



Odette MacDonald benefitted from everyone in the Pre-school Program, including Anna Ramsey, one of her teachers.

Fall 2023

# Building Blocks

Impact and Innovation  
from the Glickman Lauder Center of Excellence

## A Toddler Makes Steady Progress

### A Thoughtful Plan, Provided by Center of Excellence Staff, Transforms Child

*At age five, Odette MacDonald is a happy a little girl. "She has an endearing personality," notes Kathy Hill, MEd, Pre-school Director at the Glickman Lauder Center of Excellence. Although the staff saw glimmers of that personality when she arrived at the center, they were fleeting. She was frantic and engaged in self-injurious behavior. But a thoughtful care plan, developed and carried out by experienced staff, brought Odette to where she is today.*

At Odette's 15-month checkup, her parents were informed that their daughter might have autism. "When her doctor asked if she was walking, we said 'not yet,'" recalls Ashley Morrill, her mother. "We were in denial for some time, because Odette was alert, making eye contact and talking normal baby jabber."

A subsequent evaluation indicated that Odette indeed had autism. Her parents sought appropriate developmental daycare—one center followed by another. But with no way to communicate, Odette instead used behavior, including crying and injuring herself. "When we took her to Pathways of Maine in Brunswick, where we live, a teacher there felt that Odette needed to be assessed," says Ashley. "She contacted Colleen at the Glickman Lauder Center, who spent three days with Odette."

## A Letter from Matthew Siegel, MD

Vice President of Medical Affairs, Glickman Lauder Center



I am pleased to share how we are beginning to use the expertise and excellence at the Glickman Lauder Center to extend beyond our walls and improve care for people with developmental disorders across the state.

This fall we will initiate the Early Intervention Learning Health Network in partnership with the Department of Health & Human Services (DHHS). We have been funded to train, supervise and coach other agencies in replicating the work we do with toddlers with autism. More than 3,500 children in Maine have autism; comprehensive, evidence-based early intervention has been repeatedly shown to improve lifelong outcomes, strengthen families and reduce costs.

**We will . . . exponentially increase our impact by reaching many more children around the state.**

During the first year, we will train and coach two sites and, in year two, expand to four sites. We will take the carefully designed, evidence-based practices we have implemented for children at our site and exponentially increase our impact by reaching many more children around the state.

We are also having an impact statewide through another new initiative: the RUBI training program. We have partnered with the DHHS Office of Child & Family Services to bring the Research Units in Behavioral Intervention program to Maine. RUBI is the leading evidence-based practice for training parents in how to understand and manage their children's disruptive behavior.

After identifying this best practice for our state partners, we connected them with our colleagues at Seattle Children's—who developed RUBI—and quickly began working together. DHHS provided more than \$1 million to fund a program to train 400 providers across the state. Close to 300 have already been trained and will use the RUBI intervention in serving countless children and families.

As we begin our third year at the Glickman Lauder Center, we increasingly spread evidence-based practice into the community across Maine. Much work lies ahead. We thank you for your ongoing interest and support.

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Andrew Hall received a gentle blood draw at the center thanks to Tina Schwartz, RN, nurse manager.

## Maine Behavioral Healthcare

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To learn more about Maine Behavioral Healthcare and the Glickman Lauder Center of Excellence or to schedule a visit to see the difference you make through your support of our mission, please contact us.

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## *A Toddler Makes Steady Progress*

(continued from cover)

Colleen Ingersoll-Foley, MEd/BCBA, Senior Director, observed a child who regularly slammed her head on the wall or the floor; she was covered with bruises. “We needed to do three things for Odette: put a positive behavior support plan in place, provide her with a way to communicate and teach her coping strategies,” Colleen explains. “The first step was showing Odette how to use symbols to communicate.”

GLCOE and Maine Behavioral Healthcare leadership worked to rapidly approve the hiring of another staff in order to create a spot for Odette. At the center, she received one-on-one care from Kathy. “Odette was sad, confused and in pain, but even then you could see the sparkly little girl she is,” says Kathy. “I needed her to know that I was going to keep her safe.” Once Odette received consistent care and understood how to communicate using a picture system, she could ask for what she wanted. The episodes of self-injury decreased, and her bruises disappeared.

At first Kathy held Odette as they walked in the hallway at the center. “Over time, we began playing in the hallway, then playing ball, and finally Odette could join the toddler classroom,” she recalls.

### **The Moment Arrives: “This Is Going to Work”**

Those milestones meant everything to her parents. “Four schools in two years is difficult for any child,” says Ashley. “But a child with autism? It just crushed her; she couldn’t cope. We even had to take Odette to the ER a few times so that she could have a dose of Ativan, a sedative, to calm her down.”

