



NYS Office of Mental Retardation & Developmental Disabilities

Putting People First



Autism Platform

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Governor

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In some communities
one in every 150
people younger
than 22 may be
diagnosed with autism.



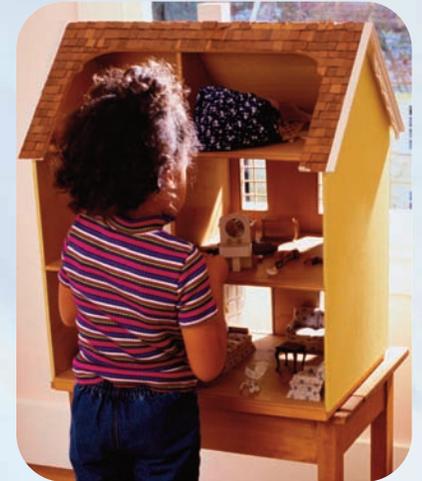
NYS Office of Mental Retardation & Developmental Disabilities

Putting People First

OMRDD Autism Platform

New York State's Office of Mental Retardation and Developmental Disabilities (OMRDD) helps people with developmental disabilities lead richer lives. It currently supports more than 125,000 individuals with disabilities that range from cerebral palsy to down syndrome to epilepsy and other developmental disabilities that impact their ability to function independently. Within this inclusive mandate, OMRDD currently supports 17,000 people with autism or disabilities within the continuum known as Autism Spectrum Disorder (ASD), providing both residential and day services. In addition, OMRDD's research arm, The Institute for Basic Research (IBR), is conducting internationally recognized research in all facets of the disorder, from diagnosis and treatment to innovative ways to support individuals with these disabilities. Diagnoses of autism and ASD are on the rise across the country. The Centers for Disease Control and Prevention have reported that, within some communities, ASD is now affecting 1 in every 150 children. The need to study ASD and develop the appropriate supports and services looms larger than ever before. OMRDD is committed to increasing both the effectiveness and capacity of its supports for individuals and families faced with this disability and join others in devising new ways for our communities and schools to better support them as they pursue their richest lives.

Based upon input gathered from families and advocates over the past year, OMRDD has prepared a comprehensive platform of initiatives that responds to the challenges faced by those living with autism. The platform commits OMRDD to confronting autism on multiple fronts – expanding research and training, developing effective treatment, and providing expanded family and individual supports – immediately and into the years to come. It commits OMRDD to doing so within a system of supports and services that responds to the needs of a much broader universe of people with developmental disabilities.



OMRDD's Autism Platform:

- Increasing Research
- Translating Research Results into Improved Treatment Options
- Uniting Public, Private and Non-Profit Interests to Establish Statewide Research, Evaluation and Treatment Capacity
- Working across state and local government to enhance our "People-First" System of Comprehensive Services
- Providing Information to Families and Self Advocates



Foundation for Action

Systems Change, Research and Services

Systems Change

The Autism Platform is an integral part of OMRDD's larger mission and an ongoing agenda of system-wide improvement.

OMRDD Mission – OMRDD helps people with developmental disabilities lead richer lives.

OMRDD Agenda – OMRDD is committed to transforming its system of care into one that:

- Offers a balanced array of person-centered services,
- Operates with fiscal prudence and accountability, and
- Delivers services through a public and private workforce that is effectively trained and empowered for this all important work.

As OMRDD enhances its person-first focus, the quality of its services, its accountability, and its coordination with other state human service agencies, it is intentionally charting a course of continuous improvement for a system that serves more than 125,000 unique individuals. These improvements will include developing more 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 we measure progress and communicate, and supporting and developing the dedicated workers who are so vital to the success of the OMRDD system. The changes already begun, and yet to come, will enhance the lives of everyone OMRDD supports. They hold much promise for those with autism and ASD.

Research

Through OMRDD's research arm, the Institute for Basic Research in Developmental Disabilities (IBR), a team of elite research scientists continuously studies the causes, treatment and prevention of mental retardation and developmental disabilities. OMRDD has recently expanded the team of scientists at IBR who are dedicated to autism research, adding internationally recognized experts in research psychology and neuropathology in relation to autism. This team is engaged in a range of ongoing scientific research into the genetic causes of ASD, physiological manifestations, and the nature of the increased incidence. This team is also continually expanding its scientific collaboration with key research centers and experts around the nation and the world.

