

Subject: Best Practices for Individuals with Pica

January 2012

Pica is the unusual sounding name for what is a common safety concern within our system—the ingestion of non-food substances (latex gloves, cigarette butts, cleaning liquids, coins, etc.). Ingestion of non-food items can cause airway obstruction, dental injury, poisoning, and other severe internal injuries. It has also been known in some instances to lead to invasive surgery and/or death.

Anyone may encounter an individual whose life is in danger because of pica. Therefore, developing an effective and individualized assessment, intervention, and monitoring plan is vital to reducing this dangerous behavior. The following clinical, environmental monitoring, and immediate response strategies should always be taken into consideration when dealing with pica.

Clinical: The assessment of pica risk conditions and appropriate interventions should initially include a medical checkup to determine if a nutritional deficiency or metabolic condition underlies the behavior.

Interventions for pica behaviors should be based on an evaluation of the individual’s history, and should document: the types of non-food substances the individual seeks to ingest; the function that the ingestion may serve for the individual; the times and conditions under which the ingestion is most likely to occur; and the level of intensity that the individual demonstrates in seeking to ingest non-food items.

Environmental: A safe living environment requires specific controls and regular sweeps to ensure the absence of pica hazards, which can include using clothing, furniture, and bedding made from durable materials that cannot be easily shredded, torn or disassembled. In addition:

- Restrict access to garbage (including proper disposal of cigarette butts), medical supplies (such as latex gloves, medication cups, thermometers), and devices with small batteries.
- Use decorations that cannot be ingested; safeguard electrical outlets; and utilize covers or protective shields on appliances such as televisions, smoke detectors, clocks, and computers.
- Routinely monitor areas and remove easily ingestible items such as paper clips, pens, paper, etc.

Training and Monitoring: Comprehensive staff training and supervision are essential. Training must emphasize the need for the level of supervision and vigilance described in the plan; the need to discard or safely store ingestible items; and the high risk of injury or death for individuals who engage in pica behaviors. All living areas and/or program areas that have pica protections in place should have clear signage indicating the protections and all visitors to such areas should be informed of the risk factors and required precautions. Use of plans should be closely monitored, and data should be obtained to determine the effectiveness of the interventions in the plan.

Response: It is imperative that an appropriate and timely medical evaluation take place when it is discovered or suspected that an individual has ingested a non-food substance. Referral for medical evaluation may be based on actual observation of the individual ingesting the non-food substance, the discovery of a missing item, self-report of ingestion by the individual, or the physical symptoms displayed by the individual. Physical symptoms may include coughing/gagging, nausea, vomiting, diarrhea, respiratory distress such as wheezing or difficulty breathing, general discomfort, and/or abdominal discomfort or pain.

Most Importantly: Mandating and maintaining a high level of awareness of pica risk conditions is essential to ensuring the health and safety of individuals who engage in pica behaviors.



A Letter from the Commissioner

Dear Friends and Colleagues:

In this year’s proposed budget, Governor Andrew Cuomo has demonstrated a strong commitment to our field and the individuals we serve. I would like to share with you a few aspects of his proposal.

With the many fiscal constraints facing the state and the nation, budget reductions for OPWDD total less than one percent. And if enacted, the governor’s budget will allow for significant investment in group home safety; support development of the 1115 People First Waiver; and set us on firm ground for the future by allowing for a restructuring of our service delivery and oversight. Additionally, the governor’s budget provides greater opportunities for individuals to receive services from OPWDD.

Investing in Fire Safety

The safety of group homes is a top priority as we seek to keep the individuals we serve, as well as the great employees who provide their care, safe from harm. As you know, last year we created a partnership with the Office of Fire Prevention and Control to provide external oversight and surveys of all homes, evacuation plans, etc. In addition, we established a consistent fire safety training curriculum. The governor’s proposed budget includes critical funding in his five-year capital plan for improvements to community residential programs to meet more intensive fire safety standards, consistent with the recommendations of the 2010 Fire Safety Panel of State and National Experts. The budget also provides resources to support all necessary fire safety improvements in state and voluntary residential programs over the next several years.

New Opportunities for Individuals

The proposed budget provides \$48 million in state funds (which double if they can be matched with federal Medicaid funds) to support new opportunities, including low cost residential, employment, and community habilitation opportunities. The budget also allows for the expansion of services that support families and caregivers, such as respite services. These new community opportunities will support people with developmental disabilities who are currently living in an institutional setting, graduating from residential schools and other education programs, and living on their own or with families and others.

