



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.

A PWS-Aware Valentine's Day

By Patrice Carroll, LICSW, Director of PWS Services

Valentine's Day is a day to celebrate love and relationships. Many individuals with Prader-Willi syndrome struggle with finding success in relationships and long for the partnerships that they see in their families and in society in general. In our social groups and families, we must begin to alter the way in which we celebrate and bring attention to cultural milestones such as Valentine's Day. Within your family, celebrate every accomplishment (and not just the major milestones) to help the person with PWS in your life feel included. We need to send the message that a different life is equally as joyous and worthy as a traditional life.

I encourage you to use Valentine's Day as a day to find out what your loved one wishes. Do they want a boyfriend or girlfriend? If they do, what do they want in a partner, and how can we help them achieve this personal goal? I challenge you to help them make connections this year and be there to guide and coach them through this journey. People with PWS have so much love to give, and we have a duty of care to ensure that they can live a life of their design and to be there for them along the way.

"...find out what your loved one wishes."



Relationships and Media:

Media tells us that being in a relationship, getting married, and having children is the meaning of success. We, as family and caregivers, need to change that narrative. Images on television and in movies depict men and women in a stereotypical way that does not match what the person with PWS looks like, feels, and experiences in day-to-day life. Individuals with PWS typically do not meet the expectations of social norms because society does not embrace any variance from the norm.

People with PWS have interpersonal strengths and skills that often go unnoticed because the opportunities for relationships are sparse. Lack of opportunity does not equal lack of interest or need. Quality of life includes having meaningful relationships, and we have an obligation to ensure that opportunities are available for the person with PWS to experience those relationships.

Tips Based on How Latham Celebrates Valentine's Day on Campus

- As a group, each classroom makes valentines for all the other classrooms, rather than individuals. We do this so no one feels excluded.
- During residential time, the focus is on activities which may include a Valentine's Day dance, a Valentine's Day parade, and Valentine's day crafts.
- We have a Valentine's Day Dinner with healthy and delicious foods that are still within calorie count; this is something a bit out of the ordinary, but still fits within our students' schedule.
- For Valentine's Day gifts, students each receive a couple of non-edible gifts such as sensory items.
- Students receive a couple small pieces of candy and eat them in one sitting. (This prevents candy from being taken back to someone's room for food trading or hoarding).

Joy and Fun at Adult Program's Holiday Party

Our Adult Program came together in December with residents, staff, and families to celebrate the season. It is a true delight to share reflections from this special occasion.

"This is my second year attending the holiday party, and there was even more magic in the air because we were able to include parents and guardians this year. The managers worked together to create an evening filled with decorations, music, dancing, and fun. Because we all still feel some of the lasting effects of the pandemic, we are incredibly grateful for the opportunity to watch the individuals interact joyfully with each other, with Shared Living, and with their loved ones."

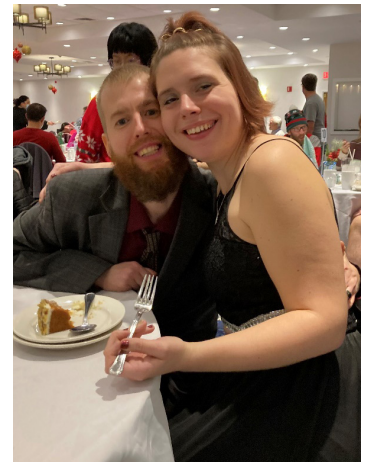
– Residential Manager Kendra King-Blischke

"The feeling of being surrounded by grateful parents, their loved ones, and stakeholders for this holiday party was a truly amazing scene. To watch how proud each Residential Manager was of their house and how much work their clients put into the fun of the holiday spirit was well worth it. Getting to be at the center of all the activity with the "elf squad" was an enjoyable experience for sure. Can't wait for next year! More laughter, smiles, and holiday joy."