In addition, IBR's newly established Autism Treatment Research Laboratory is poised to transfer the results of IBR's scientific research into practical applications that will improve lives.

Services

OMRDD currently provides individualized supports and services to 17,000 individuals with autism and ASD and is continuously expanding to support more. At its own state-run residences and day programs and in partnership with more than 750 nonprofit service providers, OMRDD has developed a wide range of services and supports for persons with ASD and other disorders accompanied by behavioral challenges. OMRDD serves more than 4,500 individuals with ASD in residential settings operated by nonprofit providers and more than 5,500 with individualized services including day and employment activities. Medicaid Service Coordination and Family Support Services reach more than 15,000 individuals with ASD.

In the past two years, with the support of the Governor and the Legislature, OMRDD has significantly increased its use of Family Support Services for supporting individuals with autism, ASD or challenging behaviors who live at home. Service providers used these monies to increase respite services, after school opportunities and specialized ASD training. The 2008-2009 OMRDD budget contains \$2 million for continuing these targeted services so critical to supporting families.

OMRDD encourages service providers to think “outside the box” about the best ways to individualize services. In response, agencies have developed services that provide hundreds of individuals affected by ASD with:

- Supported employment,
- After school respite,
- Community inclusion activities
- Day habilitation
- In-home supports that will allow individuals to remain in their homes,
- Creative arts expression,
- Structured leisure activities,
- Community college experience, and
- Individualized residential opportunities.

IBR scientists developed the PDD Behavior Inventory (PDDBI) rating scale for children with autism and related developmental disabilities ages 2 -12 years. This rating scale provides quantitative measures of behaviors linked to autism and is now in wide use by NYS school districts and educational and research centers across the US.



A Platform of Action

Increasing Research

OMRDD will continue to make autism research an agency priority and engage the staff at IBR in national and international dialogue around improved understanding of ASD, its prevention, detection and treatment. In April 2008, IBR received a \$1.9 million grant from the US Department of Defense Autism Spectrum Disorders Research Program. This grant will fund a study of postmortem brains of individuals with and without autism to establish correlations between structural and chemical abnormalities in the autistic brain and the clinical symptoms of the disability. This study will seek to identify the most crucial period for brain development in children with autism and the mechanisms that cause the dramatic delay of neuron growth during the first years of their lives.

Several other promising areas of IBR's basic and applied ASD research include:

- Examining the association between autism and fragile X syndrome;
- Identifying a gene that may predict the severity of autism and responses to drug therapy;
- Uncovering causal factors;
- Identifying laboratory biomarkers to aid in early diagnosis;
- Expanding its specialized brain tissue collection to become a world class resource for the international autism research community; and
- Developing the Asperger's Disorder Behavior Inventory (ADBI) that will provide quantitative, age-standardized scores for behavior relevant to children ages 2-12 with Asperger's Disorder.

Beyond this sampling, the full slate of studies is extensive. It ranges from exploring possible perinatal contributions and neurogenesis studies in support of future diagnostic tests to identifying and studying high risk sibling populations to enhance our understanding of the earliest stages of ASD.



Translating Research into Practice

The new Autism Treatment Research Lab adds an agenda of applied research that will lead to improved diagnosis, treatment and support of those living with ASD. IBR researchers are seeking funds to study the effectiveness of a variety of treatments at reducing the challenging behaviors often associated with ASD.

OMRDD is also examining its array of residential and day treatment services for individuals with ASD across the state. In the Capital District, OMRDD will be closing its adolescent transition program for youth with ASD and developing new residential services to provide person-centered services in smaller settings within the community. OMRDD is also developing plans for a statewide program for intensive, but short term, assessment, treatment and stabilization for adults with ASD. Such a program would provide a place for individuals in crisis to benefit from targeted services with the goal of stabilization and a return to less intensive, community based services in the locations of their choice.

