Task Force on Autism, and numerous public forums held around New York State, OMRDD has heard repeatedly of the urgent need to provide families with assistance in supporting individuals with ASD who present with challenging behaviors. Promoting positive behavior and responding to challenging behavior when it occurs is perhaps the most difficult aspect of caring for someone with ASD and the most disruptive to families. OMRDD recognizes the importance of helping families address the behavioral needs of their loved ones with ASD so that individuals with ASD can remain together with their families in their homes. The agency is committed to finding ways to effectively share the most current information available about effective behavioral support with families and caregivers. The current fiscal climate will limit, but not prevent, efforts to address this most pressing need.

OMRDD is exploring possibilities for providing useful information for families in four distinct ways:

- On-line instructional videos – These brief videos would convey information related to effective parenting, with emphasis on parenting children with developmental disabilities. To make the information helpful to busy parents, each topic would be covered in a series of three 20-minute video segments that can be viewed independently. They would be accessible via OMRDD's public Web site.
- Parenting Skills Lecture Series – OMRDD is devising a 12-week course made up of weekly 2-hour classes that will highlight different aspects of behavior support and management. These courses could be provided to families across the state by using videoconferencing technology.
- In-depth Parent Training Modules – OMRDD is developing a proposal for a Train-the-Trainer program that would train clinicians to deliver individualized behavior management techniques focused on specific problem behaviors related to toileting, eating and challenging behavior to individual families experiencing severe needs.
- Quarterly Parenting Articles – OMRDD has begun providing articles for parents on its Web site. The articles pertain to issues and challenges in behavior management related to ASD and other topics of interest to parents. They are prepared by ASD experts and written in lay terms to convey practical information useful to families. OMRDD posts a new article each quarter, retaining past articles on the site as well.

In this time of tremendous fiscal constraint, OMRDD is exploring grant funding opportunities and low or no-cost options for providing the above information in conjunction with existing projects, trainings and services or in conjunction with planned activities of interested stakeholder partners.

In addition, OMRDD is in the process of developing a new Intensive Behavioral service under the Home and Community-Based Services waiver. This service will provide funding for time-limited (6 months), behavioral supports and services for waiver enrolled individuals living in non-certified settings or in Family Care. Allowable services are to be provided by clinical staff who meet specific educational and experiential requirements and will include: completion of a Functional Behavioral Assessment; development of a Behavior Management Plan (BMP); implementation and monitoring of behavioral interventions and strategies as specified in the BMP; and training of primary caregivers or direct support staff that provides services in the home in the use of behavioral interventions and strategies as specified in the BMP. This service will be reserved for those individuals who are at imminent risk of placement in a more restrictive living environment due to severe behavioral episodes. It is hoped that this service will provide an additional support to these individuals and their families to maintain a placement at home.

Model Residences for Youth and Adults - OMRDD recognizes the need to support youth with developmental disabilities, including ASDs, into adulthood with a range of appropriate supports and services to meet the full range of individuals' needs. Providing supportive residential services for those who desire to move out of their family home and into an adult setting in the community is an important part of doing that. OMRDD has begun working in collaboration with SUNY Binghamton's Institute for Child Development to design a state-of-the-art residential model and staff training program for delivering residential services to this population. The project seeks to identify the elements of a successful residential model that is informed and guided by the most advanced diagnostic techniques and clinical research and assists individuals with ASD to live and work in their home communities. This information can then inform and improve OMRDD's provision of residential services to individuals with ASD throughout the state.

OMRDD is defining the residential services model by developing four individualized residences for youth, young adults and adults in different locations across the state (Staten Island, Long Island, Broome and Capital District DDSOs). Together, these residences will serve 22 individuals with a diagnosis of ASD whose ages range from 13 to 43 years. Many of these individuals engage in challenging behaviors and will move into the new residences with individualized behavior plans in place. Each residence will employ evidence-based interventions and entail collaboration with other parties such as schools and families. Each individual will also receive services that address their social and vocational skills.

OMRDD's IBR is directing this project and designing and coordinating a comprehensive evaluation that will report the progress of individuals in attaining their goals and also the satisfaction of the staff, family and individuals residing in the homes. Data collection will occur in a standard manner across all four residences. While each residence will be unique in its physical layout and the numbers and ages of the individuals served, each will reflect state-of-the-art understanding of the home environment needs of individuals with ASD and incorporate specialized ASD training for staff, managers and clinicians. Two of the homes will be State-operated, and two will be operated by nonprofit service providing agencies.