At home, Odette began to sleep normal hours. “Because she was wired with emotion, she would stay up until 2:00 am and then be up again at 4:00 am. She wasn’t sleeping, so I wasn’t sleeping. But now she’s in her own bedroom and sleeps through the night.” She has begun playing with neighborhood kids, as well as her brother, Cameron, who is nine.

A fussy eater as a toddler, Odette began to enjoy chicken nuggets and French fries at the center. “We’ve all done runs to McDonald’s so that Odette has chicken nuggets,” Kathy says with a smile. “Everyone here would do absolutely anything for Odette.”

Colleen agrees. “Odette is engaging and fun to work with,” she says. “She learned quickly. She’s one of those children who gives a lot back to you.”



“I thought to myself: this is going to work,” recalls Ashley Morrill of when she saw Odette with her teachers at the Glickman Lauder Center of Excellence.

Ashley knows what everyone at the center gave her daughter. “They deeply care for your child,” she says. “They’re genuine; they’re there to help you. Seeing Odette with her teachers at the center opened up my eyes. I thought to myself: this is going to work. The amount of happiness we felt and the peace that came over our home after so long—we could finally breathe.”

**“We needed to do three things for Odette: put a positive behavior support plan in place, provide her with a way to communicate and teach her coping strategies.”**

– Colleen Ingersoll-Foley, MEd/BCBA, Senior Director

Odette entered kindergarten at the center in August—a guarantee that she will receive consistent care, attention and support from experienced staff who know her and know how to help her make further progress.

Ashley looks back on the day she received the word that Odette would be welcomed into the Glickman Lauder Center of Excellence pre-school. “I cried a lot that day,” she recalls. “I’m firm in my belief that Colleen coming to assess Odette and getting her to the Center of Excellence is going to be the biggest blessing in my life.”





Matthew Siegel, MD, discusses the Autism Care Network research now underway at the center with Talia Greene, clinical research coordinator.

## Refining Treatment for Specific Problems in Autism

*GLCOE Staff Join National Research Study That Is Focusing on ADHD*

*Diagnosis and treatment for autism has steadily improved during the past decade. But challenges remain, including how to best manage significant conditions that often coexist with autism. The Glickman Lauder Center of Excellence is participating in a new, national study with the goal of determining the best treatment for ADHD—attention deficit hyperactivity disorder, which occurs in more than 50 percent of those diagnosed with autism.*

The new research initiative, which is just getting underway, is an example of how the field is advancing. “We’re now at a place where we are trying to refine our treatments for very specific problems, such as ADHD,” explains Matthew Siegel, MD, Vice President of Medical Affairs. Other conditions that can occur along with autism include anxiety, depression, aggression and self-injury.

The Autism Care Network (ACNet), a national learning health network funded by Autism Speaks, asked the Center of Excellence to join their network of autism treatment clinics. “This gives us access to a large peer network and the ability to compare practices, as well as participate in research studies,” says Dr. Siegel. “It’s an honor and kind of a big deal, because we’re collaborating with Yale-New Haven Hospital, Boston Children’s Hospital and Children’s Hospital Colorado, among others.”

Together, these organizations will answer the question: can we improve clinical outcomes, as well as the patient and family experience, by using a systematic process to diagnose, measure and treat ADHD in individuals with autism?

Throughout medicine, best practices are defined and applied systematically for treating conditions ranging from heart failure to cancer. “Mental health care has been slow to adopt best practice guidelines in the form of a clinical care pathway,” Dr. Siegel notes. “If we determine that better outcomes result, along with a better experience for the patient and family, we will continue to apply the defined best practice in ADHD systematically, but with an ability to individualize care a bit, based on the patient’s needs.”

### Gaining Skills While Heading to a “Best Practice” Approach

The ACNet research study provides important additional benefits to Glickman Lauder staff and thus the center’s patients. “The staff are gaining the process improvement skills that will allow them to participate in the research,” says Kimberly Loika-Smith, Clinical Director. “They also will be prepared for future initiatives that involve systematic improvement.”

Improving parent confidence is one goal of the research study. “We do a lot of caregiver education, of course, but we

will provide it in a more systematic way,” says Kimberly. “Families all want to help their children live the best lives they can. We can provide them with the skills needed to support their children—and meet one of the primary aims of the network: to improve parent confidence.”

Research plays an important role at the Glickman Lauder Center. “Providers here welcome research because it leads to high-quality care,” Kimberly notes. “In preparation for the ACNet study, we are conducting chart reviews to gather baseline data and understand where the ‘gaps’ are in our treatment. We’ve also participated in network group learning sessions on quality improvement tools and how to implement them.”

As part of the study, the center’s staff will gather data, on a quarterly basis, on a group of patients and submit it for the benefit of the larger ACNet project. “This will feed the ongoing research in which we now participate,” says Dr. Siegel.



