



Living Healthy *with* PWS

LathamCenters Quarterly Newsletter



Latham Centers creates opportunities for independence, self-worth, and happiness for children and adults with complex special needs.

Positivity on Campus Guides Latham Smoothly through the Pandemic

The COVID-19 pandemic has affected all of us differently – and deeply. But students and staff here at Latham Centers have adapted with incredible resilience and become even closer as a community. Despite countless aspects of life changing for the children in our Program who thrive on consistency and routine, they have encouraged each other, adapted, remained upbeat, and reinforced to our staff why we chose to work at this special place of hope.

Student friendships continue to thrive as they learn to use new technology (along with staff) to connect with other students, families, and friends. Virtual learning has taken them to new places and fostered relationships. When businesses and favorite outside trails closed and outings were postponed, students understood why. They are keenly aware of all of us being “in this together,” and of what it means to stay safe. Students look forward to their new routines, including walks in open outdoor areas. Rarely have they fixated on canceled visits, perhaps one of the hardest changes for students here at their home-away-from-home. The Latham staff has masterfully adapted to teaching with new tools and online classrooms, while continuing to support one another and our students both on campus and in their homes.

We asked students and staff in the Children’s Program a few questions about their recent experiences on campus, and what they are most proud of during this challenging time. Their words are a reflection of the heartwarming collaborative efforts of our staff, parents, and the greater Latham community who have been so supportive.

Staff quotes: Adapting, Learning, Enjoying

- “I am extremely proud of how our students have handled multiple changes over the course of Covid-19. Especially the last-minute changes that have occurred.”



- “Students are asking thoughtful questions and enjoying participating in virtual learning... The days feel filled with classwork and learning while making sure to remain calm through coping.”
- “Achieving consistency when all else has seemed to fall away has been a positive landmark for my classroom and makes everything still seem somewhat normal!”
- “Everyone has learned to cope by working together in an awesome display of teamwork. Whatever needed to be done to keep staff and students healthy was done without complaint! What an amazing group we have here!”
- “Our Latham community is strong and makes me proud to be doing this important work during such an uncertain and stressful time for all of us.”
- “The students in my class have enjoyed doing special in-class arts and crafts and we devote time in the afternoons outside if the weather is nice. This time of year, we are getting more and more of those days!”
- “I have seen every single Latham staff adapt with incredible flexibility in every situation. Every staff has had to increase their daily task list immensely, so the new hustle is noticeable and makes me even more proud to work with such an incredible, caring team.”
- “The most positive change that I have seen over the past few months on campus is how flexible and adaptable our staff and students have been with the changes they have had to navigate.”

- “I noticed that some of the staff are hanging up rainbows on their windows to play the rainbow scavenger hunt... They are utilizing this to help lighten the mood of Covid-19!”
- “I have seen the students really doing their best to support one another.”
- “It’s been really fun being able to take the kids to the beach. It’s relaxing not only for the students but staff as well!”
- “The most positive thing I have noticed on campus is how both staff and students have come together to support and care for one another, whether in big or little ways. Latham truly is one big family!”
- “There have been so many changes over the last couple of months. I have been blown away by the adaptability of the students and the staff. Staff are working together across components to make sure the kids are happy and safe. I believe this has brought us all closer. I am so honored every day to be a part of this team.”

Student Quotes: Proud, Coping, Supporting, Happy

- “I have been proud of myself for learning to be okay with not knowing all the answers and “living in the gray.”
- “I’ve noticed that staff are risking their health for us during this time by coming to work and it makes me feel really cared about.”
- “Everyone is doing good at Latham Centers. We’re working during the day and hanging out in residence, outside, or going on beach outings.”
- “I have been able to Facetime more!”
- “I see a positive change when my behavior is doing good.”
- “My peers are doing good at school, and that makes me feel good about myself.”
- “I am proud to have been working on my behaviors and not allowing myself to get frustrated during this tough time.”
- “Some fun things I have been doing on campus are yoga and Pilates!”
- “I really love being able to play soccer with my friends!”
- “I am proud to stay safe even though things are hard right now!” “During this challenging time, I feel good when I’m doing my work at Latham Centers.”

