

PWCF Receives Guidance from Centers for Medicare & Medicaid Services
by Lisa Graziano, M.A., Chair, Home and Community-Based Services Task Force

There are significant changes in the services that Regional Centers can provide to their “consumers.” These changes are being made in order to comply with the Centers for Medicare and Medicaid Services’ (CMS) new Home and Community-Based Services (HCBS) Rules and Regulations. In short, without compliance, the Regional Centers won’t receive payment, and without guarantee of payment, the Regional Center won’t offer the service.

Earlier this year PWCF’s HCBS Task Force had a lengthy conversation with high-ranking officials* at CMS. We had a list of questions about the new Rules, including the critical provision that explicitly gives all disabled individuals **the right to food at any time**. For anyone diagnosed with PWS, this new “right” is deadly.

PCWF is grateful to CMS for the amount of time and expertise they shared with us. Our Task Force gained significant insight into how to help ensure the health and safety of our loved ones with PWS. Probably the two greatest takeaways the Task Force received from CMS are:

- 1. Obtain Conservatorship** because without it all decisions are driven by your loved one with PWS
and
- 2. Document every symptom, every need, everything in the Person-Centered Plan/Individual Program Plan (PCP/IPP).**

What follows is first a summary of the answers CMS provided to PWCF’s HCBS Task Force in response to our questions. Following this summary are a list of tools the task force created and links to those tools.

If you have any questions or would like help or support, please know that PWCF’s HCBS Task Force is available to speak with you.

Summary of Answers by CMS to PWCF’s HCBS Task Force Questions

- 1. What is the difference between the Federal legislature’s use of “Person-Centered Plan” and California agencies’ usage of “Individual Program Plan”?**

CMS calls the Individual’s “care plan” the Person-Centered Plan (PCP). California’s agencies (e.g., Department of Developmental Services, Regional Centers, and Community Care Licensing) call the “care plan” an Individual Program Plan (IPP).

The intent of CMS’s Person-Centered Plan is to reflect the Individual’s wants, wishes, dreams, desires, goals and needs, and to develop a plan with the PCP team to meet those wants and needs.

CMS’s “PCP” and California’s “IPP” are the same process and document.

For clarification purposes, we use “PCP/IPP” throughout this article.

2. What authority does a Conservator have when there is disagreement between what the conservator believes is in the best interest of the consumer, and what the consumer wants, or what is written in the IPP?

If the Individual has a Conservator, and the Conservator has the legal right to speak on behalf of the Individual, and the Conservator is present at the Regional Center meeting, then the Conservator has final decision-making rights.

A Conservator must have been granted one or more of the following powers:

1. To have access to the confidential records and papers of the conservatee.
2. The right to control the conservatee's right to contract.
3. To give or withhold consent to medical treatment for the conservatee.
4. To fix the residence or specific dwelling of the conservatee.
5. The power to control social and sexual contacts of the conservatee.
6. To make decisions concerning the education/training of the conservatee.
7. The power to withhold or give consent to the marriage of the conservatee.

If the Individual has no Conservator or if the Conservator chooses not to participate in the Regional Center meeting, then the wants, wishes, desires, dreams and goals of the Individual will be given priority, potentially even over health and safety considerations.

In regard to PWS's hallmark hyperphagia symptom (defined as a life-threatening biochemical drive to eat that is not satiated no matter how much food is consumed), there is no "blanket" determination regarding an Individual's access to food. Just because someone has a diagnosis of Prader-Willi syndrome does not mean the Individual's PCP/IPP will automatically authorize restricted diet/access to food to avoid obesity or death. Similarly, just because someone has a diagnosis of diabetes, their PCP/IPP will not automatically authorize controlling blood sugar through restricted diet or use of medications to avoid obesity or death. The management of each symptom caused by any medical or genetic disorder must be addressed and documented on an individual, case-by-case basis.

It should be documented in the PCP/IPP that "*Because Name of Individual has a medical disorder that causes the symptom hyperphagia (insatiable appetite), Name of Individual shall not be given unauthorized access to food at any time, despite any and all expressed desires in the moment. The name of this medical disorder is Prader-Willi syndrome; more information may be found at PWCF.org and pwsausa.org.*"

If the Individual's wants, wishes, dreams, desires and goals are in conflict with the Individual's health and safety, the PCP/IPP should document this conflict and specify how to get as close as safely possible to meeting the Individual's wishes and goals without endangering their health and safety.

3. Which takes precedence: Conservator or Person-Centered IPP?

If the Individual has a Conservator, and the Conservator has the legal right to speak on behalf of the Individual, and the Conservator is present at the PCP/IPP meeting, then the Conservator shall have decision-making rights. The wishes and goals of the Individual should always be given the utmost consideration.

There must be appropriate documentation in the PCP/IPP to justify any attempt to reduce an Individual's right to direct their life. Appropriate documentation includes a clear description of the life-long genetic condition, a clear description of the symptoms, assessed needs and the fact that symptoms will not diminish so that restrictions should not be faded, and a description of things previously tried and which were and were not successful. A Physician's Note would serve as appropriate documentation.