Kimberly Loika-Smith, clinical director, describes the process improvement skills—a feature of the new research—to Colin Lamb, MD, a child and adolescent psychiatrist.

**“We’re now at a place where we are trying to refine our treatments for very specific problems, such as ADHD.”**

– Matthew Siegel, MD

The Glickman Lauder Center participates in other large national studies, including the Autism Inpatient Collection, a six-site inpatient research network aimed at identifying genetic subgroups within the autism spectrum, and another Autism Speaks-funded study, which aims to take treatment for challenging behaviors to the next level.

Dr. Siegel sees a future where there is better genetic diagnosis of people with autism, and better recognition, identification and standardization of treatment for psychiatric conditions, such as anxiety and ADHD. “And there is also quite a bit of development in how to best disseminate training of staff who can then provide evidence-based psychosocial—non-medication—treatments to address challenging behaviors and emotion regulation.

“There is a lot of energy and excitement about autism research on multiple fronts,” he says. “The Glickman Lauder Center is a proud participant and leader in this area to benefit our patients, families, staff and the wider organization.”

## Playground Sun Shades Are a Hit



The Glickman Lauder Center’s “An Evening of Possibility,” held earlier this year, raised more than \$70,000, which was used to support the purchase of sun shades for the center’s playground. The sun shades were installed this summer, which meant lots of happy playtime on hot days.



## Paul and Irene Kapothanasis: Grateful for a “Blueprint” And Ongoing Care

*Their Son, Gregory, Continues to Benefit*

Many parents who have an adult son or daughter with autism describe a time when there were few, if any, specialists to provide guidance. Maine families often made the long drive to Boston for a diagnosis and ongoing care.

Paul and Irene Kapothanasis began the search for autism expertise when their son, Gregory, was three. Irene had given birth to triplets. “The triplets just turned 30, so we’ve been here, with autism, for a very long time,” she says. “When we started out 27 years ago, there was nothing up here—just one pediatric neurologist who had a long waiting list.” The couple, who live in Westbrook, spent the following decade driving with their son back and forth to a Boston area autism center.

Things looked up when Paul and Irene heard that a psychiatrist specializing in autism and development disorders had arrived in Portland. “Gregory was in junior high school, his hormones were kicking in, and he became very dysregulated,” Irene recalls. “We were referred to Dr. Siegel, and we’ve been with him ever since.”

It was 2011, and the Center for Autism and Developmental Disorders (CADD) was beginning to form around Matthew Siegel, MD, who knew how to help Gregory. “Dr. Siegel suggested a six-week stay at Spring Harbor Hospital, which gave us the blueprint we needed,” says Irene. “We still use some of the techniques we were taught then and apply them to our son.”

“I can’t say enough about the six-week turnaround of Gregory and the ongoing support,” adds Paul, whose family owns Prompto Oil. “It’s a miracle what the whole group provides to these children. When it’s your child, it is one of the most touching things you can experience.”

Paul and Irene contrast Gregory’s visits to the Morrison Center, a facility in Scarborough, before Spring Harbor’s “blueprint” and after it. “When he started the day program there, Gregory stayed in a corner by himself, isolated,” says Irene. “Now he’s an integral part of the group, hanging out and doing all the same activities as his friends.”



At the center, Irene and Paul Kapothanasis have seen the best of people coming together to help their son, Gregory.

The family schedules regular appointments so that the Glickman Lauder Center can monitor Gregory’s progress and ongoing needs, which include speech therapy. In general, they see how their son is making inroads using his iPad, is far less anxious than he was and functions well. “These kids are just like everybody: they want to be loved,” says Paul. “He’s loved; he may be a little spoiled. Gregory’s a great guy and has a great personality.”

### “A Life of Goal-setting, Happiness and Friendships”

For more than ten years, Paul and Irene have made regular gifts to support autism care—at Spring Harbor Hospital, CADD and the Glickman Lauder Center of Excellence. They are grateful for the care their son has received and aware that so many other families have similar needs. “There are a lot of Gregories out there,” says Irene. “Paul and I feel that, in making donations to the center, we are doing more than support this wonderful endeavor. We are hopefully helping others who may not have the resources behind them that Gregory does.”

“When I hear the stories of how parents have been able to pull their son or daughter out of the abyss thanks to the expertise and care they found at Maine Behavioral Healthcare and the Glickman Lauder Center, I wonder: how do you not support this organization?”

Gregory’s parents are still struck by his turnaround. “None of this happens without the MBH Developmental Disorders Program, which turned it around and gave us a blueprint,” says Irene. “It is amazing: from one pediatric neurologist 27 years ago to the incredible center they’ve built. Look how far we’ve come.”