Supporting the 1115 Waiver, Positioning OPWDD for the Future

In addition to the continued creation of more community-based opportunities, the governor’s proposed budget supports the development and implementation of OPWDD’s 1115 People First Waiver, as well as our commitment to becoming a service delivery system that is truly person-centered. In addition to support for the waiver, the budget empowers OPWDD to undertake a much needed organizational restructuring that will better position us today and in the future. The restructuring will heighten the agency’s focus on service delivery, provide for enhanced oversight of our vast network of nonprofit providers, and realign the agency’s operations (human resources, training, budget offices, IT, etc.) to ensure consistency statewide.

We will provide updates about each of these items—and more—in the coming weeks and months as information becomes available to us. In the interim, I applaud the governor for his leadership and thank him for his support in strengthening our system.

Sincerely,

Courtney Burke
Commissioner



Issue Highlights

IBR Scientists Identify Link between Early Behaviors and Later Autism Spectrum Disorders in NICU Infants

Comprehensive Genetic Disease Program of Richmond County Provides a Team Approach to Genetics Services

A Mission Shared: IBR Researchers and Parent Support Group Work Toward Treatments for Rare Disorder

HRC Holds Appreciation Breakfast

IBR Scientists Identify Link between Early Behaviors and Later Autism Spectrum Disorders in NICU Infants



L to R: Bernard Karmel, PhD; Judith Gardner, PhD; and Ira Cohen, PhD

Researchers in IBR's Department of Infant Development have been conducting longitudinal studies of infants from birth who are medically at-risk and received care in neonatal intensive care units (NICUs). A major objective, said Judith Gardner, PhD, Chair of Infant Development, is to identify early behaviors occurring more frequently in NICU infants later diagnosed with autism spectrum disorders (ASDs). Identification of early behavioral markers or precursors to ASD could provide insights into the emergence of ASDs, helping explain the mechanisms underlying the neurodevelopment of behaviors linked to ASD, which could lead to earlier diagnosis and intervention. The researchers recently received a three-year grant from Autism Speaks to further pursue these studies.

Infants who experienced complications of pregnancy and delivery, including multiple-gestation births, and births of very small, preterm infants, have a greater risk of later diagnosis of ASDs. Rates

of both these complications have increased as a result of advances in obstetric and neonatal medicine. Infants experiencing such complications require intensive hospitalization, typically in an NICU. These infants recently have been shown to be at almost a two times-higher risk for later diagnosis of ASD than infants from the regular term nursery. As many as 20–25% of infants later diagnosed with ASD may be NICU graduates.

In a 2010 article in *Pediatrics* (lead author Bernard Karmel, PhD, of Infant Development), the IBR researchers reported that infants later diagnosed with ASD showed a unique behavioral profile. When 1 month old, children with later ASD had persistent neurobehavioral abnormalities and higher incidences of asymmetric visual tracking and arm tone deficits compared to their matched non-ASD controls. When 4 months old, children with later ASD continued to show visual preference for higher amounts of stimulation than controls, behaving more like

newborns. Unlike controls, children with ASD had declining mental and motor performance by 7 to 10 months, resembling infants with severe central nervous system involvement.¹

With Ira Cohen, PhD, Chair of IBR's Department of Psychology, the researchers have applied their findings further to predict ASD. Using the PDD Behavioral Index, developed by Dr. Cohen and IBR psychologist Vicki Sudhalter, PhD, they found that the increased preference for more stimulation at 4 months was highly related to problems in social competence 3 years later. This association was much more likely in infants with abnormal auditory brainstem responses, suggesting potential problems in brainstem function. The early onset problems with visual attention and preference for more stimulation may be markers for ASD.

Whether these effects are specific to preterm birth and/or being an NICU graduate remains to be determined. Future studies of NICU infants also will aim to differentiate risk for ASD from risk for other developmental disabilities at much younger ages than is currently possible.

¹ Karmel BZ, Gardner JM, Meade LS, Cohen IL, London E, Flory MJ, Lennon EM, Miroshnichenko I, Rabinowitz S, Parab S, Barone A, Harin A: Early medical and behavioral characteristics of NICU infants later classified with ASD. *Pediatrics* 2010; 126:457–467.

Comprehensive Genetic Disease Program at Richmond County Provides a Team Approach to Genetics Services

For 28 years, IBR has been providing genetics services through the Comprehensive Genetic Disease Program at Richmond County, based at IBR's Jervis Clinic. The program offers prenatal testing, genetic evaluations, and genetic counseling for people who have, or are at risk for, genetic or congenital disorders or developmental disabilities.