– Residential Manager Bethany Franklin

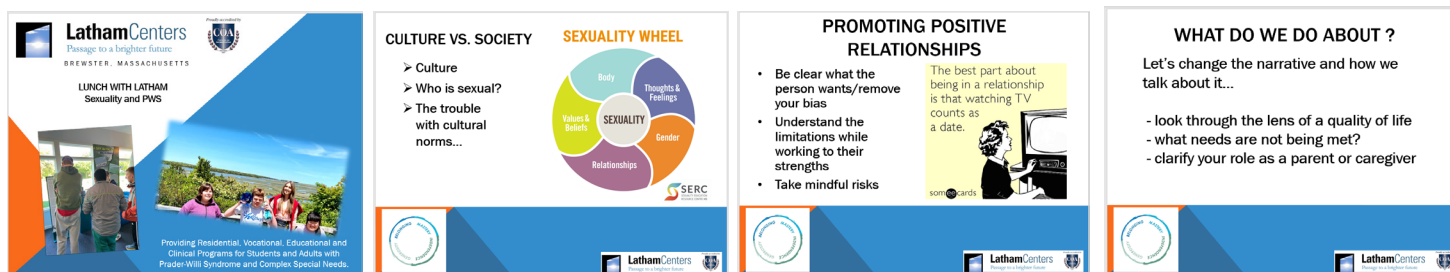
"Honestly, this year's party was awesome!! Thank you to all managers, Adult Nursing staff, Anne, Gerry, and Gina for a fantastic holiday party. I really enjoyed myself that night!!"

– Adult Program participant D.M.



PWS Webinar Recap: Sexuality and PWS *(and what's ahead)*

In our Lunch with Latham Webinar Series, our PWS Outreach team, led by Director of PWS Services Patrice Carroll, LICSW, seeks to provide education to our Prader-Willi community about common threads of curiosity. Please join us!



The above slides were discussed during our second Lunch with Latham Webinar

At the Foundation for Prader-Willi Research (FPWR) Conference in Chicago recently, a parent approached the Latham Centers table and said, “Help! How do I talk to my child about sex?!” Parents frequently tackle this challenging scenario with consideration of their child’s biology, intellectual ability, developmental age, interests, and abilities. Latham’s PWS Outreach team presented on the topic at their second Lunch with Latham Webinar held over Zoom on January 12, 2023.

Latham hosted the webinar entitled “Lunch with Latham: Sexuality and PWS” with an audience of more than 20 parents and caregivers. Attendees’ questions included “Can my child still get married?” and “Do I correct my child if his understanding about sex is different than the cultural norm?” Below are “Cliff Notes” of the topics discussed. We welcome you to email additional questions to admissions@lathamcenters.org.

- **BIOLOGY:**
people with PWS traditionally have a lower sex drive that said, many are interested in having children women can have children and they are born with Angelman’s Syndrome
- **CULTURE VS. SOCIETY:**
Men and women with PWS typically don’t meet the cultural expectations of being masculine or feminine, and what’s considered “normal” or “natural”. We can celebrate the milestones for people with PWS that are different than traditional milestones, i.e. while we may not celebrate having children, buying a house, or going to college, we can celebrate paid employment, appropriate friendship, and skill building.

- **DEVELOPMENTAL AGE:**
Individuals with PWS all have different developmental ages, meaning that a 12yo may developmentally be at the same level as a 4yo, or a 22yo that may be at the same level as a 15yo. Consider this when talking about sexuality to the person in your life with PWS.
- **QUALITY OF LIFE =** meaningful work + meaningful relationships
Talk about what people with PWS can do rather than what they can’t
Consider how you would talk about vocational opportunity and parallel the conversation, for example:

Vocational Example – Desire from Individual	Vocation Example – How you can talk about it as caregiver	Sex/Sexuality Example – Desire from Individual	Sex/Sexuality Example – How to talk about it as a caregiver
“I want to be a pilot.”	“While you may not be able to be a pilot, let’s see what else we can do in the aviation field, like working at an airport so that you are around planes.”	“I want to have six children.”	“It seems like you really want to take care of people, what about if you were to work at a senior center to help take care of the people that live there?”