- “My mom has helped me and I’m proud of myself for fighting the challenges.”
- “My poems make me proud.”
- “I am learning to cope by making new coping skills.”
- “I am proud that I am able to take it day by day.”
- “I’ve been part of the running club and that is a lot of fun!”
- “I’ve noticed that communication has been a key part of facing the challenges we are all going through!”
- “I have been able to talk out my feelings with staff more and I’m proud!”
- “I’ve been learning to cope with the consequences of my actions rather acting out and becoming aggressive and that makes me proud.”
- “I am happy we are still able to go on fun outings and be outside!”
- “I am proud that I keep achieving when things are hard!”

The reflections by students and staff on how Latham has adapted in the midst of this unfathomable global health crisis uplifts the entire Latham community.



New activities: Latham parents, guardians, and friends donated “wish list” items. (See “Generosity & Kindness: Part 3” <https://www.lathamcenters.org/blog/generosity-kindness-part-3-huge-thanks-to-latham-families-and-friends/>).

Latham's Adult Services Program: Adapting During COVID-19

The adults in Latham's residential program range in age from their early 20s to late 60s. Our program participants are resilient, and throughout the pandemic, they have been upbeat despite having their day programs close. Staff and residents have worked together to create a safe environment in each group home in which the residents continue to feel supported, cared for, and busy with new activities!

We asked our Adult Services Program staff how the group residences are coping with today's challenges. Alan Milsted, Case Manager, wrote:

"Changes, changes, changes! Over the last two months, our individuals have adjusted to life without day program, donkey care, the library, case management trips, and appointments with health care providers. Instead, we have all learned to live with Google Meets and Zoom, thanks to our new Kindle, with CCI in Plymouth, doctors and others; learned new games; completed absentee mail-in ballot papers for the State Senate Special Election; and become very well-acquainted with two nearby areas for walking, watching spring unfold. There has been much collective problem-solving! With staff support and guidance, the five young women and men in the Plymouth House have responded to the new and unexpected demands and challenges we have faced together."

Case Manager Debra Anderson wrote, *"Our guys have enjoyed multiple craft projects, long walks along the water, preparing our garden plot at The Valley Farm Community Garden, playing virtual bingo, dance parties to a resident's selected Mystery Song, and one of our favorite simple activities has been the Mystery Caller Game where we've connected via FaceTime with former staff and current staff. Our next adventure will be our own version of Zip Trip and Chronicle all wrapped up in one. Each client will pick a town to explore within an hour drive, and with the help of staff, they will come up with a place to walk, have a picnic, and a learning experience."*

Brenda Chouinard, Weir Road Residential Manager, shared, *"I'm so impressed with how the guys at Weir are handling this challenging time. They are staying positive and patient... Staff are going out on walks regularly, playing games, and bringing in movies to watch. They come to work with a smile and keep the guys healthy, happy, and feeling secure!"*

Latham also received some terrific feedback from residents:

- "I am handling things like not seeing my family, and handling it well. I am keeping myself busy doing crafts and playing games. Spending more time with my second family."
- "Positive changes, Plymouth handling COVID well, most having a positive outlook on things."
- "We have been playing games like Sequence, Trouble, Yahtzee, Sorry, exercising a lot, which means Fro-Yo! A fun activity was Easter Egg Hunt!"
- "I have really enjoyed walking and playing games together, and eating dinner outside on our porch in the sun."
- "I'm impressed by how clients are handling this situation even though it's not easy. I appreciate how staff are handling this and checking on us to make sure we're ok."
- "I am proud that I have handled this situation with a positive attitude and am waiting patiently during this uncertain time."
- "I am enjoying the 'quiet,' people are doing social distancing and following protocols and staff are handling it well with us."

As one staff member said, "Teamwork makes the Dreamwork!" We are so proud of (and grateful for) our Adult Services Program team, working hard in the midst of tremendous challenges.

Pictured below, Adult Program staff members and residents enjoy playing some games and participating in art group together.

