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Andrew M. Cuomo
Governor

Courtney Burke
Commissioner



People First: Inside IBR

The Institute for Basic Research
in Developmental Disabilities



News and Information from the New York State Office for People With Developmental Disabilities

December 2011



A Letter from the Commissioner

Dear Friends and Colleagues:

As the New Year approaches, I would like to take a moment to reflect on 2011 and the great strides we've made to strengthen our system, as well as look toward our priorities in 2012.

As you know, we spent much of this year hearing from individuals and families about what improvements they would want to see in a redesigned system under a Medicaid waiver. We also spent a great deal of time and

effort making our system safer and our practices consistent statewide.

Despite the many challenges, employees, individuals, family members, nonprofit provider agencies, and advocates alike have responded, and we have made many positive changes, which were outlined in our six-month progress report released in October. Highlights from these accomplishments include the fact that nearly every allegation of physical and sexual abuse is now reported to law enforcement. We have 51 newly certified investigators, and more on the way, and have required nonprofit providers to meet similar requirements. We have created more transparency in the performance of our providers, and raised the quality of our workforce through new standards. In addition, this month we are announcing an overhaul of regulations on behavior modification, an important first step toward New York becoming a system that better supports individuals with developmental disabilities.

Because of the importance of the work we all do, and because of the dedication of those who choose to work in this field, our system will continue to move forward in seeking ways to improve services and care.

As we look toward 2012, you will see a continued focus on safety, as well as steps we are taking to make our system stronger, more flexible, and sustainable for the future.

We will act on priorities such as creating a culture of awareness, respect, and teamwork, which means that every one of us recognizes our responsibility to be aware of the ways we can improve our system, work together, and ensure that everyone is treated with dignity and respect.

We will soon announce a common sense reorganization of our agency that will put our attention where it should be: on supporting and enhancing the lives of individuals with developmental disabilities.

And finally, we will continue working with individuals, parents, stakeholders, and partners in government to strengthen the delivery and oversight of our services through the launch of pilot programs for the People First Waiver.

We should all be proud of the work we've done in 2011. Significant work remains, but our successes will continue in 2012 with your continued engagement, constructive criticism, and suggestions.

I wish you all a very happy and healthy New Year.

Sincerely,
Courtney Burke, Commissioner



Issue Highlights

IBR Hosts Delegation from China's Largest Children's Hospital

IBR Holds Workshop on Sexuality in Adolescents with Autism

James Maynard Named IBR's 2010 Employee of the Year

Dr. Thomas Wisniewski Runs in NYC Marathon to Raise Autism Awareness

IBR Hosts Delegation from China's Largest Children's Hospital

IBR hosted a visit on October 17 of a delegation from Hunan Children's Hospital of Changsha, the largest children's hospital in China. The visitors were welcomed by IBR Director W. Ted Brown, MD, PhD, and Mazhar Malik, PhD, and Xiaohong Li, PhD, of IBR's Department of Neurochemistry.

The delegation was led by president Yimin Zhu, MD, and included Xiaoyu Zhou, MD, chairman, Department of Surgery; Xiyong Huang, MD, chairman, Department of Medicine; Lihui Zhu, head, international cooperation; and Yan Xie, director, human resources. They toured the Jervis Clinic and IBR's laboratories.

IBR hosted the visit to deepen its collaboration with Hunan Children's Hospital, initiated last April. IBR has helped the hospital establish its center for autism research, diagnosis, and treatment, which opened last April, and will provide training in IBR laboratories for hospital staff in genetic testing for syndromes associated with autism.

Dr. Brown said, "We believe that the international collaboration between Hunan Children's Hospital and IBR will be of great benefit in facilitating autism research and seeking potential effective treatments for autism."



Yimin Zhu, MD, president, Hunan Children's Hospital, and W. Ted Brown, MD, PhD, IBR director



A delegation from Hunan Children's Hospital (HCH), China, visited IBR on October 17. L to R: Lihui Zhu, head, international cooperation, HCH; Mazhar Malik, PhD, IBR Department of Neurochemistry; W. Ted Brown, MD, PhD, IBR director; Yimin Zhu, MD, president, HCH; Xiaohong Li, PhD, IBR Department of Neurochemistry; Xiaoyu Zhou, MD, chair, Department of Surgery, HCH; Ashfaq Shiekh, PhD, IBR Department of Neurochemistry; Xiyong Huang, MD, chair, Department of Surgery, HCH; and Yan Xie, Director, human resources, HCH.