While finding suitable properties for these residences has been challenging, one of the four residences (Long Island) began operating in July 2009, serving six young men. A voluntary service provider has recently purchased a property for a second residence on Staten Island, and OMRDD is nearing final ownership of a property in the Broome region. A search continues for suitable property or housing in the Capital District. Thus far, only the Broome project involves building a new house. Others have involved modifications of existing structures.

In conjunction with these residential projects, SUNY Binghamton's Institute for Child Development has developed and executed staff training modules, preparing taped training videos and a complete training curriculum for future use. OMRDD is now planning the pilot of this curriculum. The lessons learned through the development, operation and evaluation of these residences will improve the delivery of residential services throughout OMRDD's entire service system.

Intensive Treatment Stabilization Center - OMRDD's Consaul Road Program has transitioned its focus from a campus-based Intermediate Care Facility (ICF) program serving adults with ASD to a specialized short term ICF program tailored to meet the more intensive treatment and stabilization needs of individuals with autism whose behavior challenges prevent placement in less restrictive settings. The program now serves as a transitional program to assist individuals from across the state who require behavioral stabilization through intensive behavioral supports, sensory integration assessment/intervention, and medication management so that they may stabilize and return to an appropriate residential opportunity within their home community. The program ensures ongoing active treatment through the development of effective, proactive behavioral strategies and intensive clinical/medical monitoring and intervention. The clinical team works closely with the home DDSO or involved voluntary agency to ensure less restrictive residential opportunities are available upon the stabilization of individuals' behavior.

The Consaul Road Program provides significant clinical supports and a direct support staffing ratio to meet individuals' special needs. The program anticipates that once an individual is admitted, he or she will stay between two to five years while effective treatment and behavior strategies are formulated based on assessments, incorporated into their plan of care, and the individual progresses so he or she can successfully return to their community. The focus of the clinical program is on teaching communication, identifying proactive behavior strategies and creating a structured, predictable

environment that meets individuals' sensory needs and helps individuals to become more independent in their daily lives. This treatment focus has resulted in many individuals demonstrating significantly improved adaptive behavior and stabilization. The clinical team is now reviewing an average of two referrals per month for individuals in significant behavioral crisis for possible treatment and intervention at the Consaul Road Program.

Through the community placement planning process, individuals who have been admitted in recent years as well as those who have been served in the program for many years have planned opportunities for less restrictive, community based residences underway. The program has worked with each DDSO and with provider agencies to ensure that individuals residing in the program are provided opportunities in their home districts. To date, the Consaul Road Program has successfully placed 12 individuals into less structured community based settings. The program has identified additional opportunities for more individuals who will also be able to move into their communities with appropriate supports.

The OMRDD mission to help individuals' live richer lives is realized at the Consaul Road Program as it assists individuals to gain behavioral stabilization and prepare for greater community integration through treatment focused on the unique aspects of their diagnosis of autism.

Uniting Public, Private and Non-Profit Interests – The New York State Autism Consortium

The intent of the Autism Platform is to commit New York State to taking steps to better understand ASD and better support those living with it. Pooling the energy and resources of our schools, researchers, service providers and families and applying them together to these objectives will ensure New York State leverages the greatest progress. To this end, OMRDD is working to partner with and bring together resources wherever they exist in collaborative projects. Its researchers are reaching out to private sector scientists to partner in collaborative grant applications and research projects, and the agency is partnering with entities such as the SUNY Binghamton's Institute for Child Development and the Westchester Institute for Human Development on specific service and training initiatives.

Perhaps the largest collaboration, however, is OMRDD's creation of the New York State Autism Consortium, a dynamic convergence of organizations from across the state with expertise in ASD research, treatment, education or service delivery. As members of the consortium, New York's most acclaimed researchers, medical centers, educational centers and State agency staff are coming together to collaborate on projects around their common goals. Together, these ASD experts will be able to design, secure funding for, and implement large scale research studies, both basic and applied, and undertake statewide initiatives that will improve our ability to serve individuals with ASDs and their families.

In 2009, OMRDD selected and hired an Executive Director for the New York State Autism Consortium. The Director is now working to organize and establish the operating structure for the consortium. A planning committee met in October 2009 and recommended the formation of an executive committee and scientific working groups to pursue a research agenda. The research agenda includes the following priorities: training and education, treatment, early identification and intervention, and translational research. The planning committee also discussed the longer term potential for an autism registry for New York State that could provide a source of valuable research data to support long term studies related to causation, diagnosis, and treatment of ASD.