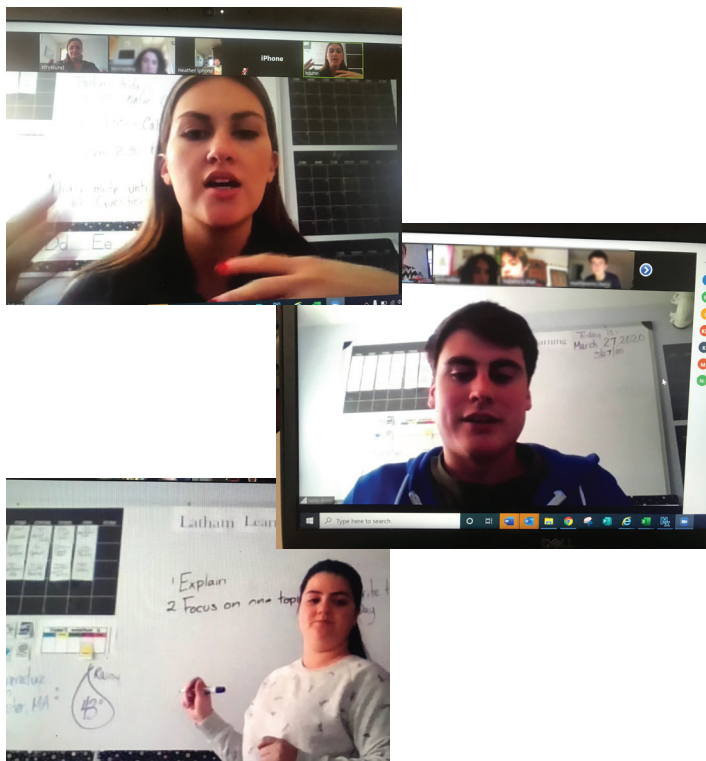


Virtual Learning: Creating a Program for Students at Home and Students on Campus

by Brittini Kliment

Latham Centers embarked on the virtual learning experience on March 26th, starting with our small number of kiddos who were home, then quickly adapting the programming schedule to address the students on campus as well. The structured schedule allowed for the students to continue to maintain their day to day academics in a format that they are familiar with. The independent academics ranged from their iReady reading to the Seven Wonders of the World unit. Students also participated in a long-term vocational unit called "My Dream Job" where they could explore career options of interest. The students embraced the Zoom platform and have been extremely interactive with both teachers and their peers. All students participate in a clinical session each morning, and a variety of classes with our incredible teachers each afternoon. We are staying up to speed with the new regulations put out by the Department of Elementary and Secondary Education (DESE) and identifying new ways to enhance our Virtual Learning program!

To learn more about some of those Zoom sessions, please visit our blog at <https://www.lathamcenters.org/blog/>



Giving Your Family the Credit You Deserve While Adjusting to the New Normal

by Patrice Carroll

We went from our daily lives of working, sending the kids to school, and running to the store many times a week to being forced into homeschooling, being together with our immediate families more than we ever thought possible, and hoping that toilet paper is restocked before it's too late.

Everything has changed, some for the better, but that does not take away the fact that if you are home with a child with PWS, your life went from hard to *let's just make it through the next 15 minutes*. And that is what it needs to be right now.

We all know that structure is a lifesaver, bribes are only going to come back and hurt more in the long run, and giving in is a sure bet to losing the war. While all of that remains to be true, you do need to give yourselves permission to do what you need to do to make it through the day right now.

If your child's school has remote learning with an expectation of 2-3 hours per day then reach for that. But on a day that started with tears and words that you wish that you could take back, it is ok to do the minimum for that day. Tomorrow, try for the full academic day; today may not be that day and it's ok. You want to be the mom or dad who doesn't resort to using electronics to babysit, you want freshly bathed children in clean clothes. You had plans and you were going to meet this new normal and take charge and after the first week, reality set in. You have an incredibly difficult job that no one prepared you for.

Give yourself permission to use the iPad if you need a few minutes (or hours) to regain your sanity. Schedules are great unless they cause more anxiety. Use schedules if they work, and if they don't work then don't use them. Even if they work for every other family that you have ever spoken to, if it doesn't work for you, don't do it. Use Zoom and facetime to have extended family read to your kids or play virtual games with them. Talk about your feelings to other parents—I promise you that whatever feelings you may have had, they have had them too.

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The new normal is that we are being asked to do something extraordinary, and something never done before, so if the best that you can do is survive the day then celebrate that you got through the day! During this time, it is important to celebrate each success, no matter how small. Do what works and when we finally are able to open our doors and rejoin our communities we will tackle the next steps of getting back to school, work, and the lives we left behind.

Celebrating PWS Awareness Month at Latham: Creating a Virtual Community

by Katrina Fryklund

Throughout the month of May each year, Latham's campus and group homes light up with residents and staff celebrating National PWS Awareness Month. Latham Centers is proud to enhance awareness and education about Prader-Willi syndrome, and although our celebrations looked a little different this year, staff, residents, and professionals came together to shine attention to PWS like never before.

In an effort to connect Latham students on campus with those learning from home, as well as children with PWS from across the country ages eight to 22, our staff created a virtual initiative to continue the tradition of celebrating PWS Awareness. Leaders from the national PWS community were invited to read on Virtual Storytime, and Virtual Social Hour gave students the opportunity to truly get to know one another from living rooms throughout the country.

