



# 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.*

## Taking Latham Centers on the Road: Consultations for our PWS Community

Latham Centers' Prader-Willi Syndrome Consultation Team provides customized consultation services tailored to the specific challenges and needs of children and adults with PWS. As leaders in the field, Latham consultants provide best-practice education and training to families, educators, and providers.

Consultation topics range from day program, classroom, and group-residence management to the challenges of managing a home and family setting.

Latham Centers' consult team covers an array of topics including genetics, medical, anxiety, behaviors, food seeking, best practices, strategies for success, and coping tools. Consultations typically include case studies, workshops, and team review of previously used plans. Consultants will provide notes and recommendations specific to the environmental analyses and trainings.

Reflecting on their recent consultation in the Midwest, Patrice and Katrina noted, *"Working with the student, parent, educational and nursing staff has been rewarding. It has been a pleasure getting to know the student and observing him in both his classroom and home environment. We look forward to returning for our next visit, when we will follow up with his educational team and his extended school year programs, and we hope to see his continued success after implementing our recommendations."*

To learn more about Latham Centers' PWS Consultations and rates, please contact Katrina Fryklund, Director of National Outreach, at [kfryklund@lathamcenters.org](mailto:kfryklund@lathamcenters.org) or (774) 353-9126.

### About Latham's Team:

#### Patrice Carroll, LCSW, Director of PWS Services:

Patrice is internationally recognized for her expertise in Prader-Willi syndrome. Since 1995, she has worked with individuals and families impacted by PWS. Patrice earned an MSW from Simmons College in Boston, she co-chairs the PWSA(USA) Professional Providers Advisory Board, and she is the United States delegate for IPWSO. Patrice specializes in person-centered vocational programming, and multi-modal management of skin and rectal picking using intensive, non-contingent, sensory stimulation.



*Patrice and Katrina at a recent consultation in the Midwest. In the presentation pictured, they provided guidance to the district's transportation company on safe and food-safe transports.*

#### Katrina Fryklund, MSPC, Director of National Outreach:

Katrina has been part of Latham Centers' leadership team since 2013. She is co-editor/author of Latham's Living Healthy with PWS Cookbook series and has produced numerous resources at Latham Centers, including videos "And they said my child would never..." and "A Day in the Life." Katrina works with parents and PWS Associations nationally and internationally, presenting at PWS conferences and producing materials to assist parents, guardians, and caregivers in the PWS community.

*"We have found your consultation to be very helpful and look forward to our follow-up visit. The staff are so grateful for all of the tools they have taken away from this."*

-Director of Student Services

*"On behalf of the entire team, thank you for your time and expertise; we found the workshop profoundly helpful to our work with [our student]. We began to introduce [her favorite staff's] leaving and utilized a social story to introduce this transition. In addition, we're working with [our student] to create her list of people who help her with school, feelings, or problems."*

-Special Education Department Chair

## Life at Latham: A Glimpse of the Impact of Special Olympics

*In the words of our Latham School students:*

"I like all the Special Olympics athletics because I get to get more physically fit while hanging out with my peers."  
– Chris S.

"I like to play basketball and bowl in Special Olympics. I love going to the tournaments because I get to meet all sorts of people." – Evan

*In the words of our Latham staff:*

"The Latham Hawks Special Olympics team works hard and applies what they have been learning in practice to every game or meet." – Monique W.

"Watching students practice for Special Olympics is a daily highlight for me. Seeing their smiling faces, skill growth, and exercise with our dedicated and caring staff is inspiring." – Ashley P.

"At an evening basketball practice, our students cheered each other on as they took turns sprinting, shooting hoops against staff, and working together as a team. The hour of laughter and camaraderie exemplified happiness and belonging at Latham." – Dawn D.