IBR Holds Workshop on Sexuality in Adolescents with ASD

IBR, in collaboration with District 75 of the New York City Department of Education, presented a workshop on October 28 about responding to inappropriate sexual behaviors of adolescents with ASDs. Held at Mount Loretto, Staten Island, the workshop was conducted by Jenny Tuzikow, PsyD, BCBA-D, a senior behavior analyst and clinical psychologist in IBR's Department of Psychology. Attendees included parents of adolescents with autism as well as teachers and staff who support them.

The workshop was part of a series of programs that the New York State Education Department has funded over the last two and a half years for IBR to work with District 75 staff, students, and parents. District 75 provides educational, vocational, and behavior support programs throughout New York City for students with autism and other developmental disabilities, as well as emotional challenges and physical disabilities.

As Dr. Tuzikow began her presentation, she explained the context for inappropriate sexual behaviors in teens with ASD. She said that although the physical maturity and sexual curiosity of teens with ASD are comparable to those of adolescents without ASD, their social maturity may lag behind, because of difficulties in communication, socialization, and behavior. Inappropriate sexual behaviors can occur as a result. Families have reported that these behaviors can include touching oneself, touching others, masturbation in public, and disrobing in public.

The psychologist offered this practical advice on strategies for preventing or

interrupting inappropriate sexual behaviors:

- Teach skills before they are needed. It will be more difficult to learn skills at the moment they are needed.
- Teach adolescents what to do, not what not to do.
- Identify inappropriate sexual behaviors early on and respond accordingly. The longer a parent waits to intervene, the more difficult it will be to address the behavior.
- When negative behaviors occur, consider them a teachable moment: teach the appropriate behavior, and then figure out ways to motivate the adolescent to use the correct behavior.
- Interrupt negative behaviors, but don't pay too much attention to them. Instead, redirect the teen's attention.

Dr. Tuzikow also discussed the risk of sexual abuse of adolescents with ASD. She recommended teaching teens with ASD to become independent, to minimize the situations in which they could be subjected to sexual abuse.

Audience members were eager to discuss the presentation with Dr. Tuzikow. A related service coordinator from a local high school sought advice on helping his students with ASD learn to read body language to be able to understand, for example, whether or not a classmate wishes to be hugged. Dr. Tuzikow suggested that first, he show the teens photos of facial expressions and arm and hand gestures that convey willingness or unwillingness to receive a hug, and



then teach the teens to read those expressions and gestures in the people around them.

Another attendee was a mother of an 11-year-old boy with autism who, she explained, has been saying inappropriate things in public and to her and her husband at home. "I learned some good strategies today to help us address these problems."

"Sexuality issues won't go away," Dr. Tuzikow concluded. "We can't say, 'These inappropriate behaviors will go away after my child has gone through puberty.' They won't. We need to address these behaviors immediately and consistently."



James Maynard Named IBR's 2010 Employee of the Year

James "Jim" Maynard, supervisor in

IBR's Housekeeping Department, has been voted IBR 2010 Employee of the Year by his colleagues. The 23-year employee of IBR was recognized for how capably and willingly he handles his responsibilities.

Jim's responsibilities include issuing department staff their daily work assignments and overseeing their work. He must ensure adequate housekeeping coverage each day for all 270,000 square feet of the three buildings on IBR's campus. Taking care of such a large facility has its challenges. The main ones, he said, are the age of the facilities and the size of the department staff. "We

make the most of the staffing and resources we have available," he said.

"Jim is a major asset to this facility and consistently demonstrates excellence and a high degree of professionalism in the performance of his duties," said IBR Director W. Ted Brown, MD, PhD. "He has proven his willingness to extend himself to help others at IBR."

In addition to maintaining the cleanliness of the IBR facilities, Jim and his staff, working with IBR meeting space coordinator and payroll officer Diane Troyano, set up rooms at IBR for conferences and workshops.