- **COMMUNICATION**
We suggest that as a parent, communicate beliefs, values, etc. to all members of the family, including those with PWS
- **SEXUAL RELATIONSHIPS**
It’s a human right and even with guardianship, you can’t take the right away from someone
As a caregiver, we need to make sure to support their opportunities to explore, as long as it’s healthy

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Topics to explore:

- Consent
- Safe sex
- What does sex mean?
 - Ask what they want regarding “having sex” and remove any bias. (Maybe they feel that a sexual relationship is the ability to hold hands at the movies.)
- MINDFUL RISKS
Provide a safe place to ask questions
Supervise interactions if possible
Increase comfort level by normalizing “real words”
- SOCIAL MEDIA
Number of blocks that you can put into place because our population can be easily victimized
 - There are also blocks on food delivery apps
 - Apps on phones let you see what is happening on another device
 Create chatrooms with similar people where they can practice appropriate communication that you can monitor – example: GroupMe

Katrina Kozak, Director of National Outreach and webinar facilitator, welcomes others to join the educational PWS series. “It has been fantastic to see a community grow in anticipation of these webinars. Attendees are asking pertinent questions that affect everyone in the audience. Whether you are staff person working with someone diagnosed with PWS or grandparents of an individual with PWS, we invite you to join these informative sessions.” Our next Lunch with Latham Webinar will be about Psychiatric Issues in PWS. Stay tuned for more details and contact us if you’d like to join (kkozak@lathamcenters.org).

Exciting Milestone for Max Uplifts Us All

Max M achieved a very special personal goal this winter! Adult Services Manager Holly Hanlon shared Max’s exciting news. “*Max has made great strides in healthy living, meeting his goal weight in order to begin his horseback riding lessons after two years with Emerald Hollow Farm. A very proud day!*”

Max is delighted to be able to share this HUGE accomplishment, Holly said. Thank you, Max, Holly, and Emerald Hollow Farm in Brewster, for this phenomenal inspiration.



More ways to become involved with our PWS Community:

- Lunch with Latham Webinars – Bi-monthly
- Virtual opportunities for students with PWS ages 8-22 – Weekly
- Virtual opportunities for adults with PWS age 22+ – Monthly
- Latham Centers Blogs and Social Media – Daily
- FPWR Canada (Toronto) – May 2023
- PWSA USA (Orlando) – June 2023

Contact Katrina Kozak for more information – kkozak@lathamcenters.org

Celebrating Students' Creativity at Well-Attended Artist Reception

Students proudly showed their colorful collection of paintings at an evening reception at the Brewster Ladies' Library on January 24, 2023. The event was an hour of sheer happiness and celebrated the month-long Latham Student Art Show at Brewster Ladies' Library. The room was filled with acrylic pouring paintings as well as an inspirational slide show created by Job Coach Kevin Cole.

At the Artist Reception, Latham students praised each other's artwork, helped host the event and show admiring attendees around, and invited staff and family members to visit the refreshment table. Attendees at the reception were thrilled to see the beautiful and diverse art on exhibit, and to talk with students and staff. Career Services Manager Laura Heilmann said the students did such an incredible job with this project -- and they had a lot of fun with their peers and with staff!

Both the Art Exhibit and Reception were promoted throughout the community by the Brewster Chamber of Commerce and the Brewster Ladies' Library, two incredible organizations that have supported Latham Centers' mission-driven work for many years.



Art Shows for our PWS Community

“Children are naturally creative. It is our job to give them the freedom, materials, and space to let their creativity blossom to its full potential.”