*The Latham Hawks participate in bowling and basketball in the winter.*

## Delivering Your Ultimate P.R.O.M.I.S.E.

*This piece on financial management is an excerpt from an article written by Patrick MacGrath – bio below.*



*Patrick MacGrath will be presenting at Latham's 2020 PWS Conference (see conference announcement on page 3)*

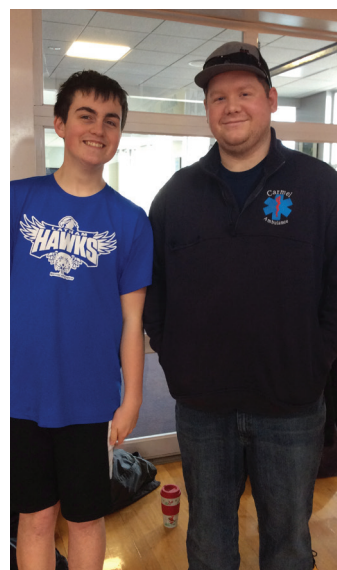
Special Needs Planning isn't simple, it certainly isn't easy, and it doesn't get accomplished in a day. In fact, this may be the most challenging planning that you'll ever encounter. Having the tools and resources available to help make smart, collaborative decisions can make all the difference in the world.

The creation of the **P.R.O.M.I.S.E** outline gives families the knowledge to begin the life-long process of securing the future for their loved one. The reality is that you are planning for two generations. This process isn't easy, and it takes time.

**The P is simply Preparing a Clear Vision.** We have a special needs population that is growing, but resources that are shrinking. We have increasing costs associated with all facets of care, but limited options for where to receive that care. Once we understand our WHY we can begin the planning process.

**The R is Researching Your Options.** There are questions surrounding SSI and SSDI, Medicaid and Medicare, when do these benefits begin and how do I apply for my loved one? How do I ensure that my child has a free and public education? The key is having an understanding of what needs to be done when, and where to go at those important stages to get the right guidance.

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**The O is Open the Door.** It all comes down to the question, “How do I ensure that my child will be taken care of after I’m gone?” Open the Door is simply a phrase to let the individual, trustee, or institution know what it would be like if and when they may be responsible for your loved one. These are often called Letters of Memorandum, or Letters of Intent.

**The M is Managing a Legacy.** How do we financially plan to ensure that our child, and other children are protected, but also have the resources needed to live the life that they would enjoy? Leveraging the best financial strategies and concepts can help ease the burden of determining your family’s financial needs in the future. Take the time to find a team that you trust to help build that blueprint and you’ll be rewarded.

**The I is for Interpreting your Legal Options.** One member of your team that is an absolute must is an attorney that specializes in Special Needs Trusts. First party trusts, third party trusts? What do I need? How do I maintain my loved one’s benefits? What happens if my loved one is receiving benefits and inherits some money? This area of planning is so complex that there are books written just on the legal topics within special needs planning. Guardianship? How does that differ from Conservatorship?

**The S is for Seek Support.** From time to time we all need a shoulder to lean on. Days and circumstances will come up that challenge every fiber of our being. Life isn’t easy period, and life with a loved one with special needs is even more challenging. There are many fine organizations in every community that help with support, whether for the parents, the siblings, or the person in your life with PWS.

**And finally, the E is for Evaluate and Execute.** Evaluate your options for your planning team, take action on the pieces of the plan that are easy to accomplish, and make a concerted effort to plan a strategy for the more complicated elements of your special needs plan. Government regulation and legal precedents will surely change. The key is to remember that this is a life-long process and changes will be necessary. Private Wealth Management Group and its partners understand the challenges you face. We are empathetic to your immeasurable responsibility for the lives of your loved ones. We have the experience to help guide you through life’s transitions and the passion to pursue your success. Special Needs Planning has evolved over the years, you deserve to work professionals who have also walked the path.