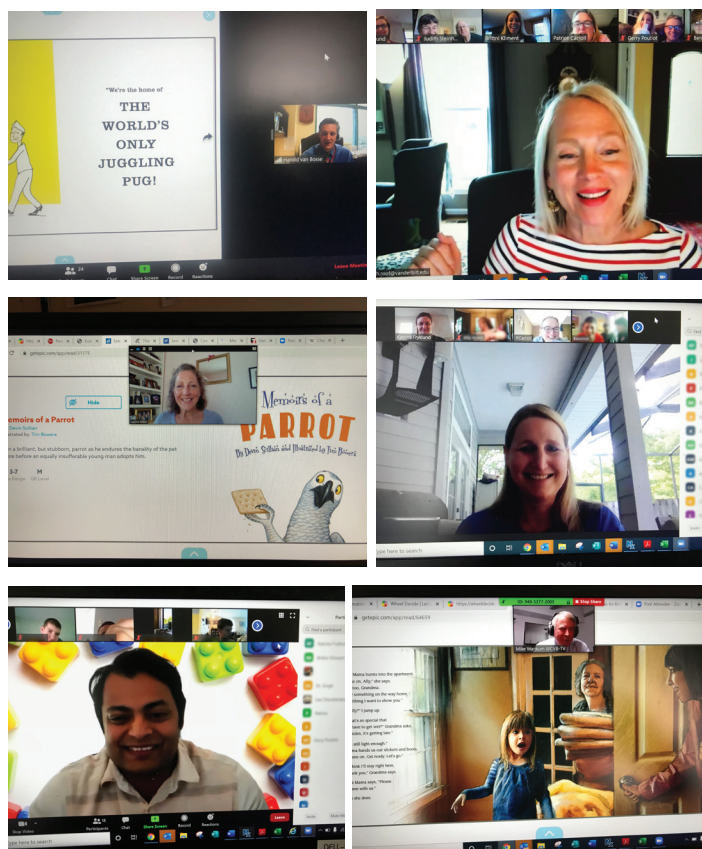
Latham Centers' Virtual Storytime grew as influential leaders in the PWS field read. Doctors, care coordinators, PWS parents, and local celebrities and political leaders read to students. Amy McTighe and Elizabeth Roof kicked off the series, while BJ Goff and State Representative Sarah Peake finished out the month. Throughout May, the forty-plus individuals joining met Dr. Deepan Singh, Dr. Jennifer Miller, and Dr. Harold van Bosse. Community leaders such as meteorologist Mike Wankum and Massachusetts First Lady Lauren Baker were new faces to the PWS community and loved learning about the amazing kiddos on Virtual Storytime. Each reader was asked how they got involved in their field.

Doctors and specialists, all well-versed in PWS, touched upon the many positives of helping people with PWS. Dr. Singh explained, *"I wanted to work with people, and I noticed that it was rare in psychiatry for people to say that*

they like to see their psychiatrist. It's different in the world of PWS though; I love seeing my clients and they love seeing me!" As creators, we felt it important to involve those who didn't already know about PWS as it truly honored the month-long awareness mission by engaging new people in our PWS Community. After Storytime they each wrote to let us know how great it was to see the students on Storytime and to learn more about them.

The success of Storytime inspired us to hold a Virtual Social Hour. Creating a virtual wheel with 60 questions like, "Would you rather be covered in fur or covered in scales?" and "What is your favorite place to go on vacation?" and "What is your best talent that you could teach someone?" gave every student the opportunity to participate. They loved the opportunity to meet one another, and parents wrote about how incredible it was to see this level of engagement—with kids coming together from all around the country.

We are so delighted with the positive outcomes of our Virtual Connection initiative in celebration of PWS Awareness Month. We can't thank our guest readers enough for making this experience so exciting for our Virtual participants. We thank the 30-plus participants for their open hearts and their willingness to meet people from across the country. Now more than ever, we feel the incredible connection within the PWS Community.



LivingHealthy Podcast Features Timely Parent Q&A

Latham Centers has published its ninth **LivingHealthy** Podcast which targets specific questions from families around the country with a child in their life diagnosed with PWS. Patrice Carroll and Katrina Fryklund tackle the following four questions in “PWS University Episode 8: Parent Questions #1” (<https://pwsuniversity.podbean.com/e/pws-university-episode-8-parent-questions/>). They invite you to give suggestions – or ask questions of your own at LivingHealthyPodcast@lathamcenters.org.