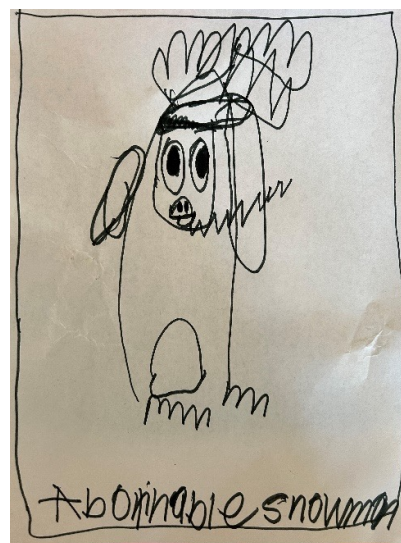
– Jean Van’t Hul, Kids Art Spot, Founder

Staff throughout Latham truly value the importance of artistic opportunity. Whether it’s our Children’s Program team, our Adult Program managers and staff, or our Virtual Community instructors, creativity is a constant. Our students on campus recently completed a Winter Art Show at the Brewster Ladies’ Library down the road on Main Street.

Inspired by the art completed by the students on campus, I wanted to provide our Virtual Students with the opportunity to show their art as well! Please join us on our blog and social media to see students’ beautiful masterpieces in a variety of videos and posts. Some of these ‘art show videos’ show images from the in-person Art Show at our local library by students on campus, while others describe the creative processes in our virtual community.

@LathamCenters on Facebook and Instagram, and www.lathamcenters.org/blog

If your child with PWS would like to join our online art groups on Monday and Tuesday, we would love to engage your child (ages 8-22) in our virtual community as well. I welcome you to contact me if you’d like to learn more about these opportunities. (kkozak@lathamcenters.org)



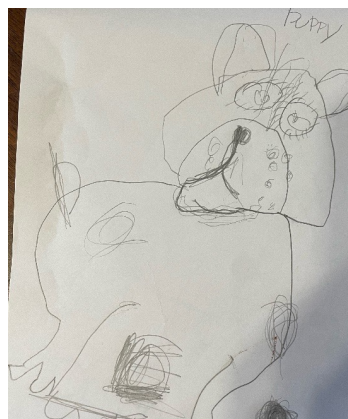
Abominable Snowman – by BB – Student, Virtual



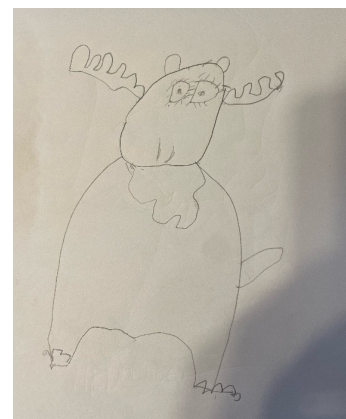
Tree of Life – by BB – Student, Virtual



Reindeer – Instructor Led (KK) – Virtual Community



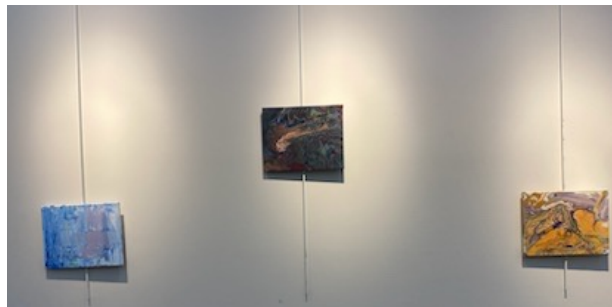
Puppy – by CM – Student, Virtual



Reindeer – by CM – Student, Virtual



Art Show, Brewster Ladies Library – Students, Campus



Art Show, Brewster Ladies Library – Students, Campus

Gratitude for Our Team – and Our PWS Community

As we begin a new year at Latham Centers with abundant hope and promise, we'd like to honor our incredible team of 240-plus employees. More than half of our organization gathered for a staff appreciation holiday party in December. Sincere thanks to all who staffed our programs that evening, as well as the committee that planned the terrific celebration held at *The Loft at The Cove* in West Yarmouth. (Photo collage includes an all-staff photo as well as Children's Nursing; Adult Nursing; Adult Managers; Maintenance; and Senior Administration.) It is an honor to work in the human services field – at such a highly regarded organization. We are grateful to work with outstanding professionals and to be part of a caring and committed global PWS community. #Gratitude #Belonging #Generosity #Community