*More about the writer: Patrick R. MacGrath is the President and CEO of Private Wealth Management Group located in Appleton, Wisconsin. They are a comprehensive wealth planning firm that also specializes in Special Needs Planning. Patrick says, “My sister Heather has soft Cerebral Palsy and Epilepsy. I know, firsthand, how difficult it can be to not only plan for the future, but just get through the day. Early in my financial planning career, the disconnect between the traditional wealth planning model and the special needs planning world became evident. Our primary goal is to integrate the appropriate planning needed for financial security and Special Needs care assurance.” [patrick@pwmgt.com](mailto:patrick@pwmgt.com) / <https://www.pwmgt.com/>*

## Regional PWS Conference Scheduled for December at Ocean Edge Resort:

### ‘Changing Perspectives, Changing Lives’

Save the date for December 4-5, when Latham Centers will co-host a regional Prader-Willi syndrome conference on Cape Cod. Latham Centers is joining with the New England PWS Association to create the PWS-specific two-day conference with experts in the field from near and far. More details will follow, but here are just a few highlights:

- Full day of sessions on Friday and half-day on Saturday at Ocean Edge Mansion and Carriage House, Main Street, Brewster
- Featured speakers will include Dr. Deepen Singh, Elizabeth Roof, Melanie Silverman (and more)
- Panel topics will include vocation, students and adults with PWS, sibling success, financial management (and more)
- Friday evening will feature Latham Centers’ 50<sup>th</sup> Anniversary Gala, a celebration in the Ocean Edge Mansion Ball Room
- Professional Development credits will be available

Please save the date and join us for this opportunity to learn from experts, from each other, and share in the promise of creating brighter futures together.



*Pictured at last year's PWS Conference in Connecticut are Latham staff members Katrina Fryklund, Lee Chamberlain, Ben Mundy, and Gina Sheehan, as well as presenters Dr. Deepen Singh, Elizabeth Roof, and Melanie Silverman.*

## Transitional Classes Visit Adult Program Group Residence

By Dawn Dinnan

Several of the students from Latham School's "transitional classes" (Race Point, Breakwater, Bass River, and Rock Harbor) recently visited the Adult Services Program's Peter Cooper home to interview residents and staff and learn about living in a group residence. It was a great success, thanks to teachers Fred Walters, Jeffrey Lee, Katie Jaeger, and Catherine Christianson who headed up this endeavor, along with Adult Services Residential Manager Patricia Morgan. Here are just a few of the questions students asked during their house tour and interviews:

*What do people living there do in their free time?* (Answers: Things like hiking, going to the YMCA to exercise, video games...) *What do you do for activities on the weekend, and how much does it cost?* (Answers: We do free activities like hiking, Special Olympics, going to parks and the library... We have to pay for movies and any activity that requires admission.)

*How do we get to the activities?* (Answers: Staff drives; sometimes we use public transportation or Uber.)

*Are we responsible for our own transportation to work, adult day program, school, and medical appointments?* (Answers: Yes; staff or a bus will transport you – but if you are late and miss your ride, you have to pay for a taxi or Uber ride, and that is expensive. If you have a job, vocational staff will drive you.)

*What skills are helpful to know when moving to Adult Services?* (Answers: Money management skills; you will have a bank account, so you need to know how to budget your money and pay bills – also knowing how to use a debit and credit card; follow directions; complete morning-time and night-time routines independently; know how to tell time...)

*How do you do conflict resolution between peers?* (Answer: We talk to our housemates; we have a house meeting about issues.)

*Is there a bedtime?* (Answer: No, but there is a quiet time starting at 11:00 p.m. You have to be responsible to yourself and get enough sleep to work or go to day program.)

Students are keeping their interview questions and answers in a transitional binder that they will be building throughout the year. Teacher Fred Walters noted, "The students are very keen on learning as much as they can about adult life. It's really nice to see our young adults take a strong interest in their future and build upon their experiences in making the transition to adulthood less mysterious."



## Latham's LivingHealthy 'PWS University'

### Episode 6 provides tips on Sensory Processing and Executive Functioning Disorders

By Katrina Fryklund

Our directors of National Outreach and Prader-Willi Syndrome Services continue to develop a series of helpful "LivingHealthy" audio podcasts to share Latham Centers' expertise beyond our programs. The PWS-focused podcast series called "PWS University" highlights important aspects of Prader-Willi syndrome (PWS) — the good, the challenging, and everything in-between. The most recent PWS University podcast offers insights into two oftentimes-related disorders.