An estimated 15,000 people have received services from the program since it was established in 1984. It is one of 24 regional programs statewide, partially funded by the New York State Department of Health.

The program is staffed by a team of medical geneticists and genetic counselors. Its director since 2004 has been medical geneticist and research scientist Milen Velinov, MD, PhD. He evaluates patients through physical examination and review of family history; conducts diagnostic genetic testing of patients and family members; provides counseling, with the assistance of genetic counselors; and conducts or refers for specific treatment, if available.

"The most gratifying aspect," Dr. Velinov explained, "is the ability to directly help patients and families and to directly communicate with them."

IBR Director and Jervis Clinic Director W. Ted Brown, MD, PhD, a medical geneticist, also conducts genetic evaluations in the program, especially those related to fragile X syndrome, about which he is an expert.

The program's genetic counselors—Jacquelyn Krogh MS, CGC, and Nancy Zellers, MS, CGC—are among the most experienced counselors in the New York City area: they have a combined total of 51 years in the

field. Both are graduates of the highly regarded Master's Program in Human Genetics at Sarah Lawrence College, Bronxville, NY.

The genetic counselors help the medical geneticists obtain informed consents; record family histories; determine which tests are needed and where they can be obtained; and counsel patients and families about the sensitivity and results of testing, the natural history and causes of disorders, recurrence risk for future pregnancies, and necessary clinical or other follow-ups. They provide these services at the Jervis Clinic as well as at Richmond University Medical Center, Staten Island, and Staten Island University Hospital. Another important role of the genetic counselors is to provide consultation and guidance to clinicians at the Jervis Clinic regarding possible diagnoses and diagnostic tests.

"I find it fascinating when families share their medical histories," said Ms. Krogh. She also appreciates keeping up with the rapidly

expanding knowledge base in genetics.

"The most challenging aspect of genetic counseling for me," explained Ms. Zellers, "is meeting with a family that has a child with a developmental disability and trying to find out the cause of that disability."

Working with adults who have not received a diagnosis for their lifelong condition until adulthood is another interest of hers. "Helping families at that point understand the condition and how it happened, and determining whether other family members are at risk of having a child with the same condition is very rewarding," she said.



Left to right: Nancy Zellers, MS, CGC; Milen Velinov, MD, PhD; and Jacquelyn Krogh MS, CGC

A Mission Shared: IBR Researchers and Parent Support Group Work Toward Treatments for Rare Disorder

IBR scientists are studying a group of rare neurodevelopmental disorders collectively called chromosome 15 duplication syndrome (dup15q). This syndrome results from duplications of chromosome 15, which most commonly occur either as an extra chromosome 15 or as an extra segment of duplicated material within chromosome 15, called an interstitial duplication. Large interstitial duplications of maternal origin confer a high risk of abnormal development, autism, cognitive delays or impairments, low muscle tone, and seizures. In fact, dup15q is the most frequently identified chromosome abnormality among individuals with autism.

A research group in IBR's Department of Developmental Neurobiology, led by department chair Jerzy Wegiel, VMD, PhD, and supported by a grant from the Department of Defense Congressionally Directed Medical Research Program's Autism Research Program, is studying the brains of individuals with dup15q. This research was made possible through the cooperation of the Dup15q Alliance, a support group of families and professionals, parent members of which donated tissue for the

research; the Autism Tissue Program (ATP; a branch of Autism Speaks), which coordinated tissue recovery; and brain and tissue banks, which preserve tissue for research, a process called biobanking. Dr. Wegiel, Director of the Brain and Tissue Bank for Developmental Disabilities and Aging, located at IBR, serves as a steward for donations of tissues of individuals with dup15q.

At a recent meeting of the New York Autism Consortium held at IBR, Kadi Luchsinger, Executive Director of the Dup15q Alliance, described the role of biobanking in research on dup15q. Her 10-year-old son, Ethan, has the disorder. She discussed the expectations of families of individuals with dup15q, and of families donating brain and other tissues for research. Affected families have already donated the brains of 12 individuals with dup15q.

Ms. Luchsinger defined as one of the research priorities study of the mechanisms of the sudden unexpected deaths of children with



Kadi Luchsinger, Executive Director of the Dup15q Alliance, and her son, Ethan Luchsinger

dup15q.

The Dup15q Alliance has organized the cooperation of geneticists, clinicians, and neuropathologists nationwide for studies of dup15q.

With its mission to provide family support and promote awareness, research, and targeted treatments for dup15q, the alliance has just established the Dup15q Alliance International Registry. To date, 150 families have joined the registry.

