



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

Latham Centers staff members honored with back-to-back NATSAP "Excellence in Teaching" awards

By Katrina Fryklund and Latham Centers' Program Staff

The National Association of Therapeutic Schools and Programs (NATSAP) awards an "Excellence in Teaching" Award annually. A myriad of applications are reviewed and processed, and many teachers are deserving for their life-changing work and diligence in the field of special education. There are no two people who are more deserving, however, than Latham Education Team members Monique Williams (2016) and Meghan Pouliot (2017).

Monique Williams, 2016 recipient, is the Health and Physical Education Teacher on our Children's Campus. Physical activity and healthy eating play a large role in the health of our students, especially those diagnosed with PWS. Monique has implemented curriculums in both her health and physical education classes to assist our students in being aware of how to maintain a healthy diet.

She writes IEP goals addressing concerns about physical education and health needs as they pertain to each student at Latham, and effectively drives her curriculum and lessons to meet these goals. Monique consistently looks for creative approaches to utilize with our students. She is a role model amongst her colleagues and is always willing to lend a helping hand wherever she is needed.

Monique's creative approach has aided our students in being engaged and interested in physical activity, healthy eating, and personal growth and development. She has implemented a yoga curriculum utilizing small body movements to practice deep breathing and calming techniques. She has created a weight training program using circuit rotations for large and small motor skills.

Monique has taken a Sports Club that meets every Friday, and balanced both an educationally fun curriculum about the history of sports, and matched it with full body activities such as ice skating and swimming. Through grant funding, she has created an on-campus fitness space full of new and specialized equipment ranging from treadmills to free-weights.

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Monique with proud students after participating in 2017 Bowling Special Olympics

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Monique implemented a sexual education curriculum with modifications and materials that are easily understandable. Additionally, Monique leads the Latham School Field Day every spring and enjoys creating fun activities for the students to engage in. She is conscious to choose different muscle movements so that each activity brings fun, but also physical activity. Her love for what she teaches is evident every day. Monique's drive to help our students succeed is among the highest of all our employees.

Moreover, Monique has willingly taken on the Special Olympics Coordinator position for Latham Centers. She regularly attends informational meetings, webinars, and events, which correlate with the effective and positive implementation of Special Olympics events with our students.

Her organizational and leadership skills have effectively assisted in gaining participation from 100% of the students. Monique has successfully led soccer, basketball, football, bowling, and track and field teams at Latham. Finally, Monique participates in our summer field-trip based learning program, and acts as head life-guard during all beach and pond outings.

In addition to receiving the Excellence in Teaching award, Monique received the 2017 Roy T. Morgan Award for leadership and commitment at Latham Centers.



Left to Right – Latham staff: Anne McManus; Kara McDowell; Lee Chamberlain, Meghan Pouliot; Brittni Taylor; Gerry Pouliot.

Meghan Pouliot, 2017 recipient, is the Special Education Teacher in our “Nauset” Classroom. Since 2013, Meghan has led students ages 20-22 who are in both the educational and transitional stage of their development.

She created and instructs our “Lights Camera Action” club which uses digital media to create the announcements that are played in our classrooms each morning. Meghan expanded her mastery of technology by creating more differentiated forms of media, and is teaching the students how to use each one. Meghan's students are often seen around campus and in the community participating in engaging and thoughtful activities such as interactive scavenger hunts. She challenges the students



Meghan's Classroom participating in a photo scavenger hunt.

to think outside of the box, and encourages them to exceed their goals.

Working with students throughout the year to take photos, she utilizes a computer program to design a yearbook. Meghan also uses the iPad and Promethean Board in her classroom, regularly teaching her students about new technology. She is consistently finding new resources to integrate into her curriculum.

Recently, the Nauset Classroom Teachers Aide spoke of their students' reactions to a photo-based scavenger hunt. “The project provided opportunities for individual creativity, and students were enthusiastically engaged with their peers to share ideas and make suggestions. The activity became very collaborative. There was 100% participation.”

One of Meghan's most outstanding contributions is her integration of a class entitled “Nauset Circle.” Meghan has created a time block dedicated to students learning how to communicate with one another on a variety of topics. Meghan has created a curriculum that encompasses the need for positive, effective communication amongst both staff and peers. Students actively participate in this class; raising hands, speaking clearly and softly, and engaged. Meghan ensures that all her students' voices are heard, and that all thoughts and feelings are shared; what one student brings up, the entire class discusses.