In Latham's PWS University Podcast #6 launched on February 11th, Patrice Carroll (Director of PWS Services) and Katrina Fryklund (Director of National Outreach) discuss Executive Functioning Disorder (EFD) and Sensory Processing Disorder (SPD). They suggest that for someone with PWS and Executive Functioning Disorder, it may be most beneficial to break tasks down step-by-step. For someone with Sensory Processing Disorder, high-stimulus environments with bright lights and loud noises may make it difficult to focus on the task at hand. In the podcast, Patrice and Katrina explore the relationship between Prader-Willi syndrome and EFD/SPD, and touch upon the difference between genetics, environment, and behaviors. Additionally, they investigate helpful tools for someone with EFD and SPD, ranging from an individualized Sensory Toolbox to Wiping Wands. Ultimately, Patrice explains, "It's important not to assume that something is behavioral or non-compliance, rather ask yourself, 'How can I best control the environment to help the person in my life with EFD and SPD?'"

We invite you to download, follow, and share our Podbean podcasts. <https://pwsuniversity.podbean.com/>



## Clinical Team's Professional Development Series Includes PWS Education

By Dawn Dinnan

The clinicians at Latham Centers share their knowledge with colleagues through a highly regarded interactive professional development seminar series.

Our Social Services team leads the monthly workshop to provide information and answer questions from staff about the clinical diagnoses and needs of our diverse student body. Each session offers the opportunity for staff across components to come together to learn and brainstorm new ideas about how to work with students who display the clinical need being discussed.

The seminar series includes topics such as trauma; anxiety disorders; mood disorders; OCD and related disorders; autism spectrum disorder; Prader-Willi syndrome; and more. The feedback has been overwhelmingly positive. Presentations include the definition of each diagnosis; details about the specific diagnosis or clinical challenge; and how the information can be applied to a case. Participants do activities together that mimic clinical activities used with the students, talk in small groups about how the information is reflected in students we serve, and share insights and experiences with each other.

The goals of the seminars include:

- to increase awareness of various psychiatric diagnoses and clusters of clinical issues we encounter daily at Latham;
- to facilitate thoughtful conversation about common techniques for addressing symptoms students may exhibit; and
- to offer time to consult and ask questions of clinical staff.

One presenter said that staff have found the information very useful in their work with our population. Latham staff members also appreciate the time they get to spend brainstorming and talking with staff and administrators from across departments about the topic at hand.

Presenters have heard staff members say things like, *"When I was dealing with \*student\*, I remembered what you said about..."* It has been a great opportunity to reinforce the information staff already have, or encourage them to think about a problem or issue in a different way.

Assistant Residential Director Patti Hynes-Morris said the Clinical Seminar Series is invaluable, and something staff are really excited about. *"It puts our kids in context. Staff have a better understanding of the diagnoses and how they impact our students; they learn more about what our clinicians are doing; they have an opportunity to connect with one another; and they are gaining tools to better help our students and be more effective."*

Latham Centers is committed to continually broadening the expertise of our staff. *"Continuing education is the cornerstone of what we do here at Latham, giving staff the tools they need for growth and development,"* noted Latham President Anne McManus.



Clinicians Samantha Cronin and Chelsea Crowe present at Latham's Training Center.

## Latham Celebrates 50th Anniversary



Founded in 1970 in Brewster, Latham Centers creates brighter futures for children and adults

**LathamCenters**  
*Passage to a brighter future*

with complex special needs. Latham will honor the agency's 50-year milestone at events throughout the year, including a fundraiser to help support its Asinotherapy (miniature donkey therapy) Program in April (visit [LathamCenters.org/events](http://LathamCenters.org/events)); the annual Latham Charity Golf Classic in October at Ocean Edge Resort & Golf Club; and the Prader-Willi Syndrome Conference in conjunction with Latham's 50th Anniversary Gala in December, also at Ocean Edge. Please visit or subscribe to the Latham blog for event information and updates: [LathamCenters.org/blog](http://LathamCenters.org/blog).