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*Testimony Re: CT DDS
Robert Haydon Jones III (11-22-84)*

My name is Robert Haydon Jones Jr. I am here to talk to you about four disabled young people from Connecticut who have Prader Willi Syndrome and are clients of the Department of Developmental Services.

It appears that this committee is the only authority within the Connecticut Legislature that can restrain the CT DDS from a course of action -- done in the name of economy -- that expert, nationally respected doctors have testified is not at all in these clients best interests -- indeed, it is almost certain to do these young people great harm -- and cost the state a lot of extra money.

People with Prader-Willi Syndrome have a constellation of symptoms and conditions and behaviors far beyond intellectual disability.

PWS is a genetic disorder involving the Hypothalamus. People with Prader Willi are constantly ravenous. And they have a low metabolism. Without a special diet and constant scrutiny PWS people become morbidly obese and often die at an early age.

They are also plagued by chronic skin picking which generates serious life-threatening infections. PWS clients are obsessive compulsive and have to be guided away from repetitive behaviors. They live in a state of constant anxiety and need ongoing reassurance. They can and do react combatively when frustrated.

The point is the State has long recognized that PWS is a special condition different than "general" Intellectual Disability. The PWS disability is not so much IQ related as is OCD/ Behavioral related. These PWS Clients need the constant presence of specialty trained staff and supervisors to deal with these issues.

My son, Beau, was morbidly obese, extremely depressed and frequently highly agitated when he arrived at Latham nine years ago. He had serious Type II Diabetes.

Since then he has lost 90 pounds; he has received four Certificates of Completion from Cape Cod Community College; he has won two Gold, Two Silver and a Bronze at the Special Olympics in Boston; he is a well known, active Member of the Unitarian Church in Barnstable, which he attends weekly; he has been happily married for nearly three years to Sylvia, a disabled woman who suffers from a Seizure Disorder from a nearby community.



In the past nine years, Beau has developed deep ties with his Latham staff. (He thinks of them as family). He sees the Latham Head Nurse weekly to check for body sores. He is well known by his Therapist, and by the four Physicians, an Internist, a Dermatologist, an Endocrinologist, and the Wound Care Center he needs to see regularly for chronic issues.

Beau lives with his wife, (a disabled person maintained by MA) in a basement "mother-in-law apartment" in a Group Home that houses five other PWS clients. He has one-on-one support from 9am to 6pm. He and his wife, Sylvia, often visit with her family in a nearby town and go on outings with them.

The Trauma of suddenly being uprooted from a safe, familiar environment and to lose these relationships after nine years will be terrible. (A key facet of PWS is chronic anxiety - and an inability to adapt to change.)

Every PWS expert we have contacted has stated that removing Beau and the other three CT DDS Prader Willi clients from the Latham Massachusetts Community will be extremely traumatic for him and is likely to result in very serious emotional and mental problems.

DDS has said we shouldn't worry. They say they aren't going to move these clients until Latham opens a facility in Connecticut or a comparable PWS Specialist facility is opened in CT by another vendor.

But DDS is ignoring the expert Testimony from the nation's top PWS Doctors. (I am appending these Medical Opinions to my testimony)

They say ANY move away from Latham Massachusetts where these clients have lived for virtually their entire adult lives is definitely NOT in their best interests and is likely to be HARMFUL and result in tremendous extra expense to the state.

They say people with Prader Willi are a unique group among the disabled - by far the most likely to be plunged into depression and despair by such a change.

The Doctors also testify that if these clients are moved they would lose the very important knowledge-based relationships they have developed over the years with the local Physicians and care givers they must see.

So, any move away from Latham Mass is virtually certain to do great harm to these clients and in the end cost the state more money. That's what the experts say. It's all there in black and white. I urge you to read it.

Why would DDS contravene these experts and risk all the hard-won gains CT DDS and Latham Mass has achieved for these clients over the years?

Evidently, CT DDS thinks that the budget imperative entitles them to take this kind of chance.

My son and the three other young Connecticut citizens with PWS who are residing at Latham are trusting that you will protect them. Please keep them where they have found recovery.

Please instruct the DDS to not move them ever.

Thank you.



**Pittsburgh
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February 12, 2013

To whom it may concern:

It is our understanding that the state of Connecticut is currently negotiating with the Latham Centers to provide PWS specific housing for Connecticut residents who are currently served in Massachusetts. Also, it is our understanding that the newest arrivals to Latham Centers know that once this agreement is finalized, they will be returning to their home state. However, there are several residents who have lived in group homes in Massachusetts run by Latham Centers for most of their adult lives, and they consider Latham Centers to be their permanent home. This letter of appeal is intended to explain why a move to a new system of care would not be in the best interest for the four Connecticut residents in question. Although each of the four persons has PWS, their situations are unique. Ideally, a decision to relocate should take all of the following itemized opinions into consideration.

