

A Full Life Without Limits

November 2018

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Prader-Willi California
Foundation is a proud
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Our Mission

Individuals with PWS should have the opportunity to pursue their hopes and dreams to the full extent of their talents and capabilities. The success of people with PWS depends greatly upon the knowledge and support of the community around them. PWCF provides individuals with PWS, their families, and professionals with a state network of information, advocacy and support services.

Dear Adult Residential Facility Owner and Operator:

Information with this letter is intended to help you obtain authorization from Community Care Licensing (Licensing), California's Department of Developmental Services, and your Regional Center for the waivers you need to **ensure the health and welfare of your residents diagnosed with Prader-Willi syndrome (PWS).**

The new Centers for Medicare/Medicaid's Home and Community-Based Services Rules and Regulations include a provision that "individuals have freedom and support to control their schedules and activities and have access to food any time." As you know, **this provision is life-threatening to persons diagnosed with PWS** because *all persons with PWS have some degree of the PWS hyperphagia symptom that drives their brain to find food and eat but does not feel full no matter how much food is eaten.*

There is *no medication or any behavior modification program* that eliminates or even reduces the biochemical PWS drive to eat. Therefore, **all persons diagnosed with PWS must have a food-secure environment defined as locked refrigerators and food pantries** to address one of their most basic health and welfare and safety needs. Even just one overeating episode can lead to death from choking, stomach or bowel rupture, or stomach or bowel necrosis.

PWCF's HCBS Task Force has been working closely with the Centers for Medicare/Medicaid, Community Care Licensing, the Department of Developmental Services, and various PWS specialists **to develop new tools to help you comply with the new Rules while ensuring the health and safety of your residents with PWS.** These tools will help you receive and maintain your Waiver to keep your food and beverages locked at all times in order to prevent unauthorized access by your residents with PWS. These tools are posted on PWCF's website and include:

- **Request to CCL for Locking Waiver template** This template is designed to be personalized by you on your letterhead to help you receive a waiver to lock your food and beverages.
- **Physician's Note Symptom & Treatment Checklist** This document is designed to meet CMA's requirement that a locking waiver may be granted if it is supported by a specific need, if it is justified in the Person-Centered Plan, and if there is documentation for the need in the Person-Centered Plan.

The Physician's Note is to be completed by each of your resident's physician and included in each resident's Person-Centered Plan as part of their Regional Center Individual Program Plan (IPP). The Physician's Note should be shared with every service provider of each resident including the day program, vocational work site provider, recreational program provider, volunteer site administrator.

- **Individual Agreement Regarding Food and Locks** Another new tool developed to help you meet health and safety documentation requirements. This new tool is an "agreement" with the individual with PWS that he or she may not have access to unauthorized food, even and especially when expressing emotional upset, and is to be incorporated into the PCP/IPP and distributed to all professional providers. This Agreement document is recommended because new Federal and State regulations lean heavily toward meeting the expressed wants and wishes of the disabled

individual who, in the case of PWS will likely at some point request food outside their snack and meal schedule. This Agreement is not a legally binding contract but does serve as additional documentation to help all professional providers *not* give food if/when it is requested or demanded.

- **Individual Agreement Regarding Elopement and Locks** If your resident has a history of eloping or running away, this new Agreement can help ensure their health and safety. Like the Agreement Regarding Food, this new tool serves as documentation that your resident authorizes the doors and windows are locked to prevent them from eloping. The Agreement Regarding Elopement and Locks should be incorporated into the PCP/IPP and distributed to all professional providers.
- **Brief PWS Overview Training Video** Developed specifically for and shared in 2018 with Community Care Licensing, you can share this video with your CCL contact or with whomever you believe it would be helpful.
- **PCP/IPP Cheat Sheet** Now more than ever before, creating a detailed and appropriate Individual Program Plan is critically important. Every service and aspect of care your resident receives from any entity that is funded in any way by the Regional Center system and/or Medicare and/or Medi-Cal must comply with the new HCBS Rules and Regulations. Every aspect and detail of the delivery of that service must be clearly written in the PCP/IPP. If it's not included or described in the IPP, service providers can't/won't do it. PWCF has created a new template PCP/IPP Cheat Sheet to help you know what to should or could be addressed in your resident's PCP/IPP.