IBR and the New York State Education Department (SED) Office of Vocational and Educational Services for Individuals with Disabilities (VESID) are currently developing a Behavioral Assessment and Intervention Program to begin in September 2008 within the five boroughs of the New York City region. Behavioral specialists will provide intensive individualized functional behavioral assessment and intervention for students with developmental disabilities who are experiencing severe behavior problems. Teachers, staff and caregivers will also receive support and training that will allow them to work with students within the school setting and avert the need for more intensive treatment and crisis placement. The program is intensive, individualized and will make use of the most current research-based methods of assessment and behavioral interventions. It will bring together educators, clinicians and families to address individual needs in a proactive way. OMRDD and SED will continuously evaluate the program's effectiveness.

In addition, OMRDD is drawing upon recent field studies in a variety of ways to improve the services it provides to individuals with ASD:

- Developing standardized guidelines for the screening, diagnosis and assessment of ASD that will facilitate determinations of OMRDD eligibility;
- Adapting and promoting behavioral intervention instruction for parents and teachers;
- Developing evidence-based guidelines for evaluating and treating those with ASD;
- Exploring ways to more effectively meet the needs of those with ASD who currently receive OMRDD services; and
- Further developing positive approaches for addressing challenging behaviors and reducing the need for physical restraint.



**Boys are four times more likely
than girls to have autism.**



Uniting Public, Private and Non-Profit Interests

OMRDD is committed to bringing the collective knowledge, experience and research capacity throughout New York State to bear on the quest to understand all intellectual and developmental disabilities. This Autism Platform supports a heightened effort to better understand ASD and to better support those living with it. Pooling the energy and resources of our schools, researchers, service providers and families will ensure we leverage the greatest progress. To this end, OMRDD will work to partner with and bring together resources wherever they exist in collaborative projects.

Creating New York's Autism Spectrum Disorders Consortium

OMRDD, through IBR, is spearheading the development of a New York State consortium of organizations with expertise in ASD. The consortium will bring together academic and research facilities, program providers, parents, advocates and educators to undertake seminal research projects and translate research into state-of-the-art training and practice in serving individuals. This consortium creates the first-of-its-kind public-private enterprise in New York dedicated to pursuing large scale federal and private funding for extensive and ongoing collaborative research into the causes and treatment of autism.

Universities and Service Providers

In addition to launching the New York State Autism Spectrum Disorders Consortium, OMRDD has begun and will continue working to unite the expertise of IBR with that of New York universities and voluntary service providers to develop specialized in-home supports and residential services for adolescents and adults with autism. Projects are now underway in three of OMRDD's Developmental Disabilities Services Offices (DDSO): Long Island, Staten Island, and Broome. In each of these locations, OMRDD is working with university researchers and/or service providing agencies to develop state-of-the-art residential and in-home supports for individuals. As OMRDD gains experience through these programs, it will expand the most successful strategies to serve individuals across the state.

IBR and university research centers also continue to work together to develop methods for early identification of children at risk for ASD and appropriate early interventions. As New York State expands the availability of all public services to eligible children, this work will enable OMRDD to identify young children with autism and other developmental disabilities and begin intervention earlier when it is most effective.

FAR Fund

The FAR Fund supports projects in New York City that improve services for people with autism, prevent violence against youth, and prevent homelessness. Since 2003, OMRDD has partnered with the FAR Fund to bring person centered planning and individualized services to adolescents and young adults with autism. Phase I, now completed, met with clear success: nearly 30 individuals who previously presented significant challenges to the safety of themselves and others, who were not able to live near family, and who were not involved in community activities, have come alive with new interests, more stable and appropriate behavior, and greater involvement. In addition, the provider agencies that implemented the projects have demonstrated how to create a more person centered climate within organizations.

In Phase II, launched in June 2007, three more agencies have initiated a person centered planning process and innovative service design for ten individuals with ASD. Phase I agencies are sharing their experience with the new grantees. Again, OMRDD is giving priority consideration within available funds to the residential and day resources that will be required to implement these

**Autism is
more
common in
childhood
than cancer,
diabetes
and AIDS
combined.**

projects. As in Phase I, IBR will evaluate the achievements of the projects, focusing on any changes in the quality of life of the participants and the organization of the agencies.

Putting People First: Expanding New York's People-First System of Care

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.

Inter-Office Coordinating Council (IOCC)

The Inter-Office Coordinating Council is charged with comprehensive planning and coordinating of services related to mental illness, mental retardation and developmental disabilities, alcoholism and substance abuse, and eliminating gaps in services to people with multiple disabilities. OMRDD is working with its sister agencies to re-invigorate the IOCC as a mechanism for examining our progress toward "Putting People First" throughout state service systems.