Consultant Opinions:

1. Individuals with PWS require a specialized placement like Latham Centers that has the **programmatic elements**, the **skilled and experienced staff**, and the **depth of experienced supervisors** to manage PWS-specific behaviors. A new home would provide the programmatic elements, but it would take some time to acquire the skill, experience and depth of supervision required to optimally manage the syndrome and each individual in their care. This learning curve of caregiving for both the syndrome and for each individual with the syndrome is universal. During the time of adjustment **which can take more than a year even in the best programs, experience tells us that we can expect an increase in disruptive, aggressive and self injurious behaviors**. These behaviors alone can delay the person's adjustment as well as the staff adjustment to the needs of the individual, while the management of acute problems crowds out long-term needs.
2. The individuals in question, as well as their parents, believe that Latham Centers provides the best opportunity for a community placement that provides exposure to peers who also have the syndrome. The Best Practice Guidelines for Standard of Care for Persons with PWS in Residential Living highlight the importance of homogeneous pairings in the care of individuals with PWS. Living with other people who have the syndrome provides an opportunity for peer

reference among those with this rare disorder and facilitates acceptance of the restrictions required for successful management and adjustment.

3. In a smaller PWS program, the individuals in question are at risk for psychiatric or medical hospitalization due to their aberrant behaviors. There is ample evidence to suggest that triggers for aberrant behaviors include environmental over-stimulation or under-stimulation, unfamiliarity with caregivers which leads to uncertainty, frustration and escape/avoidance of demands. Therefore, a change of living situation is likely to precipitate an adjustment disturbance with emotional and behavioral consequences. ***Situational stress is commonplace in PWS; it is the response of the experienced staff that determines for each individual whether the situation escalates to a psychiatric crisis.*** Once the person is hospitalized, further deterioration occurs due to additional environmental change. Paradoxically, psychiatric hospitalization can *add* to morbidity due to uncontrolled weight gain (as much as 20 pounds in one week), side effects of psychotropic medication (toxic reactions and over sedation), and persons with PWS are at greater risk for dying as a result of physical restraint that is inappropriately administered (failing to account for hypotonia and risk for respiratory compromise). Management of the crisis by experienced staff in the context in which it occurs is always preferred.
4. Latham Centers provides a family-like environment for persons of all ages who have PWS. It provides the necessary social stimulation that can come only from a PWS peer group. Because Latham Centers has specialized services for PWS and serves 40 adults with PWS in a community of group homes, Latham Centers has the ability to ***select for peer compatibility, developmental appropriateness*** and ***setting specificity*** to more optimally meet the needs of each person. This provides the individuals with positive role models and offers the possibility of protecting them from entrenched and maladaptive peer interactions that perpetuate behavioral reactions. This pattern is frequently seen in smaller PWS facilities.
5. Because of the rarity of the disorder, most physicians have extremely limited experience with caring for person with PWS. Parents are rightfully concerned since they have years of experience consulting with medical practitioners who do not know enough about PWS to be helpful. Latham Centers has spent years building up a network of medical and psychiatric consultants who have familiarity with PWS. This component of PWS programming is frequently overlooked or underestimated in new programs.

It is well accepted that due to the nature of the genetic deficit in PWS, the most effective tool for managing syndromal behaviors is the ***controlled environment***. Almost always, deterioration in level of function can be related to changes in environmental structure that precipitate stress. ***Stress sensitivity*** in PWS is genetically determined and related to the ***cognitive inflexibility*** and ***impulse control deficits*** that are the major underpinnings of the phenotypic behaviors associated with the syndrome. Among all individuals with neurodevelopmental disorders, tailoring the environment to the needs of the individual is one of the most important factors that determines their level of function. Compared to other individuals with neurodevelopmental disorders, people who have PWS are the ***least able to adapt to environmental changes and interpersonal challenges***. Despite this fact, it is consistently

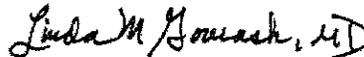
expected that people with neurodevelopmental disabilities conform to fit in to existing opportunities in the community for living, work and leisure. In fact, the most compelling reason for individuals with PWS to be in group home residence with trained staff, who offer 24 hour-7 day per week supervision, is because the parents are not able to provide the degree of structure and predictability that these individuals require in order to be successful. Please see the attached Appendices I-V for further detail about the needs of individuals with PWS and how Latham Centers has developed the unique expertise to meet those needs.

