



# Living Healthy *with* PWS

LathamCenters Quarterly Newsletter



*Latham Centers compassionately and creatively helps children and adults with complex special needs, including Prader-Willi syndrome, to lead meaningful, abundant lives.*

## LATHAM HIGHLIGHTS

### PWSA (USA): A Presentation on Positive Behavioral Supports

*By Katrina Fryklund, Director of National Outreach*

At the Prader-Willi Syndrome Association (USA) conference in Orlando, Florida last month, Latham staff members presented an in-depth analysis of Positive Behavioral Supports (PBS). Presenter Kayla Cox, Latham Centers' Adult Services Residential Manager, has a wealth of experience in adult programs. Presenter Gina Sheehan, LCSW, who began working at Latham as a clinician, was promoted to Director of Residential Services in the Children's Program and maintains a clinical caseload. Their presentation, entitled *Transforming a Residential Program with Positive Behavioral Supports*, was geared toward providers throughout the country with residential and day programs, and was well-received by the audience of about 50 professionals.

Beginning with an analysis of the proactive model of care, Kayla and Gina explained how PBS helps us understand and address problem behaviors. Ultimately,

every behavior serves a function. PBS helps us, as providers, predict what leads to unwanted behavior—and what follows that behavior—to prevent it. PBS is a person-centered model which addresses the individual and respects his or her dignity, and includes listening to the person's needs and recognizing their skills, strengths, and goals.

PBS results in positive change and reinforces adaptive behaviors, as opposed to maladaptive behaviors ("problem behaviors"). Additionally, PBS eliminates the need for punishment or restrictiveness such as seclusion or removal of privileges. PBS works because it is outcome focused. It places emphasis on outcomes important to the individual and to society, and makes homes, communities, hospitals, and schools safer.

In the past, many residential organizations used a level-system which is a "black and white" model outlining consequences when an individual has not maintained appropriate behaviors. At Latham Centers, focusing on positive behaviors and integrating the model into the staff culture has been essential.

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*Ben Mundy, Kayla Cox, Gina Sheehan, Brittini Taylor, Katrina Fryklund, Kara McDowell, Kristi Dolbec, and Patrice Carroll represented Latham Centers at the PWSA(USA) National Convention last month.*

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Latham has seen an overall 78% reduction of General Event Reports (GERs) since 2014 when the organization transitioned to this model of care, Kayla and Gina explained. To accomplish these results, Latham's implementation included an agency-wide culture shift; establishment of a continuum of behavior tailored to address the needs of all individuals; selection and use of evidence based practices; and recording of data to see what worked best.

Latham Centers engaged the entire community which consisted of medical professionals, staff, residents, community members, and emergency collaterals. To fit the PBS model, Latham instituted policies to guide staff to anticipate, predict, and respond to undesired behaviors. Individual Education Programs (IEPs) are also tailored to fit the model.

"PBS has become essential to staff training at Latham Centers," Gina said in her presentation. "As part of our culture, all staff understand that by acknowledging good behaviors rather than perseverating on the bad, positive results are felt agency-wide."



## LATHAM HIGHLIGHTS

### Clinical staff implements Play Therapy

Two of our Children's Program clinicians were so positively moved by a recent professional development training that they are spreading the power of optimism campus-wide. Melissa Hyer-Mitchell and Kalyn Mika attended the two-day experiential training called "Playmakers", hosted by the Life is Good Foundation.

The goal of the training is to engage clinicians in therapeutic play, as playfulness is the "single most important trait of childhood." The experience of playfulness is a monumental piece of a child developing resiliency, and our Clinical Team felt it vital to engage students on the Latham School campus.

Following the fun-filled experiential training with the Playmakers community, our clinicians returned to their roles with a new perspective on "play," and new ways to bring the essence of Playfulness into their everyday work. The clinicians introduced these concepts into both individual therapy and weekly clinical groups. They have already seen an evolution in their interactions with students. There are more smiles and laughter, and students are more willing and able to listen to one another. They respect the process of engaging with one another and their clinicians.

The clinicians introduced brightly colored beach balls, rhythmic music, and a giant parachute. Students and staff have embraced the role of being a "Playmaker," which includes playfulness, joyfulness, active engagement, social connection and internal control. This training has had a profound impact on Latham Centers' clinicians, as well as the students with whom they have the honor of working each day.



Clinicians Kalyn and Melissa at the Life is Good Foundation "Playmakers" training.

## FROM OUR PWS EXPERT

### My experience as co-chair of the 34th PWSA (USA) Professional Providers Conference

By Patrice Carroll, LCSW, Director of PWS Services



The 2017 PWSA (USA) Professional Providers Conference in Orlando was a huge success. As co-chair of the Professional Providers Advisory Board, I had a unique and amazing experience. This conference enabled me to connect with other PWS providers across the country, all of whom have given me insight into the challenges and successes that providers experience on both a micro and macro level.

