

TIPS for working with Individuals Diagnosed with PWS

1. In Food Secure environments those diagnosed know there is food, but that it is locked away. Do your best to make YOUR environment Food Secure.
 - a. Be sure that your provider understands the need for food safety, and the accompanying dangers when unsafe.
 - b. Do not incentivize good behavior with food, this perpetuates the cycle and leads to an unsafe environment.
2. As much as possible reinforce wanted behaviors and ignore unwanted behaviors as long as they are not unsafe.
3. Do not try to argue with someone with PWS. Instead try to redirect.
4. Anticipate a possible change in plans by always having a Plan B in case the original plan falls through.

About Latham Centers

Founded in 1970, Latham Centers helps children and adults with complex special needs, including Prader-Willi Syndrome, to lead meaningful, abundant lives. Latham is internationally recognized for its expertise and success in working with individuals with Prader-Willi Syndrome. Latham's programs include a residential school in Brewster and 14 group residences. Currently we are expanding opportunities for adult residents through our independent and shared living environments.

Latham Centers is an equal opportunity provider and employer.



To learn more about the diagnoses of
Latham Centers' residents, please contact:

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Latham Centers' RESIDENTIAL POPULATION

*Prader-Willi Syndrome and
Other Complex Special Needs*

FACTS AT A GLANCE



"We provide a different, well-rounded approach to people with intellectual disabilities. We have the professional supports in place and are hugely interested in community participation."

– Latham Centers Adult Residential Staff

TTY and ASCII Users: 800-720-3480

LathamCenters

Cape Cod, Massachusetts

What is Prader-Willi Syndrome (PWS)

Prader-Willi Syndrome (PWS) is a genetic disorder that occurs in 1 out of 15,000 births as a result of an abnormality of the 15th chromosome. PWS affects appetite and metabolism as well as cognition and behavior. Most often, PWS manifests itself with an insatiable appetite, behavioral challenges and cognitive limitations. Most individuals diagnosed with PWS will require lifelong oversight from endocrinologists, orthopedic doctors, nutritionists and psychiatrists.

PWS at Latham Centers

Half of the residents who attend Latham have PWS. Latham is the leading provider in North America that specializes in the treatment of PWS because of its innovative programs and dedicated staff.

Latham's approach to the treatment of PWS is a unique combination of food security, nutrition and diet management, exercise, weight monitoring, counseling and education, skill building, medication management and positive behavioral support. The results show our graduates are living safe, healthy and positive lives.



Working with Providers on Cape Cod

Many providers have not had previous experience working with a person diagnosed with PWS. We encourage providers to reach out to us with general questions. We also offer comprehensive training. Our relationship with community providers is essential in maintaining the health and well-being of the people that we support.

Other Complex Special Needs at Latham Centers

RAD - Reactive Attachment Disorder

Developmental trauma during the first two years of life due to abuse, neglect and multiple disrupted placements. This results in deficits and an inability to develop "normal" healthy interactions and attachments with others.

PTSD - Post-Traumatic Stress Disorder

Direct experience or witnessing of traumatic event(s). Individuals may then experience intrusive thoughts and prolonged distress, at exposure of cues, that are reminiscent of traumatic event(s).

AUTISM

Persistent deficits in social communication and interactions. This may include deficits in verbal and nonverbal communication while developing, maintaining and understanding social relationships. Autism may also include restrictive or repetitive patterns of behavior; interests and activities, and hyper or hypo-reactivity to sensory input.

NON-VERBAL LEARNING DISABILITY

High risk for anxiety and depressive disorders. Individuals are faced with the inability to understand non-verbal skills such as tone of voice, facial expression, lack of coordination and fine motor skills. Those diagnosed may also have difficulty understanding connections between different factors, i.e. getting the "big picture." Finally, individuals lack in social understanding & cognitive rigidity.

ANXIETY DISORDERS

Significant difficulty in controlling worry. This may present as feelings of restlessness/feeling "on edge," very easily fatigued, concentration difficulties, irritability, muscle tension and sleep disturbance.

DEPRESSIVE DISORDERS

Those diagnosed face possible symptoms of depressed mood, diminished interest in activities, weight gain or loss, insomnia or hypersomnia, psychomotor agitation or retardation, fatigue or loss of energy, feelings of worthlessness or excessive guilt, diminished concentration and recurrent thoughts of death.

Success Stories

Derek

Derek has been thriving in the Latham Adult Residential Program since 2012. He is an example of somebody with a high IQ, however his food seeking behavior inhibits him from working and living a "normal," life. At Latham Centers, however, he has found a way to cope with Prader-Willi Syndrome, and is prospering in our environment.

"In the time that Derek has lived at Latham, his life has improved immensely. He has lost almost 150 pounds, has dropped many of the medications he was on, and no longer needs a CPAP machine to sleep at night. For the first time in his life, Derek has made friends with whom he can share common interests. He now enjoys many activities, such as bowling, acting and singing, learning to care for animals and exercising daily. Derek is very proud of the accomplishments he has made since coming to Latham Centers, and has much to look forward to in life. He hopes to go to college and eventually live more independently. I feel that this will only be possible with the help of Latham Centers."

- Sharon, Mother of Derek



"Success was possible because of my own commitment but also that of a compassionate and caring team of support staff, and community inclusion.

Living with Prader-Willi Syndrome is quite the journey."

- Derek M., Adult Resident