Finally, due to the nature of the syndrome, individuals with PWS have little choice in many facets of their lives, despite the fact that they may be considered competent to consent for themselves. ***These four individuals in question and their parents choose to continue to reside at Latham Centers.*** Your consideration for the needs of each of these individuals is deeply appreciated.

Most sincerely,



Janice L. Forster, MD



Linda M. Gourash, MD

ATTACHMENTS:

- I. Description and Needs of Persons with PWS
- II. Description of Latham Centers
- III. The PWS Personality
- IV. Global Assessment of Function for PWS
- V. The Consultants

USA
PRADER-WILLI SYNDROME ASSOCIATION
Still hungry for a cure.

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February 14, 2013

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To Whom It May Concern:

We are writing this letter on behalf of several families in Connecticut who presently have children with Prader-Willi syndrome (PWS) residing successfully – and in most cases for several years – at the Latham Center in Massachusetts. It is our understanding that the state of CT is proposing to move these individuals back to a CT placement which we strongly oppose because it would damage the quality of life and sense of community these individuals – along with their care providers at Latham – have worked so hard to create.

Through this letter, we want to help those involved with this decision to understand Prader-Willi syndrome (PWS) and its impact on the very important decision about where a person with PWS should live. In order to maintain health, safety, quality of life, and maximum independence, people with PWS need life long assistance in a supported living placement that adheres to PWS specific residential guidelines. These guidelines include:

- Strict food security
- Individualized Positive behavioral support planning and intervention
- 1:1 support as needed with daily activities and routine
- Predictable and structured schedule
- Appropriate medical management

Most importantly, the need for this level of support will not fade over time. It is required across the lifespan of a person with PWS. If a person with PWS, for example, is doing well in a PWS specific residential placement this is not an indication that they no longer need the support provide – or that it can be easily duplicated elsewhere. Instead, it indicates an appropriate residential placement is working and should continue. It is also an indication that the residential program has taken the time, and made the necessary effort, to create an individualized PWS specific plan that is not easily duplicated elsewhere. Because an appropriate and successful PWS placement is difficult to create, removal from such a setting has detrimental consequences for a person with PWS leading to a steep decline in quality of life and potentially life threatening outcomes.

To further help you understand our perspective on placement issues, we want to give you a very concise overview of PWS. PWS is a very complex disability which affects all aspects of a person's life. Because of a defect on the 15th chromosome, these

still hungry for a cure.

individuals face lifelong challenges. The three most outstanding features of PWS include an uncontrollable appetite, behavior problems and learning challenges. Because of an abnormality in the area of the brain called the hypothalamus, these individuals never receive the message of fullness; they are always hungry. Due to hormone deficiencies, they can also gain weight on half of the calories of other persons their age. Without proper environmental supports and dietary measures, these individuals can literally eat themselves to death. Most have obsessive compulsive tendencies and exhibit challenging behaviors. The combination of an uncontrollable food drive, challenging behaviors along with cognitive limitations creates significant challenges for these individuals. Even if they do not have severe cognitive limitations, their ability to safely control their food seeking behavior and control their behavior necessitates having a guardian in place to provide "legalized advocacy". They are unable to live independently in our communities; they are often unable to secure jobs and remain gainfully employed, and there is a constant battle to remain healthy. **They must have 24 hour a-day supervision, every day, all of their lives and should not be given access to food.**

There are a significant number of people with PWS who exhibit major behavior problems. The same part of the brain that controls appetite/satiety (the hypothalamus) also controls anger. Most persons with PWS become agitated when change is introduced or if they perceive a situation to be "unfair". They easily become anxious with change; if the anxiety is not dealt with they become frustrated; if frustration is not addressed; it quickly escalates to anger and at times – aggression. It is common to hear reports of "tantrums". A tantrum can range from screaming, crying, and yelling ... to property destruction, assault and/or self mutilation.

There is no cure for PWS. It is a life-long, life threatening syndrome. Due to a variety of problems related to the insatiable appetite, it is common to have a person with PWS face enormous challenges in many environments – home, school, work, and community.