Throughout the year, providers contact the advisory board for support, suggestions, and advice on challenges they face as PWS caregivers. As we determine the agenda for the PWSA national conference, we look back at the topics that have come up throughout the year and create a day that is rich in discussion, debate, best practices, and comradery. Seventy-five providers from across the country attended this full-day conference.

Topics included skin picking, nutrition, positive behavioral supports, and current research in psychiatric medication. In addition to the learning aspect of the conference, it was equally beneficial for providers to have the chance to relax together and catch up as friends and colleagues. Being a part of this incredible community has been one of the most rewarding parts of my job.

*Patrice Carroll is Latham Centers' world-renowned Prader-Willi syndrome specialist. She works with our residents with PWS, their families, and consultants, continuously learning and teaching about PWS best practices.*

## VOCATIONAL PROGRAMMING EXPANDS

### Business support enhances community inclusion

Finding vocational jobs for children and adults with disabilities can be very challenging, but our Director of Vocational Services Maura Smith has developed relationships with many area businesses and organizations that are eager to help support our program growth. Vocational placements begin with Maura's nurturing engagement with each participant, devising individualized career plans based on their passions and talents. Individuals with Prader-Willi syndrome require careful matching to ensure food security (and avoid aromas of food). Before a job placement is made, Maura meets with the hiring employer to provide them with educational material on PWS and review expectations, goals, and potential challenges. Two community partners in particular, Agway of Cape Cod and Sasha's Yoga and Massage Studio, have provided exceptional support for our crafters and budding yoga enthusiasts.

### *Crafters participate in community events*

Vocational programming with Latham's residents who enjoy crafting exceeded its goals in 2017. For five of our adults with artistic talents and interests, crafting has become more than a hobby – it's part of their career plans. Latham's crafters range from their 20s to their 60s, some of whom have PWS. Janice and Angel knit every day, creating scarves that are perfect for winters on Cape Cod and dishcloths that can be washed and re-used. Sylvia and Michelle create a variety of jewelry, and both

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*Latham resident Janice sells her handiwork at the Holiday Pop-Up Boutique at Agway.*



“up-cycle”, repurposing items to make new and creative works of art and gifts. Each artisan benefits in so many ways – they learn fiscal management, money counting, and customer service skills; develop fine-motor skills; earn spending money; and enjoy socialization with their Latham friends and community members.

The crafters sold their goods at a variety of fairs and pop-up boutiques in 2017, culminating in a festive Holiday Pop-Up Craft Boutique inside the Dennis Agway retail store. Agway’s willingness to provide space in its busy store for our crafters to sell their handmade goods was a valuable gift to our program and underscores the importance of community partnerships in achieving our vocational program goals.



Latham resident Michelle sells handcrafted jewelry with support from staff member Christine.

### Vocational yoga pilot program has many positive ripple effects

A new yoga program developed by our Vocational Director also exceeded expectations in its first multi-week session. The “Latham Bliss Yoga” pilot project was inspired by Michelle, an adult resident who loves doing yoga and aspires to become a yoga instructor. In this first-ever Latham Centers yoga apprenticeship, Michelle served as an instructional assistant under the guidance of the owners of Sasha’s Yoga & Massage Studio in South Dennis. Michelle set up for the yoga class, and the weekly sessions were a welcome stress/anxiety-reduction tool for residents and staff alike. After the first 6 classes of the pilot program, participants surveyed said they were very happy with the yoga class, the instructors, the location, and how it made them feel. And our oldest resident loved the yoga classes so much that she went on to sign up for yoga at the local senior center. Apprentice Michelle is working toward someday co-leading a class. The next Latham Bliss Yoga session is planned for the spring.

Agway and Sasha’s Yoga are two of many area businesses who work closely with Maura and our staff to help keep our individuals with PWS safe and enhance community inclusion for our residents. The tireless commitment of Maura and Latham Centers’ residential staff has created rewarding new opportunities.



Pilot vocational program benefits yoga apprentice Michelle and other Latham residents and staff.

*Founded in 1970 in Brewster, Mass., Latham Centers is a leader in special education and residential treatment of children and adults with disabilities. Latham is internationally recognized for its expertise and success in working with individuals with PWS.*

**Coming in 2018!**

The Latham Cookbook,  
“Living Healthy with  
Prader-Willi Syndrome:

A complete resource for planning nutritious,  
delicious meals for individuals with PWS.”

Upcoming  
**PWS**  
EVENTS