Other department responsibilities, all of which Jim coordinates, include carpet- and floor-cleaning, snow removal, and furniture moving. When asked how he keeps up with the physical demands of the job, he said with a laugh, "Maybe it has something to do with the fact that

I've been walking three miles each way to and from work each day over the past 10 years!"

Jim started his IBR career in April 1988 as a cleaner in the Housekeeping Department. In December 2000, he was promoted to housekeeper, and in January 2008, to supervisor.

"Jim has improved our unit since he took over," said housekeeper Alfonso Cerrillo. "He has gotten better equipment for us to do our jobs, and the morale has improved a lot, because he shows he respects and supports us."

"It's important to me to treat everyone with respect," the easy-going awardee explained. "I'm here to do the job, and respect goes with the territory. If I have a concern with any of my staff members, I approach them professionally and privately, just like I would want to be approached."

Dr. Thomas Wisniewski Runs in NYC Marathon to Raise Autism Awareness

Thomas Wisniewski, MD, a researcher in IBR's Department of Developmental Neurobiology, can now add elite marathon runner to his list of accomplishments. He was one of 200 people who ran on November 6 with "Team Up with Autism Speaks" in the 2011 ING New York City Marathon, one of the world's premier road races. This was Dr. Wisniewski's first time running a marathon, and he completed it in 4 hours, 44 minutes.

Dr. Wisniewski's goal was to raise funds for autism research and to heighten public awareness with his 26.2-mile run through the five boroughs of New York City. His colleagues at IBR presented him with a check toward that goal.

"I ran to try to make a difference in the lives of the more than one million Americans living with autism," he said. "The New York City Marathon is the greatest in the world. It was a pleasure to participate and to raise money for a wonderful cause, despite having difficulty walking the day after the marathon!"

In spite of some promising discoveries, the cause of autism is unknown, and a cure does not exist. Research is crucial to finding ways to improve treatment for individuals with autism and to finding a cure.

Dr. Wisniewski has served since 2007 as a principal investigator on a program project at IBR funded by the Department of Defense Autism Spectrum Disorder Research program. The study, headed by Jerzy

Wegiel, VMD, PhD, chairman of IBR's Department of Developmental Neurobiology, is looking at the autopsied brains of individuals with autism and of control subjects to detect morphological and biochemical patterns of altered development, maturation, and aging of neurons. Dr. Wisniewski's studies for the project have focused on defining clearly, for the first time, the neuropathological abnormalities that are associated with autism in many of the study subjects with autism.

In addition to his research work at IBR, Dr. Wisniewski is a professor and the director of the Aging and Dementia Division in the Departments of Neurology, Pathology and Psychiatry at the New York University Langone Medical Center, Manhattan.



Thomas Wisniewski, MD



Dr. Wisniewski showing good form during his running of the ING New York City Marathon on November 6. (Photo used with the permission of Brightroom.com)



December Recipe: Sweet Potato Bake

Are you looking for a fun, easy, and satisfying dish to help you celebrate the holidays? An affordable favorite of many is Food Network star Paula Deen's sweet potato bake, which is great as a side dish or dessert. This recipe makes 8-10 servings.

Ingredients:

- 5 mashed sweet potatoes
- 1 cup sugar
- 1/3 cup melted butter
- 2 eggs
- 1 teaspoon vanilla
- 1 teaspoon ground cinnamon
- ¼ teaspoon nutmeg
- ¼ cup heavy cream (whole milk will also work)

Mix together well, until smooth, and pour into a greased casserole dish. Preheat oven to 325 degrees and mix ingredients for topping together:

- 1 cup brown sugar
- 3 tablespoons melted butter
- 1/3 cup all-purpose flour
- 1 cup pecans or walnuts, chopped

Sprinkle generously over sweet potato bake, and place in oven for 25-30 minutes.

Email your favorite recipe to Nicole.Weinstein@opwdd.ny.gov for inclusion in the next newsletter. If you have a story or photo to go along with your recipe, please send that, as well.

OPWDD Standardizes Process for New Providers

In a new process established by OPWDD, potential nonprofit providers must now complete a standardized application and submit information on their programs, governance, and fiscal capabilities. The application will be reviewed and scored based on clearly established criteria, and only those that receive a passing score based on these criteria will be considered for OPWDD funding opportunities.