The New York State Autism Consortium will begin to address the need for additional education and training related to ASD by co-sponsoring the Elizabeth Connelly Autism Conference in the Spring of

2010 with IBR. The focus of the 2010 conference will be Education in Autism. Conference presenters will include IBR researchers involved in directing the Short Term Intensive Behavioral Assessment and Intervention Program recently launched in the New York City schools in partnership with SED. Other conference presenters will include representatives from leading New York State universities, research institutions, clinical programs and schools. The goal of the conference is to explore numerous aspects of education and training related to ASD to help and support individuals and families living with ASD.

Putting People First – The Interagency Task Force on Autism

OMRDD is working with agencies throughout state and local government to ensure that New Yorkers with developmental disabilities are receiving the services they need when they need them, from wherever they need them, and with as little bureaucratic complication as possible. Putting the needs of an individual with developmental disabilities, including ASDs, above those of service system bureaucracies means finding ways to make our systems more focused on the people they are designed to serve. As part of the Autism Platform, OMRDD is engaged in several cross agency initiatives including the Most Integrated Setting Coordinating Council, the Inter-Office Coordinating Council (IOCC), the Children's Plan and other workgroups focused on particular concerns. Through these cross systems bodies, OMRDD and its sister State agencies are focusing on some of the most pressing issues facing individuals with ASD and their families: coordination of services when service needs cross systems and when individuals move from one system to another. The challenges that fall into these categories surface in specific instances:

- the individual with a developmental disability and a co-occurring mental health diagnosis who needs both OMH and OMRDD, and possibly even educational services;
- the individual who turns 15 and needs to begin planning for his or her future education, employment or adult placement; and
- the individual who has an ASD diagnosis and experiences limited success, but who does not meet State service eligibility standards.

These instances are very real for many New York citizens with developmental disabilities, including ASD, yet they pose confounding challenges for New York's service providing agencies that must execute different statutory and regulatory obligations. Nonetheless, OMRDD and New York State's other service providing agencies are continuing to dedicate staff and resources to working together to improve our responsiveness to people's needs. New Yorkers with ASD and other disabilities have made it clear that New York State must address these issues. OMRDD recognizes that the most difficult, in this instance, is among the most important to undertake.

To focus this kind of collaborative effort on the needs of those with ASD, in particular, the Autism Platform called for a short-term Interagency Task Force on Autism chaired by the Commissioners of OMRDD and the State Education Department (SED). The Task Force would examine the challenges of ASD and how New York State agencies' programs of supports and services together form a comprehensive response to those challenges. The Task Force – which would engage the leadership of ten state agencies, would then be well positioned to identify and implement recommended steps to improve how the agencies work independently and together to serve and meet the needs of individuals with ASD and their families. The Task Force began meeting in November 2008 and concluded its work in December 2009 with submission of a report (to which this progress report is appended) to the Governor, the Legislature, the Board of Regents, and the Inter-Office Coordinating Council.

The Task Force examined five specific areas of need and recommended many ways New York State agencies can address those needs in both the short and long term. The five areas are:

- Early identification of children with ASD
- Coordination of services across systems
- Adequacy and capacity of services
- Information dissemination
- Coordination of research

Details regarding the work of the Task Force and its findings and recommendations in each of these areas of concern can be found in the Task Force report.

With the submission of this report, the Task Force member agencies are committing to continue advancing the cross system understanding and collaboration that began through the Task Force process. Together and individually, they have embarked on specific recommended first steps contained in the Task Force report.

The purpose in calling together the leaders of New York's service providing systems on behalf of the increasing numbers of citizens diagnosed with ASD was to ensure our separate programs of services effectively provide what those citizens need, that together they create a multi-system network of support driven first by the needs of those it serves. The process of fulfilling that charge spurred deeper cross system awareness and moved New York State toward this ambitious, but essential goal. The collaboration that continues as State agencies implement the recommendations of the Task Force will carry forward the State's desired "people first" vision.

Providing Information

Families and individuals faced with the challenges of ASD need information. They need to know what an ASD diagnosis means for themselves or their loved one and how to find appropriate services. The Autism Platform commits OMRDD to seeking a variety of ways to get accurate and up-to-date information about ASD and available services to those who need it. OMRDD approached this task by examining all the information it was providing related to ASD and establishing new initiatives to enhance these efforts. One of the agency's first activities was to publish a brochure entitled "Facts About Autism Spectrum Disorders and Finding Autism Spectrum Disorder Services." This brochure, which is now available on OMRDD's Web site or in hard copy, provides basic information about ASDs and describes how New York's various service systems work to meet individuals' needs across the different stages of their lives. It includes helpful resources for families who want to know more and helps families understand how to get started finding the services they need. This brochure formed a starting place for additional ASD informational activities that are underway today.