"Research holds the promise to better understanding of dup15q and to the development of targeted treatments," said Ms. Luchsinger.

For more information on chromosome 15q duplication syndrome (dup15q), please contact: Dup15q Alliance, P.O. Box 674, Fayetteville, NY, 13066, USA. Telephone: 855-dup-15qa. Website: info@Dup15q.org

IBR Affirmative Action/Human Relations Committee Holds Breakfast

IBR staff gathered the morning of December 13, 2011 for a breakfast organized and prepared by members of the IBR Affirmative Action/Human Relations Committee (AA/HRC). The committee held the event, said the AA/HRC chair Violet Nealy, to express its appreciation to IBR staff for their work and their support of committee events during 2011. Pictured enjoying the breakfast are (left to right) Bruce Gundry, Stephen Chan, Cathy Aragona, Nancy Gundry, Margaret Coogan, and Iyabode Labinjo. In the background is safety officer Veronica Daly.



Sisters Together Again

Margaret "Midge" Lawless and her sister Karen did everything together growing up. They shared a room, played with dolls, rode their bicycles, and on summer days they sat on their porch and counted the cars that went by.

A year apart in age, both Midge and Karen live with developmental disabilities. They faced many challenges growing up. Midge recalled that when they rode the school bus sometimes other kids would tease Karen. When that happened, Midge would always step in and tell the other students to stop. Midge, the older of the two, takes a great deal of pride in looking out for her younger sister.

"I would take good care of Karen; we are best friends." Karen added, "Me and you, buddy buddy!"

For over 40 years, the two sisters lived together in their family home with their father. Midge did her best to care for her dad as he grew older and more increasingly frail, but eventually it became too great for her to manage on her own. Karen also needed help. For the first time in their lives, Midge and Karen were separated.

Karen moved into a residence operated by the Oneida-Lewis ARC, and shortly thereafter, Midge met Bethann and Andrew Szewczyk through Madison Cortland ARC's Family Care Program, a certified program that matches dedicated families with individuals who have a developmental disability and who are unable to live independently.

Midge moved into the Szewczyk home and was very happy. But, something was missing—her sister Karen.

Bethann and Andy knew the sisters missed each other terribly. They made sure that Midge and Karen stayed in touch by telephone and got together at least once a month, but it wasn't the same. When Midge and Karen were together, the love and devotion they had for each other was clear. As Bethann and Andy watched them together, a seed was planted.

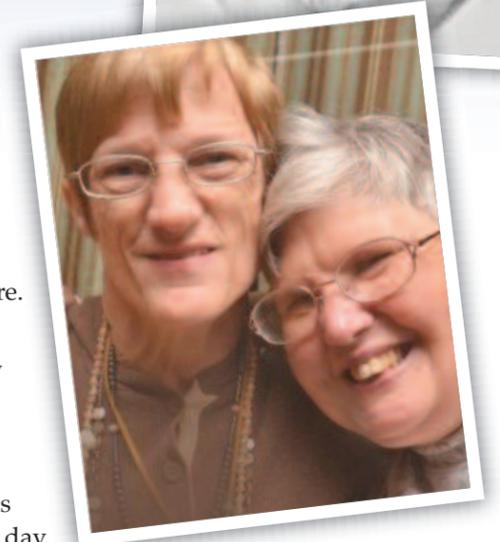
The Szewczyks worked with Madison Cortland ARC for approval to have another person move in with them. They had someone in mind, but they knew that it would take time and paperwork, so they didn't say a word to Midge until they knew for sure.

One day earlier this year, Bethann said to Midge, "How would you like to have your sister move in?" and Midge replied with a big grin, "That would be perfect!" Midge says that she will never forget that day.

On September 29, 2011, Midge and Karen were reunited after almost 10 years apart. During the day, Karen attends the Oneida-Lewis ARC's Kirkland day habilitation program, and Midge goes to either Madison Cortland ARC or Heritage Farm.

"I would take good care of Karen; we are best friends." Karen added, "Me and you, buddy buddy!"

When they get home, they help around the house, feed their pets, have dinner, and share special activities.



"They are like two peas in a pod," said Andy, "They always have a good time together."

When asked about the Family Care Program, Bethann said, "It's so much more than I thought it would be. I

can't imagine my life without Midge or Karen. We are a family." Midge and Karen, sitting next to each other, locked their fingers together. Midge said, "Finger friends forever!" Karen replied "Sisters together!" Both smiled from ear to ear.