- *Trying to get my child to exercise is near impossible, what are some non-food incentives that have worked for you?*
- *Most of the time, around others my child is so kind and sweet, while around me his worst behaviors ALWAYS come out. What can I do differently?*
- *I'm a single parent who is primary caretaker of my child, but it feels like I have no support, especially right now. What resources are available that I'm missing?*
- *Due to today's circumstances, we've been spending a lot of time at home....being at home so much means more requests for food and snacks. Please help! What can I do to help curb this when our entire routine has been turned upside down?*

We also invite you to follow Latham Centers' podcast by downloading the Podbean application. As a follower, you'll be the first to know when we've posted a new podcast! In the App Store, search for Podbean; once in the application you can quickly create an account, and the process is complete!

In order to see our most recent Podcast and go to our Podbean Site, visit: <https://pwsuniversity.podbean.com/>



Patrice Carroll, Director of PWS Services, and Katrina Fryklund, Director of National Outreach, continue to publish audio podcasts on Latham's "LivingHealthy" Podbean site.



'Vision Boards' Project Gives Hope in Adult Services Program

"Welcome aboard the SS Peter Cooper!" The residents at Latham's Peter Cooper home recently shared some of the fun they've been having.

"We're running as if we are on a cruise ship," reported Case Manager/Vocational Counselor Debra Anderson. *"Each night, the next day's activities are posted on an Activity Board with scheduled times. This has helped clients stay motivated, active, and interested in getting going each morning. There have been yoga classes, Spanish lessons, long walks, movie marathons, and one of our favorite projects—Vision Boards—with the theme being Life after Corona."*

Residents and staff participated, and Deb said the project gave them all hope in moving forward during this challenging time. *"Every member of our staff is upping their game with creative ideas, and it's amazing the talent pool we are drawing from and how much we are learning about each other."*

In sharing their Vision Boards, the Peter Cooper folks hope they inspire others to do their own.



Staff Rally to Make the Prom Happen

By Campus Staff

We have extraordinary staff, and this heartwarming news about how they adapted plans for a Latham prom for our students last month is yet another example of their creativity and dedication. Despite the challenging times, and with many restrictions in place, staff collaborated to coordinate structure for our students on campus so they could still enjoy a prom.

The gentlemen wore tuxes, our Dress Show was in full effect for our ladies, and students did their hair, put on some makeup, and danced the night away! Residential Supervisor Dominic Monick shared highlights:

"Our first-ever Latham-hosted prom featured six party locations decorated with games, lights, and DJed by our residential supervisory team Neomie, Cara, Danny, and me. Every student was split up into smaller groups and given a map of their party hopping destinations, along with the trip to the photo stage before heading over to the Fire Museum (Latham Training Center) for a live performance from Mindy. Ensuring that the prom still happened meant the world to the kids; it gave them a moment to cut loose and have some fun in the midst of everything going on. Even faced with social distancing and spreading the groups out, we never seemed more together than Friday night's dance."

In addition to appreciating our staff, Latham thanked a special community partner for their help with our prom. This was the sixth year that Michael Bellich, Sales Manager at Puritan of Cape Cod, and his team have come to campus to fit each of our young gentlemen for a tuxedo. Each boy chooses the color of his tie, vest, or cummerbund. Michael Bellich shared, *"We love to see their faces light up. We have watched many of them grow up, and this is something that we look forward to every year."* In thanking Puritan, Director of Development Heather Kelsey said, *"The tuxes from Puritan really make the Prom special for our young men. We are so grateful to them for the time that they spend making every student look and feel his best."*

Despite everything going on in recent weeks, our Children's Services Program staff have done an incredible job ensuring that our students had the prom that they truly deserved – and so much more. We can't think of a better way to thank staff than sharing an excerpt of a letter from a Latham School parent:

"There are not words that can adequately express how thankful we are for your hard work and long hours you willingly perform to keep Latham going during this difficult time. I can only imagine what your days are like... Please know how fortunate we feel to have our child at Latham... When I learned she was going to the prom, I nearly passed out. This speaks volumes about the care, thoughtfulness, creativity and willingness you demonstrate on a day to day basis....

In my prayers every night, I always thank God that we were led to Latham. And I ask him to bless everyone there. You are doing God's work. Thank you from the bottom of my heart."