Activities of Daily Living: People with PWS are unable to shop for and/or prepare food. They risk over-eating or binge eating which could result in death. Parents and caregivers must use locks and alarms to prevent this from happening. There must be constant vigilance to prevent overeating in all environments. Regardless of IQ, it is common to see the person with PWS steal, yell, scream and hit – in order to get food. At times, those with a high IQ can be cleverer at utilizing measures to get food. Persons with PWS often do not select appropriate clothes for the weather. The hypothalamus controls the bodies' thermostat; a malfunction in this area causes them to feel hot and cold in an abnormal manner. Requesting them to change their clothes often results in varying degrees of behavior outbursts. Most need verbal prompts to complete hygiene including brushing of teeth. Some require 1:1 assistance because of fine motor weaknesses.

Social: Most persons with PWS have few or no friends. Because of the unpredictability of social situations, they easily become frustrated and need to leave a

group activity. Many have extreme behavior outbursts when they lose a game or perceive any situation as being "unfair". Unless ongoing social skills are implemented, many become isolated.

Economic Self Sufficiency: It is a life long challenge for persons with PWS to remain employed. The constant need for supervision; incidents of stealing food and/or money and frequent behavior outbursts cause many to lose their jobs. They do not do well with change. It is common to see behavior escalation when a job task is changed or other employees have different responsibilities. If food is present, they are distracted and focus primarily on how to obtain it – not their work assignment. They often refuse to follow directions or do tasks that they do not want to do. It is also common for these individual's to quit a job because of a conflict at work. Transportation issues are often problematic. Because of the food seeking risk, they are unable to drive or take public transportation independently. Many suffer fatigue and cannot work for long periods of time without rest. Some fall asleep on the job. They have poor money management skills and need assistance to assure that they do not spend their entire paycheck on food or other misleading gimmicks.

Learning: Persons with PWS vary widely in the area of measured IQ. Most are in the borderline range of a cognitive disability. Those with higher IQ's face greater difficulty because they are often more clever and manipulative at getting food. In fact, we have found that the higher functioning they are, the more difficult the problems because they are more aware of, and frustrated with, their differences and they become more skilled at food foraging. If there is food in the environment, they become easily distracted and agitated. Some get in trouble by assaulting staff when they feel threatened (someone either takes or threatens to take their food or some other possession). They have impulse control problems and can escalate quickly. Some have language delays and become frustrated when others do not understand what they are saying.

Self Direction: People with PWS often make bad choices in many areas of their life. In addition to the food seeking, they may put themselves in very risky situations. If food is an enticement, they will go with strangers: shoplift; exit moving vehicles; lie as well as use other unsafe behaviors. Many people with PWS pick at their skin and other openings of their body. Many suffer severe skin damage and infections because of this. They do not feel pain properly so they can be injured or hurt themselves and not know this. Because of hypothalamic malfunctioning, they often do not run a fever if they are very ill. The cognitive rigidity/inflexibility usually causes poor judgment, sequential processing problems, difficulty taking another's point of view and the inability to tolerate uncertainty.

Capacity to Live Independently: To date, there have been no successful situations where a person with PWS has lived successfully in an independent situation. When attempted, persons experienced extraordinary weight gain and health complications. Many have lost their total life savings to people who prey upon their poor deductive and problem solving abilities. People with PWS are living successfully in homes

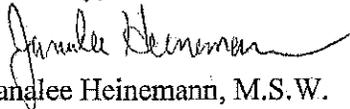
where their nutritional and behavioral needs are being addressed and they are carefully monitored.

The best long-term solution is a **Prader-Willi specific supportive living placement** with an agency/home that specializes in the management of Prader-Willi syndrome. When in a specialized home that is run well, a person with PWS can be protected from the things that will bring their life to an early, tragic end, and find acceptance from people that understand their situation. The least restrictive environment for a person with PWS is one that protects them from those things that can kill them, such as access to food. Unfortunately we continue to see cases where people with PWS rupture their stomachs from over eating or literally eat themselves to death. People with PWS who are placed in a program where others do not require the same limitations are often asked to live without the accommodations they need to support the unique aspects of PWS and they fail, are evicted or suffer serious health problems.

The individuals with PWS who are in long term placement at Latham are living successfully and well. We feel it is in their best interests, and in keeping with the State of Connecticut's commitment to providing for their well being, to continue funding their placement with the Latham Centers in Massachusetts where they have been so successful within their community.

If you have any questions, or need additional information about PWS, please let us know.