Meghan is an influential member of our team, always going above and beyond for her colleagues and students. She is the first to volunteer to stay late on a shift, come in early, or go the extra mile. She is always willing to assist students in any area, including off-campus opportunities, sensory art integration, and vocational work. She is an honest, engaging, and hard-working co-worker who is always striving to better herself and the lives of her students. Her dedication to the educational team here at Latham and her dedication to her students is inspiring. In addition to the NATSAP Excellence in Teaching Award, Meghan was awarded the 2017 Massachusetts Association of 766 Approved Private Schools (maaps) Excellence in Teaching Award.

Monique and Meghan remain leaders amongst staff and students. Latham Centers is grateful to these exceptional teachers whose innovation and perseverance help us to achieve our mission.

LATHAM HIGHLIGHTS

Learning Adulthood:

Transition from the Children's to the Adult Program

By Brittini Taylor and Kara McDowell

Imagine growing up with a sibling who has conquered high school, attended college, moved out of the house, and pursued a career. Imagine watching that unfold, and realizing that your future will not have the same trajectory. Students in therapeutic schools and programs such as Latham Centers often have different futures than their same-aged peers. Identifying and relating to their needs as adults is essential to their success, and an important responsibility of staff at Latham.

Our students require a therapeutic environment to learn and develop. They need safe and consistent relationships to encourage growth. A safe and therapeutic environment can be provided in many ways, and our evidence based approaches are refined through continuing staff training and education.

Latham Centers has grown in size as well as in knowledge of theories and philosophies, which helps students successfully transition into the adult world. Utilizing revamped curriculums, community partnerships, and our vocational program, we have developed a transitional curriculum that allows for functional academics, along with on the job vocational opportunities to ensure all students have been equipped with the tools and skills to succeed.

Revamped curriculums:

As we reflected on our transitional students and their academic progress, the educational team identified ways to adapt their curriculum to better meet the needs of adult living. Our transitional classroom teachers embarked on workshops that encompassed revamping the curriculum to ensure we were meeting all functional academic skills. This new curriculum touches on units directly correlated to reading, social studies, science and mathematics, however has a higher focus on things such as the newspaper, legal documents, directions, banking, budgeting, hygiene, and current events. We incorporated vocational work into students' schedules, allotting two full afternoons for hands-on work both on Latham campus and within the community. This time allows the students to indulge in interest inventories and identify areas of vocation that they enjoy and want to learn more about.

**Names have been changed to protect privacy.*

Community relationships:

Enhanced relationships in the community are integral to the transitional program. In 2011, Latham Centers welcomed Olivia* to campus. Olivia was 16 years of age and diagnosed with PTSD, Reactive Attachment Disorder, Bipolar Disorder, and ADHD. Olivia was an adoptee with a traumatic abuse history who struggled to form trusting relationships with adults. Olivia has grown leaps and bounds over the past six years, and we are so proud of her progress.

After learning coping mechanisms to help with her diagnoses, Latham Centers and a local Rogers and Gray Insurance branch partnered to give Olivia a job. Olivia has become an integral part of the office environment, helping with the mail route and other important tasks. She will soon



Latham student with Rogers and Gray volunteer on Field Day 2017.

advance to our Adult Shared Living Program, and will maintain her position at Rogers and Gray. One staff member from Rogers and Gray spoke about Olivia: "Her smile and positive attitude are contagious. She is part of our team, and we are so happy to be part of her success story."

Vocational Program:

In addition to off-site vocational achievements, our students have embraced internal vocational opportunities. Michael* started at Latham School hesitant and unwilling to participate in vocational work. He did not involve himself in vocational skills class, and had no desire for a job nor future occupation. Staff continued to encourage Michael to get involved. He began to take pride in helping staff with their print jobs. Michael learned how to use every feature of the copy machine, and that is when "Michael's Printing Service" was born.

Michael even started printing out copy request sheets; how many copies were needed, black and white vs. color, collated and stapled? Michael was even putting together new employee binders for the Human Resources department. Recently, he created a commercial which plays during the Morning Announcements.

Michael is thriving, and is committed to "Michael's Printing Service." It teaches him accountability and responsibility, and more importantly, he enjoys and takes pride in the importance of the job.