“At the center, you see the best of people coming together,” says Paul. “I’m grateful to everyone there because my son is living, I’m proud to say, a life of goal-setting, happiness and friendships,” says Paul. “You can’t ask for anything more.”

# Two Councils and Much Collaboration

## The Community Advisory Council And Family Advisory Council Are Key Partners

*The Community Advisory Council and Family Advisory Council offer slightly different perspectives, but they share many of the same goals. Regular quarterly meetings provide an ongoing dialogue with Glickman Lauder Center of Excellence staff—and some productive results.*

When the new Glickman Lauder Center opened its doors in 2021, everyone was impressed. The building had been thoughtfully designed to address the needs of individuals with developmental disorders, and there was room for new features, including dental care and blood draws. Along with the thought and planning, the center's leadership team established the Family Advisory Council (FAC) to obtain input on how things can be constantly improved. "As a parent, you look at other things," says Melissa Cucinotta, a member of the Family Advisory Council (FAC). "They asked us for our ideas—ways to improve the experience."

Council members had a few to offer. "Going to an appointment can make your child antsy," she explains. Center staff are making sure that distractions are minimized in waiting areas.

Another suggestion had to do with creating a separate waiting room for teenagers. "They feel like 'I'm not a kid anymore,'" says Melissa, a Windham resident. "We asked if the center would work on that." Center staff have installed a partition to create two separate waiting areas.

Angela Stewart knows that life is easier when her son, Brady, is relaxed in the waiting room. "We brainstormed about ways to improve the experience for them, so we thought about it from their perspective and how they have sensory concerns. There was one bean bag chair, and everyone wanted to sit in it."

The discussion led to the center ordering several more bean bag chairs, happy patients and relaxed family members. "It's pretty remarkable to have the kind of platform that we do as members of the Family Advisory Council," says Angela, who lives in Topsham.

"You become a stakeholder in any organization where you have a voice," she adds. "It's encouraging to families to be asked to help improve services and then see how everyone at the Glickman Lauder Center works constructively on that next thing."



Leuan Evans is just one of those who are happy to spend time in the waiting area's new bean bag chairs.

Community Advisory Council (CAC) members are contributing to the discussion of how the Maine-wide initiatives in which the center is involved—the Early Intervention Learning Health Network Program for young children and Adult Complex Care Behavior Care Team—can have an impact. "We need more providers, and we need more parents to receive education," says Cathy Dionne, Executive Director, Autism Society of Maine. "I love the concept of outside training and putting teams together."

When the society was established 47 years ago, families had no resources in the state. "Maine is so rural," she notes. "People still struggle in the northern part of the state, so we continue to provide information and referrals."

Cathy welcomes the good news that is presented at CAC meetings. "Hearing from people who work with this population and understand this population that they are launching a Maine-wide initiative—that's good news," she says.

"Council members have a breadth of experience in autism and intellectual and developmental disorders," says Tami Goldsmith, who served as a campaign cabinet member before joining the CAC. Because her son has Down syndrome, she hopes to see improvements in the provision of appropriate medical tests and routine screenings and bring awareness to the eight common medical conditions that occur in those with Down syndrome.

"The adult services community is limited," she notes. "We need to acknowledge and cover the lifespan for all Maine residents with intellectual and developmental disorders. Our goal is awareness, education and taking action. My son will turn 40 this year; he has more than doubled his life expectancy thanks to the care he has received."

*Thank you to the following Community Advisory Council members, who recently stepped down: Katherine Coster, Board Member, MaineHealth; Erin Frazier, State Director of Special Services Birth to 22, Maine Department of Education; and Lori Whittemore, Site Director, Maine Child Development Services.*

Visit [www.mainebehavioralhealthcare.org/coe](http://www.mainebehavioralhealthcare.org/coe)  
to watch the Glickman Lauder Center of Excellence  
welcome video!

## UPCOMING WEBINARS

Our free monthly webinars present a wide range of information about autism and other developmental disorders. They are held on the third Thursday of the month from 12:00 noon-1:00 pm.

**October 19**

### Healthy Relationships/Boundaries

Christine Dub, PhD, BCBA

**November 16**

### Navigating the Holidays and Breaks

Lindsay Payeur, BCBA

*Note: the Glickman Lauder Center takes a break in December. New webinars will be announced in the new year.*

Please register at the link below, where you can also access recorded sessions:

[Mainebehavioralhealthcare.org/COEevents](http://Mainebehavioralhealthcare.org/COEevents)

## ABOUT US

The Glickman Lauder Center of Excellence provides coordinated specialty care for children and adults with developmental challenges. Our outpatient services include:

### Multidisciplinary Outpatient Clinic

#### Day Treatment Program

(Kindergarten through 12th grade)

#### Preschool Day Treatment Program

(Age three to five)

#### Early Intervention

(Children under age three)

**Please contact us at 207-661-3600**

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