It would be extremely helpful to include in the PCP/IPP an agreement signed by the Individual something to the effect that they "do not waive their agreement even if they're dealing with their symptom and that this can only be changed at the PCP/IPP meeting.

4. What authority does a care provider have when the *unconserved* consumer with PWS wants something the care provider believes or *knows* is not in the best interest of or is dangerous to the unconserved consumer with PWS? In other words, which takes precedence: Unconserved Consumer or PCP/ IPP?

If the Individual has no Conservator, the Individual's wants, wishes, desires, dreams and goals will be given priority and precedence, potentially even over health and safety considerations.

The PCP/IPP team members including care providers and the state's representative will collaborate with the individual to create a plan that takes their health and safety into consideration if the individual is not able to advocate for this themselves.

If there is no Conservator, someone such as a physician would need to apply for a "waiver" in this area. This is a State matter. PWCF needs more guidance in this matter as there are *many* people with PWS in California who are unconserved.

5. What is the mechanism for documenting the need for securing food in the day program and work site? Who advocates for and ensures this security?

Documentation for managing the Individual's "care plan" is created during the PCP/IPP meeting.

6. What specific information needs to be included in which specific documents to ensure that food is locked at all times and there is restricted access to unauthorized food in residential facilities serving someone with PWS, whether in a group home or supported living site?

Again there must be appropriate documentation in the PCP/IPP to justify any attempt to reduce an Individual's "right" to direct their life. Appropriate documentation includes the description of the life-long genetic condition and symptoms, description of the assessed need, and a description of things tried previously but not successfully. These descriptions should state that the hyperphagia symptom will not diminish and so the restrictions should not be faded. A Physician's Note would serve as appropriate documentation.

It would be helpful to include in the PCP/IPP an agreement signed by the Individual something to the effect that they "do not waive their agreement even if they're dealing with their symptom and that this can only be changed at the PCP/IPP meeting."

7. What specific information needs to be included in which specific documents to ensure the health and safety of the individual when it conflicts with their right to freely come and go? E.g., When the individual with PWS wishes to leave the home at 2:00 a.m. to search for food, what options are available to providers to restrict the resident's leaving the home, and how are these options to be documented?

Once again, there must be appropriate documentation in the PCP/IPP to justify any attempt to reduce an Individual's "right" to direct their life including a detailed description of the individual's PWS symptoms and assessed needs, and a description of things previously but not successfully tried. It is critical to document that this symptom will not diminish and so the restrictions should not be faded. A Physician's Note would serve as appropriate documentation.

A residential setting can absolutely lock exits and/or install delayed egress as long as the PCP/IPP contains appropriate documentation to justify the need for each progressively restrictive intervention.

One example given by CMS, not necessarily directed at adults with PWS, is restricting access to knives in the knife drawer: "*Name of Individual* shall not have access to the key that opens the knife drawer without staff authorization."

In regard to PWS specifically, documentation in the PCP/IPP could include "*Name of Individual* has a prior history of the symptom to wander or leave the home without authorization. They may not have access to the key/code that opens the door."

It would be helpful to include in the PCP/IPP an agreement signed by the Individual something to the effect that they "agree to abide by the House Rule not to leave the home without authorization from the House Staff and they

do not waive the agreement even if they're dealing with their symptom, and that this can only be changed in the PCP/IPP.”

8. **How can a consumer protect his/her right to choose to live and/or work in a “planned community” of persons with developmental disabilities? E.g., congregate housing; congregate employment or day program, or multiple persons with the same disability living together in the same home.**

A “planned community” may be permitted if it is appropriately documented that the residential setting integrates all Individuals into the general community and does not isolate or restrict their access to the greater community.

New Tools Developed by PWCF’s HCBS Task Force

For Families & Professionals

These tools can be accessed on PWCF’s website at <https://pwcf.org/for-parents/adult-years/> and <https://pwcf.org/for-professionals/>

- **Person-Centered Plan/Individual Program Plan Cheat Sheet** To help guide families about what should be included and what could be included in the Annual IPP.
- **Physician’s Note Symptom & Treatment Checklist** To serve as documentation for the PCP/IPP, a copy of which would then be shared with all residential professionals and staff as well as day program staff, vocational and volunteer staff.

The Physician’s Note is also an excellent resource to serve as documentation for school Individual Educational Plans (IEPs).

- **Agreement with Individual Regarding Access to Food** To be completed using a collaborative-solving approach with the individual with PWS.
- **Agreement with Individual Regarding Elopement and Locks** To be completed using a Collaborative-Solving approach with the individual with PWS.

For Residential and Other Professionals Serving Adults with PWS

All of the above tools in addition to these below can be accessed on PWCF’s website at <https://pwcf.org/for-professionals/>

- **Brief PWS Overview Training Video**
- **Template Letter for Adult Residential Facility Operators to Request a Community Care Licensing to Authorize a Locking Waiver**

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**CMS participants on the April 23, 2018 conference call were Ralph Lollar (CMS Director of Long Term Services and Supports), George Faila (CMS Deputy Director of Long Term Services and Supports), and Michelle MacKenzie (CMS Technical Division). HCBS Task Force participants on the call were Lisa Graziano, Austin de Lone, and Emily Dame.*