FROM OUR PWS EXPERT

Sensory processing in the person with Prader-Willi syndrome

By Patrice Carroll, Director of PWS Services, Latham Centers

Patrice Carroll wrote the following for the South African PWS Newsletter. After receiving much attention, this article has become essential for many parents, educators, and medical professionals within the PWS Community.

Sensory processing is how we respond to the information that comes to our brains through our senses. A sensory processing disorder is the brain's difficulty receiving that information coming to it, through the senses. Each of us struggles with sensory processing difficulties in some way to varying degrees. For example: some people struggle with crowds or some struggle with noise or tight clothing, somebody with sensory processing disorder reacts negatively or avoids those situations altogether.

Schools place children in classrooms with loud noises or lights which are far too bright. We then look to the child to correct their behavior when it is unwanted or otherwise negative. The truth is that some children simply feel itchy in some types of clothing. A child's fidgeting is not always a result of ADHD, non-compliance or attention seeking as they are often labeled. In this example, the child has a sensory processing difficulty, and we should look to reduce their discomfort rather than using medication or using behavioral interventions to reduce what we see as disruptive behavior. Of course, in some cases children or adults do require medications or other interventions to reduce unwanted behaviors, but we first need to look to the basics:

- Are they comfortable?
- Can they see?
- Can they hear over the background noises?
- Are they too cold or too hot?
- Do they feel physically grounded to the floor or are they dizzy or off balance?

Because people with PWS are so good at compensating for that which they struggle they often go on for a long time before anyone picks up on the true issues. A registered occupational therapist (OT) can tell you if your child has needs in this area.

People with PWS do not always develop their senses in a typical way. This is a result of poor muscle tone and dysfunction of the endocrine system. Often it is not until they reach school age that we see the struggles that they are having. Early work with a registered OT can

save a lot of time in future meetings with teachers and administrators who will often tell you that your child can't seem to sit still or can't focus, won't follow directions or is disrupting the group. Before you let anyone tell you that your child needs medication or a special plan needs to be put in place, especially if that plan involves restrictions, ask

yourself: Is he comfortable? Is she grounded in space (not dizzy or feeling like she's tipping)? Does he feel constricted or not constricted enough? Does she always seem to bump into things, is he "clumsy" or tripping more than he should? Does she cover her ears even at the slightest noise? Is he only happy when he's moving or is he fearful of any movements other than walking? These are all signs of sensory processing disorder and the great news is that there is a lot that you can do about it.



Student participates in ring toss at 2017 field day games.

Types of sensory issues/disorders

Tactile - people who need further development of their tactile sense often seek out or avoid contrasting textures. These will be kids who constantly rub the fabric of their clothes or furniture. The avoider will refuse to wear any clothing with tags or stiff fabric. Tactile kids and adults will benefit from stress balls, sand or water tables, bubble wrap, small stones or rocks (take care with those that ingest objects), play dough, finger paints, etc.

Auditory - people who react strongly to loud noises. Earphones that block out background noise can be extremely helpful in allowing the person to remain focused without becoming agitated by extraneous noise.

Proprioception - this is this ability to sense muscle strength and position in space. People who need further development with this sense often appear clumsy or heavy footed. People will report that they often break objects by walking into them or use too much or not enough strength in picking up or moving objects. Using items such as weighted lap blankets or vests, small weights or bean bags will help to improve this sense.

Vestibular - this sense controls balance. I have personally seen marked improvement in some of the most problematic behaviors when I have focused on increasing vestibular enhancing activities. When our children feel more balanced, less “off center” they appear to be calmer in different environments. People who struggle with the vestibular sense often refuse to walk on any surface that isn’t perfectly flat, they often refuse to bend over which is sometimes mistaken for laziness but, they fear falling over. Any activity that promotes balance will enhance this sense, e.g. horseback riding, walking on a balance beam close to the ground (this will require someone holding their hand initially), yoga, learning to juggle and participation in most sports will be effective.

Oral - any activity that involves chewing or intense flavors improves this sense. Gum chewing (sugar free) has proven to be effective for lessening teeth grinding, excess drooling and also improves digestion.

Interoception - this is the sensitivity to stimuli inside the body such as body temperature and heart rate. Deep breathing and mindfulness activities are effective.

Olfactory - this is your sense of smell. Scents can be both calming and alerting depending on the need.