Autism Web Resources – In May 2009, OMRDD launched a Web page on its agency Web site dedicated to providing the public with current information about ASDs, the Autism Platform and its numerous initiatives, and OMRDD services. The Web page also includes news stories, an events calendar, a Parents Corner, helpful publications, and profiles of individuals living with ASD.

In addition, through its work with the Interagency Task Force on Autism, OMRDD staff contributed to the development of a New York State autism Web site, "New York ACTS". This site is designed to be the first stop for any family with a newly diagnosed family member. It is a comprehensive resource, offering information on ASDs and connecting users easily and directly to information about services

available from New York State's service agencies, news and events, summaries of relevant State and Federal statutes, and helpful sources of additional information. New York ACTS is a collaborative initiative launched by the Task Force member agencies, each of which will designate staff to plan and manage ongoing Web site maintenance and future expansion. The New York ACTS (www.nyacts.gov) site was launched in January 2010.

Developing Behavior Intervention Instruction for Parents – Providing parental instruction and information related to behavior management, along with in-home services, will help families to remain together in their family home and avoid the emotional impact of separation. As described above, OMRDD is working to develop a number of effective ways to bring this information to families around the state. In May 2009, with the launch of its autism Web page, the agency began posting regular, informative articles on behavior management and other topics of concern to families on OMRDD's Autism Platform Web page.

Informing First Responders - In September 2007, OMRDD's Broome DDSO held training sessions regarding autism and first response across six counties. Each training included sessions for parents, advocates and first responders (police, fire fighters and emergency medical technicians). The trainings were so well attended and received that OMRDD is now working in partnership with the Developmental Disabilities Planning Council (DDPC) to bring First Responder Training programs to the remaining regions of the state. DDPC is now developing a Request for Proposals for development and implementation of a First Response Train-the-Trainer curriculum related to Autism and other developmental disabilities.

In addition, in 2009 OMRDD developed a booklet on ASD and first response entitled "On the Scene and Informed: First Response and Autism." This booklet brings clear, concise information about ASD and ways to modify emergency response techniques to support positive outcomes when serving someone with an ASD. This booklet is available on the OMRDD Web site, and OMRDD continues to disseminate this booklet to first response agencies across the state.

In the first year of implementing the Autism Platform, OMRDD's ASD informational initiatives focused primarily on creating an informational infrastructure. With online and print resources in place, the next phase of informational activities will involve building on those structures to deliver more expanded information and to keep the information they contain current. In addition, OMRDD will examine ways to address more acute informational needs for OMRDD staff training, parent training, and cross system training as well as to improve internal agency communications to ensure that ASD information transfer to those who need it is effective throughout the agency's statewide system. Outreach conducted by the Interagency Task Force on Autism confirmed the need for greatly expanded training and dissemination of information on ASD for parents and professionals. Through partnerships with sister agencies developed through the Interagency Task Force on Autism, OMRDD is committed to adding a focus on training to its informational activities related to ASD.

Conclusion

Since its inception, the Autism Platform has been an integral part of OMRDD's larger mission and ongoing agenda of system-wide improvement. It commits OMRDD to taking specific steps to address the needs common, but not limited, to people with ASD and in this way, effectively serves two functions. It helps OMRDD to examine the effectiveness of its system at serving a growing population of individuals with a particular diagnosis *and* to improve its overall system for the benefit of all the individuals it serves. Similarly, the many initiatives currently underway to enhance OMRDD's system of supports and services that are not contained in the Autism Platform hold much promise for those with ASD. Examples of these kinds of system improvements include:

- Continuing development of community-based residential and day services,
- Helping more people with developmental disabilities find meaningful supported and competitive work,
- Examining ways to move individuals out of developmental centers and into communities,
- Expanding crisis intervention services and clinical expertise,
- Improving how OMRDD measures progress and communicates, and
- Supporting and developing the dedicated workers who are so vital to the success of the OMRDD system.

As progress on particular initiatives occurs, OMRDD will continue to advance a well rounded platform of activities to improve its system of supports and services. Pursuing the recommendations of the Interagency Task Force on Autism and expanding upon initiatives within the Autism Platform will keep OMRDD focused on its mission of helping individuals with developmental disabilities lead richer lives.

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