"OPWDD recognizes that consistent expectations translate into stronger partnerships with our great network of providers," said Commissioner Burke. "We have developed an objective, statewide process for those interested in becoming first-time OPWDD-funded nonprofit providers."

The new process will help ensure that a nonprofit agency is approved to provide services under OPWDD's auspice, and will have:

- A comprehensive plan for providing quality services to people with developmental disabilities;
- A clear understanding of regulatory and program requirements, solid governance practices as demonstrated by a diverse board of directors that actively provides agency oversight; and
- A sound fiscal plan that includes a detailed budget, an understanding of good business practices, and staff and/or board members with fiscal experience.

OPWDD's new agency interest application, scoring criteria, and related information are available at: www.opwdd.ny.gov/ifsp/ifsp_become_a_service_provider.jsp.

Gathering Public Input on People First Waiver

The 1115 People First Waiver will allow for the delivery of true person-centered models of support for individuals with developmental disabilities.

On November 15, 2011, OPWDD made an official Request for Information (RFI) available to the public:

www.opwdd.ny.gov/2011_waiver/waiver_request_for_information.jsp. The RFI is soliciting input regarding reforms and improvements recommended by waiver design teams, as summarized within OPWDD's Statewide Comprehensive Plan: www.opwdd.ny.gov/2011_waiver.

The RFI is an opportunity for stakeholders to provide input regarding the provision of supports and services to individuals with developmental disabilities and their families on a comprehensive and practical level.

Through December 27, individuals, family members, advocates, and providers from across the state may respond to the RFI. The information gathered will help OPWDD shape the Request for Applications (RFA) that will occur in 2012, which will establish designated pilot projects.

For special accommodations or technical assistance with your online RFI response, please contact the OPWDD Information Line at 1-866-946-9733 weekdays between 9 am and 5 pm.

Additionally, if you would like to participate in the RFI as a group representing a particular constituency such as a parent organization or a group of self advocates, and need assistance with the process, please contact Deborah Franchini at 518-473-3150.



Great Strides Improving Investigations

OPWDD has made several reforms over the past few months in an effort to improve its investigations process.

To enhance investigations' quality and effectiveness and to improve investigators' skills, OPWDD's Office of Investigations and Internal Affairs (OIIA) has partnered with the state Division of Criminal Justice Services (DCJS) to provide free additional investigative training to OIIA personnel. Several OPWDD investigators are scheduled to attend the "Statement of Analysis Training" with law enforcement investigators from October 2011 to March 2012 at sites across the state.

According to Anthony Bruno, director of OPWDD's OIIA, a statement analysis is the structured examination of a person's exact words. It is used as an investigative tool to gain insight and to detect areas of possible deception. The course is designed to provide investigators with a structured method of examining verbal and written communication. Investigators will develop specific linguistic tools to use in analyzing statements provided by witnesses, victims, and suspects.

Investigators will learn the importance of accurately recording the verbal and written words of witnesses. Investigators will participate in a group practical exercise to use the knowledge gained through statement analysis to gain insight into a statement, and in criminal cases, to enhance the prospects of gaining confessions through the amplification of the statement. In addition to many practical exercises, instructional methods will include case studies, demonstrations, and group discussion to reinforce the techniques taught in class. This is the same training provided to law enforcement investigators throughout New York State.

"Training is key to OIIA's goal of staff development and enhancing the quality of investigations," said Bruno. "We appreciate the contributions DCJS is making and look forward to further training with our law enforcement partners."

Other investigative changes

OPWDD's centralized investigations unit was established in April 2011 to ensure both independence of investigations and standardization of their processes and outcomes in state-operated programs. Bruno, who has a distinguished background in law enforcement, was hired in September to lead the unit, and regional interim directors have been designated to facilitate "arms-length" investigations.

To facilitate independence, all investigations involving physical and sexual abuse that occur in state-operated programs will be handled by this central investigations unit. In addition, OPWDD issued regulations effective November 1, 2011 that enhance the requirements related to the independence of investigators for serious reportable incidents and allegations of abuse.