Sincerely,



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**Second International PWS Caregivers Conference
Herne, Germany
July 6-8, 2009**

**Workgroup: Environmental Structure for PWS
Living - Best Practice Guidelines**

Chair: Hubert Soyer (Germany)

**Gayle Benet (UK)
Jackie Mallow – (USA)
Renate Scharfenberg – (Germany)
Mary K. Ziccardi – (USA)**

Note: The reader is directed to the proceedings of the Herne I workgroup on **Environmental Structure of Living** for a review of presentations, group discussion, and standards of care. The Best Practice Guidelines derived during the Herne I conference were reviewed and refined during Herne II. The consensus of the two workgroup discussions from Herne II is presented here.

All guidelines should take into account the assessment of the individual to assure health and safety and to promote quality of life.

- 1. The individual's opinion should be taken into account when following these guidelines whenever possible.**
- 2. The preferred form of living arrangement is in a PWS-specific environment.** This allows for consistency in treatment and a sense of fairness to the individual. All attempts to create a family like environment including their own space regardless of group size is important for the person with PWS to have a sense of belonging as well as a place to disengage from group living whenever necessary. In addition it is also vital for the individual to have a choice of vocational opportunities, as enjoyment and fulfillment of one's own day is crucial for anyone to feel productive and an important member of their community.
- 3. Optimal success for the person with PWS will be based on the type of supports that are in place.** Those supports require an understanding of the unique needs associated with PWS. All areas of a person with PWS' day should have proper supervision to assist with those unique needs. There

needs to be a 24 hour type of supervision in place in either the form of direct caregiver support, alarms or security systems that alert caregiver or monitoring agency that the individual has either left the designated area(s) or that they are in need of assistance. A combination of the above may also be used.

4. **At times additional support may be needed due behavioral issues or need for assistance from another caregiver.** Each supportive environment, both home and vocational, should have a system in place that allows for quick response from another caregiver to assist in the need at hand.
5. **Routine and consistency is essential to the successful living for a person with PWS.** Inclusion of their ideas and preferences should be part of the planning of the structure of their regular routine. Meals should be managed and structured in a formal way to ensure that everyone knows the plan of how meals are to be planned, monitored, and served. It is necessary for every person with PWS to have a diet plan that can be followed by all. Exercise should also be a part of their daily routine including some levels of movement or fitness every day with the amount of time to be determined on individual basis. Healthy weight management is also an important part of monitoring the progress of supporting a person with PWS. Weights should be taken at a minimum of once per week based on history.
6. **Structure of the home for a person with PWS should have some form of house rules for living with others.** This allows for everyone to understand and remain consistent with those guidelines, expectations, and boundaries that are needed when in a group living environment. Another area is the complete security of food, money, and medication which should be locked and managed by caregivers.
7. **To assist in overall self esteem it is important for everyone to feel a part of their community.** Inclusion of those activities within the community should be individually assessed to determine environmental supports that may be needed. Understanding the person's own level of independence will assist in maintaining required needs for safety. Living in a community should include good neighbor relationships, it is important to create systems explaining about PWS.
8. **It is essential to have individual behavior management plans ranging from positive motivation to crisis management.** This once again allows for consistency and proper understanding of that specific individual's needs when that person may be in a crisis or to simply avoid or redirect the situation.
9. **Training of caregivers is key to the success of the individual with PWS.** Caregivers need a good understanding of the complexity of the needs of the

syndrome as well as the compassion that is needed when supporting a person with PWS.

10. **Maintaining healthy relationships once the person with PWS is outside their family's home is important for the person with PWS.** Contact and involvement with family and friends may need additional support and guidance from caregivers. That support may consist of teaching relationship building and in some incidences may require additional counseling. Human sexuality may also require support and education.
11. **A clear structure is required to develop and maintain a healthy and stable relationship between the parents, the individual, and the caregiver.** These communications are most effective if they are team-based and have pre-determined professional boundaries established.
12. **Due to the potential for life-threatening situations, it is imperative to create an environmental structure that allows access to comprehensive medical services.**
13. **To support self determination as it relates to environmental structures, choices should be offered to assist the person to individualize their room while promoting personal safety.**
14. **In order to provide effective support services there needs to be an established form of communication and information systems in place for everyone involved in the care and treatment of the individual.**

Conclusions:

Across cultural lines, all participants agreed that in order for an individual with PWS to succeed and live a healthy and productive quality of life that a basic level of support, conducive to promoting safety and personal growth, must be in place prior to providing care. It was determined that **environmental supports were non-negotiable**, including but not limited to;

- food security,
- daily schedules,
- personal growth and development plans,
- trained caregivers, and a
- continuum of care throughout their day.

It was also agreed upon, that it is imperative that as care providers, we continue to explore this cohesive collaboration of efforts through on-going education, training, and awareness.

QED