Visual - People with PWS are often visual learners and can also become overwhelmed by too much visual stimulus. Using visual schedules as well as written schedules can be helpful. If the person becomes easily distracted or shuts down often, try allowing them to wear a hat or visor that they can pull down over their eyes when they want to “get away.”

What specific sensory activities are useful?

There is no easy answer. It is specific to individual preference. It also is dependent upon which behavior one is trying to decrease. That being said, here are some ideas for sensory tools and activities that have had great results for different needs:

For the person who picks - all tactile tools including stress balls, sand and water tables, silly putty, bubble wrap, chewlery (these are bracelets and necklaces that are designed to be chewed on), strips of material to shred and TheraBands. These also work well for decreasing agitation and increasing focus.

For daytime fatigue - TheraBands used under feet so the individuals can bounce; scents that are strong such as citrus or patchouli; and all activities that involve bouncing, jumping or climbing.

Reducing agitation - all activities that require using muscles in a positive way such as lifting objects (not too heavy), sucking thick liquid through a straw, stretching, blowing bubbles or jumping.

Preparing for transitions – we know that many children and adults diagnosed with PWS struggle with transitional times (before and after school or work, before bed, any time one activity changes to another); counting, coloring, tapping or clapping to a rhythm or rocking can be effective decreasing anxiety during these times.

Winding down - calming scents such as lavender or sandalwood, deep breathing, a warm bath or hand soaks. Due to poor muscle tone, it is often difficult for the person with PWS to take an effective deep breath. Blowing bubbles or making a game of blowing a ping pong ball across a table can ensure that they are taking a deep breath.

It is always recommended to consult an OT before starting a sensory program. After a consult, you can experiment on what works best for your child. A rich array of sensory techniques can ease many of the typical behaviors seen in PWS as you and your child master long-term coping skills.

Your child does not have to live their life being uncomfortable or feeling out of control. Sensory integration as a part of daily life will make an enormous improvement to your child’s quality of life. Always consult a registered OT before incorporating sensory integration but do it early and do it often. I have seen firsthand the transformation that takes place once we target and treat the problematic areas.



Student in the on-campus Agway Herb Garden.

SUCCESS STORY

New student Chris continues to inspire

By Dawn Dinnan and Katrina Fryklund

Chris came to Latham School in 2016, after many years of improper and ineffective placements and unhealthy weight gain. Chris has Prader-Willi syndrome, and when he arrived on campus at age 17, he weighed 430 pounds and was nearly immobile. His weight was life-threatening. With the support of a walker, Chris could only manage to slowly navigate throughout the Latham campus.

With Latham staff's careful evaluation of Chris' condition, individualized support plan, and help from a dedicated team, he is on a path to a healthy weight, inspiring everyone around him. After just 10 months, Chris has healthily lost more than 80 pounds and impressed staff, family and friends with his courageous and earnest attitude.

Chris walks farther distances than he believed possible, and uses newly learned coping skills to deal with frustrations, with the support of Latham's clinicians, teachers, nurses, and counselors. Each day, Chris was asked to walk up one set of stairs without the help of his walker. It became a daily challenge: *How many steps could he walk up without losing his breath? How many times did he have to stop? How long would it take for the entire flight?* That monumental day arrived when he accomplished his goal to reach the top of the stairs with no aid. It was a thrill for Chris and for everyone around him. In his words, "Every day that I am here, I am one step closer to becoming the kid that I want to be."

Surrounded by caring Latham School friends and staff, Chris is thriving. He continues to lose weight and for the first time in years, he can move without the support of his walker.

His mother is grateful to Latham. "After years of fighting to find the right placement for my son, we found home," she said. "His PWS is no longer debilitating, but rather it's a challenge he can overcome with support from Latham staff."

Latham Centers' intensive therapeutic Children's Program celebrates milestones like Chris' often. This nurturing place the students call home is life-changing not only for the children, but also their families, the staff, and the Cape Cod community members who help Latham Centers achieve its mission.

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.



Chris looks forward to 2017 Prom.

**PWSA(USA)'s 34th
National Convention**
November 15-18, 2017
Caribe Royale
Orlando, Florida

**Upcoming
PWS
EVENTS**

Lee Chamberlain, VP of Operations, Latham Centers, will lead a session entitled "Transforming a Youth Residential Program with Positive Behavior Support." And, Patrice Carroll, PWS Specialist, Latham Centers, will lead a PWS Panel.