Larry Murello was hired in November to serve as the regional director for the area that includes Capital District, Hudson Valley, and Taconic DDSOs. Regional director Murello has nearly 40 years of experience in investigations on the federal, state, and local levels. He holds a degree in police science and is a graduate of the prestigious FBI National Academy at Quantico.

In addition, a new training program for incident investigators was developed in June 2011, and new policies and procedures were put into place to govern how investigations are conducted to ensure both their integrity and consistency.

Eskenazi Outlines Vision for Quality Improvement

As OPWDD's new deputy commissioner for the Division of Quality Improvement (DQI), Alan Eskenazi has big plans for improving the quality of services OPWDD provides for people with developmental disabilities.

"What matters to the people we serve is what should ultimately drive OPWDD's quality improvement efforts," said Eskenazi.

Eskenazi brings nearly 25 years of experience working in the human services field, having started out as a substance abuse counselor, and serving most recently as the vice president of quality improvement and regulatory affairs at St. Vincent's Hospital in Westchester, NY.

He would like to move DQI toward a more dynamic and proactive quality improvement model. "Instead of maintaining a status quo, even if it is a good status quo, I always want to look at how to get in front of the wave, and to anticipate what types of

proactive improvements need to be made," he said.

How does Eskenazi propose to do that? By focusing on advancing quality improvement strategies, training, measurement, and data collection activities; by improving incident tracking and monitoring, and better analyzing the data that comes from that; by improving communication within DQI, and between DQI and the rest of the agency; and by enhancing the program certification process so that those activities become a tool for quality improvement.

Within DQI, he wants to enhance and ensure employee satisfaction by helping employees feel valued and recognized, and by ensuring that their strengths and abilities are aligned with the job they do. It is important that each person understands how what they do fits into the whole of the

department—and within the agency—so they can better understand how their work ultimately impacts individuals being served. He says, "A satisfied, proud, team-oriented, workforce is a motivated, dedicated, and efficient workforce."

After the work day is over, Eskenazi enjoys spending time with his wife and twin 8-year-old sons. He has visited all 50 states and is an avid guitar player.



New Fire Safety Curriculum

On December 2, Commissioner Burke announced the completion of a three-hour fire safety curriculum designed for all state and nonprofit provider employees, regardless of title or work location. The program focuses on the areas of fire safety awareness, prevention and hazards, and evacuation execution.

The curriculum, written by experts at the state Office of Fire Prevention and Control (OFPC), may be found on the OPWDD website at www.opwdd.ny.gov/training/training_curricula.jsp. To assist in the training's effectiveness, the following materials have been developed:

- Fire Safety Level One instructor guide;
- PowerPoint presentation;
- An instructional video available to fire safety instructors to become acquainted with the Fire Safety Level One curriculum, and/or to be viewed directly by employees. The video includes an actual recording of the OFPC-led three-hour Level One curriculum; and
- A post-test is available to monitor employees' understanding of the knowledge presented during the training.



Employee Discount for Verizon Cell Customers

Verizon Wireless offers a special discount for New York State employees off any voice plan of \$34.99 and higher. If you are a Verizon customer, you may be eligible for a 19 percent discount on your monthly bill. To take advantage of this offer, please contact Jill Reynolds-Cadieux, government account executive in business sales, at Jill.Reynolds-Cadieux@verizonwireless.com or at 518-464-2537. We will continue to share special offers for OPWDD employees as we learn of them.

OPWDD

HEALTH & SAFETY
ALERT!

Health and Safety Alerts

OPWDD has begun issuing health and safety alerts as a way of sharing expectations, regulations, information, and best practices about incidents and other important topics.

The first alert issued in November addressed the need to follow personalized care plans, and stemmed from suggestions Commissioner Burke has heard as she travels around the state speaking to people with developmental disabilities, their families, advocates, and employees.

"These health and safety alerts are designed to raise awareness and foster collective mindfulness in identifying where health and safety may be compromised," said Commissioner Burke.

The alerts are designed to be brief and easily understood, and will be delivered via a monthly email. "Anyone can be a driving force behind an alert," Commissioner Burke added. Please send suggestions to people.first@opwdd.ny.gov.