Schenectady ARC Social Worker Participates on President's Alzheimer's Task Group

In early 2011, President Obama signed the National Alzheimer's Project Act (NAPA), which is expected to lead to the development of a coherent and coordinated national strategy on dealing with Alzheimer's disease in the United States. The national task group is working to ensure that the concerns and needs of people with intellectual disabilities and their families, when affected by dementia, are considered as part of this national strategy.

Schenectady ARC licensed clinical social worker Tammie Morley is a member of the National Task Group on Intellectual Disabilities and Dementia Practices and the group's new report, *My Thinker's Not Working: A National Strategy for*

Enabling Adults Affected by Dementia to Remain in Their Community and Receive Quality Supports may be found online at www.rrtcadd.org/resources/NTG-Thinker-Report.pdf.

In the report, Morley addresses the living provisos developed for trying to keep an individual in his/her home for "as long as humanly and safely possible." She also speaks to the eventuality for when this is no longer possible and the patient must be placed in an alternate living arrangement. "I also go out to each of the houses that have someone with symptoms of dementia and provide education for both the staff and the residents who are living there. With my model brain in hand, I help the individuals understand that the person with dementia is not doing these things on purpose—that the person's brain is actually shrinking and deteriorating."

The report offers a series of recommendations for more effectively addressing needs and helping adults with an intellectual disability affected by dementia, which include helping individuals and their caregivers to better understand dementia and how it affects adults with intellectual disabilities; to institute effective screening and assessment of those at risk or showing the early effects of dementia; to promote health and function among adults with an intellectual disability; to produce appropriate community and social supports and care for people; and to produce a capable workforce and produce education and training materials.



fixtures, light bulbs, and refrigerators, etc. In addition, depending on the results of the energy audits, many other energy deficiencies were addressed with the overall goal of reducing energy consumption and costs. Agency management staff were provided documents that described the improvements as well as instructions on how to continue making the residence more energy efficient. The future results that will be evident include both a safer living environment for the residents as well as reduced heating and maintenance expenses for the provider agency.

IAC Receives Grant to Help Winterize Residences

In January 2010, the Interagency Council of Developmental Disabilities Agencies (IAC), which represents more than 120 nonprofit organizations, received an OPWDD grant to provide weatherization improvements to residences. This funding was provided through federal stimulus monies under the American Recovery and Reinvestment Act of 2009, administered by the US departments of Energy and Health and Human Services through the state Division of Housing and Community Renewal.

Weatherization is an important means of protecting a building and its interior from the elements, particularly from sunlight, precipitation, and wind, and of modifying a building to reduce energy consumption and optimize energy efficiency. Here in New York, the winter can make homes not only

energy inefficient, but compromise the safety of the individuals who live there.

According to Martin Barrett, chief operating officer of IAC, the project enabled them to hire four full-time employees. Using a bidding process, the employees managed the work performed by different sub-contracted firms with expertise in these areas. All of the work was performed at the residences during the daytime hours when most residents were not home. While the grant goals were to improve 562 housing units, located at 110 different locations, they actually improved 635 units in 125 different locations.

Each facility underwent an energy audit, which identified the improvements to be made. Those property improvements included: installing insulation, windows, doors, furnaces, and water heaters; and replacing ducts, pipes, faucets, toilets, electrical conduits, light



Artists Present Mural to OPWDD

It is crucial that individuals with developmental disabilities have access to the services and opportunities that improve the quality of their lives. That was the message delivered by Commissioner Burke at an event celebrating the artwork of eight men and women supported by the Institute for Community Living (ICL), an OPWDD nonprofit provider.

The artwork, commissioned by OPWDD, was presented to the commissioner on January 18 by ICL art teacher Dylan Stanfield and his students. Painted on plywood, the mural is a portrait of the artists: a representation of the daily experiences people living with developmental disabilities have in their home and community lives. It also speaks to the power and therapeutic elements of art expression for individuals living with

developmental and intellectual disabilities, and is an example of the unique perspective they offer.

Stanfield said "It made sense to create a mural as a portrait of the community that OPWDD serves by the people they serve."

Commissioner Burke said, "ICL's art program really makes a difference in the lives of these individuals. OPWDD is committed to transforming our system, through the 1115 federal waiver, to provide the individuals in our care with access to innovative supports and services that greatly improve their overall quality of life. I thank the artists for sharing their gift with us, and ICL for investing in such a meaningful program, which will become increasingly more common across the state in the coming months and years."

To receive an 11" x 17" copy of the mural, please email your name and contact information to communications.office@opwdd.ny.gov with "mural request" as the subject line.