Committee on Restraint and Crisis Intervention Techniques

At times, restraint is necessary to protect individuals, including those with autism, from harming themselves or others. Since 2006, OMRDD has participated in the Interagency Committee on Restraint and Crisis Intervention under the leadership of the Council on Children and Families. In 2007, the Committee called for human service agencies and providers that use restraints to examine their policies, regulations and training and develop a plan for bringing these elements in line with coordinated standards and guidelines. OMRDD will propose changes to its policies and regulations that will promote positive approaches to managing behavior and reducing the use of restraint.

Cross Agency Initiatives – SED, DOH

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 operate CRPs for 300 such children, each serving 12 or fewer individuals and each affiliated with a private school developed to satisfy 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.

OMRDD will invite DOH to initiate a multi-agency process of updating its Best Practices Guidelines for early assessment and intervention of autism. This will generate state-of-the-art information to be disseminated and adopted for use by pediatricians, specialists and service agencies across New York State.

Cross System Support

At some point in their lives individuals with autism and other developmental disabilities may require services from state agencies other than OMRDD. They may require support from New York State's Office of Mental Health, Department of Health, SED and even the Office of Alcohol and Substance Abuse Services. Should they find themselves in foster care or in the criminal justice system, they may also be served by the Office of Children and Family Services. To ensure that individuals receive coordinated and efficient services, OMRDD has begun and will continue to work to align the various state service systems. To this end, OMRDD is:

- Working with DOH and SED to ensure smooth transitions as children age out of one system and into the next;
- Working with OCFS to improve how the two agencies work together to serve children with developmental disabilities who are under OCFS custody;
- Working with OMH to develop a model for coordinating the two systems' regional offices;
- Developing a statewide resource directory and regional resource guides (hard copy and online) to assist parents, teachers and human services workers to identify and access supports and services; and
- Providing a single point of accountability within each state agency's system to coordinate information requests.

Providing Information

OMRDD understands the tremendous need for families and individuals faced with the challenges of autism and ASD to find appropriate services for themselves or their loved one. A diagnosis of autism can launch a family on a search for information that is as monumental and daunting as it is essential. OMRDD's Autism Platform commits OMRDD to responding to this very real need for accurate, up-to-date and useful information. In addition to the initiatives listed below, OMRDD will continue to seek ways to get the best information available into the hands of those who need it.

First Responders

In September 2007, OMRDD's Broome DDSO held an Autism and First Responders Training for parents, advocates and first responders (police, fire and emergency medical technicians) across six counties. OMRDD staff arranged for a nationally recognized trainer to present two separate training programs, one for parents and advocates and one for first responders. The trainings were

well attended and well received. Through organizations like Parent-to-Parent of New York State and the Developmental Disabilities Planning Council, OMRDD will bring First Responder training programs to the remaining regions of the state.

IBR Symposiums and Best Practice Workshops

To ensure the highest quality services for those with ASD, OMRDD will identify the best practices now occurring and develop effective means for sharing and promoting these practices in every region.

Each spring IBR holds an annual conference, the Elizabeth A. Connelly Memorial Conference on Autism, named in honor of the late Assemblywoman Elizabeth A. Connelly who was a champion of supports and services for all people with developmental disabilities. The conferences bring together experts from across the country to share recent developments in research, diagnosis and assessment, and services and treatment. IBR will also continue to support other organizations in planning and hosting conferences and training sessions on ASD.

Launching the Platform - an Interagency Task Force

Just as the Consortium will yield significant benefits in the State's public and private ASD research initiatives, efforts to collaborate across service systems will offer similar benefits to people with ASD and their families. The OMRDD and SED will co-chair the Interagency Task Force on ASD. Over the next year, this workgroup will identify cross systems improvements in supports and services for people with ASD and their families particularly in regard to early intervention services, dissemination of information to families, implementation of applied behavioral approaches, and the transition from childhood to adult services. The group will provide its recommendations to the IOCC which promotes and implements cross system solutions for NYS's citizens served by the Mental Hygiene agencies. Both the DOH and the SED are ad-hoc and active members of the IOCC.





For further information, please check the OMRDD Website:

www.omr.state.ny.us

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