Please know that PWCF is here to assist and support you and your staff as you provide a safe and caring home for your residents. Contact the PWCF Office with any questions, to schedule a PWS Residential Staff Training, or to speak with any member of PWCF's HCBS Task Force. On behalf of PWCF's Officers, Board of Directors, and the families of the residents you support, we thank you for your care and dedication.

With warmest regards,

Emily Dame, M.Ed.
Executive Director

HCBS Task Force
Lisa Graziano, M.A., Chair, Emily Dame, Austin de Lone,
Lesley de Lone, Diane Kavrell, Tom McRae
Former Members: Paula Watney, Christopher Patay, Esq.

Attachments:

HCBS PowerPoint Presentation
HCBS Questions with Answers from Centers for Medicare and Medicaid Services
Brief PWS Overview Training Video for Community Care Licensing
Request to CCL for Locking Waiver template
List of CCL Offices
Physician's Note Symptom & Treatment Checklist
Individual Agreement Regarding Food and Locks
Individual Agreement Regarding Elopement and Locks
PCP/IPP Cheat Sheet
HCBS Final Rule Fact Sheet

Additional Resources

[22 CCR § 80024 Waivers and Exceptions, Paragraph B.1](#) specifies that “such alternatives shall be carried out with provisions for safe and adequate services, and shall in no instance be detrimental to the health and safety of any facility client.”

[Manual of Policies and Procedures, Community Care Licensing Division, Adult Residential Facilities, Title 22, Division 6, Chapter 6](#) | <https://www.cdss.ca.gov/ord/entres/getinfo/pdf/arfman.pdf>

[California’s HCBS Waiver Primer & Policy Manual](#) | <http://www.dds.ca.gov/Waiver/docs/WaiverManual2008.pdf>

[Final Rule Medicaid HCBS](#) | <https://www.medicaid.gov/medicaid/hcbs/downloads/final-rule-slides-01292014.pdf>

In addition to the mandatory requirements for the qualities of home and community-based settings, and in compliance with the Americans with Disabilities Act, **the following additional conditions must also be met:**

- Each individual has privacy in their sleeping or living unit.
 - Units have entrance doors lockable by the individual, with only appropriate staff having keys to doors.
 - Individuals sharing units have a choice of roommates in that setting.
 - Individuals have the freedom to furnish and decorate their sleeping or living units within the lease or other agreement.
- Individuals have the freedom and support to control their own schedules and activities, and have access to food at any time.
- Individuals are able to have visitors of their choosing at any time.
- The setting is physically accessible to the individual.
- The unit or dwelling may be shared by no more than four waiver participants.

Any modification of the above may be granted if the modification is:

- Identified as a specific and individualized assessed need [and is documented in the Individual Program Plan (IPP)].
- Justified *and* documented in the Person-Centered Plan [and included with the IPP]

Documentation in the Person-Centered Plan of modifications of the additional requirements must:

- Document the positive interventions and supports used prior to any modifications to the IPP.
- Document less intrusive methods of meeting the need that have been tried but did not work.
- Include a clear description of the condition that is directly proportionate to the specific assessed need.
- Include regular collection and review of data to measure the ongoing effectiveness of the modification.
- Include established time limits for periodic reviews to determine if the modification is still necessary or can be terminated.
- Include the informed consent of the individual.
- Include an assurance that interventions and supports will cause no harm to the individual.

[Guidelines to PWCF’s HCBS Task Force from California’s Community Care Licensing to Help Adult Residential Facility Owners and Operators Request a Waiver](#) January 2018

When evaluating a request from a licensee for a waiver, the Licensing Program Analysts (LPA) will “ensure that the requested alternative provides equal or better protection for the client’s health and safety, considers the impact of the request on other regulations, and determines if any additional requirements are necessary to ensure compliance with the intent of the regulation.”

You are responsible for providing adequate information to justify the request for the waiver to your LPA (see [subsection 2-5000 through 2-5700 of the Reference Material and Comprehensive Evaluation Tools section of the Community Care Licensing Division \(CCLD\) Evaluator Manual](#)). It is recommended that the request submitted by the licensee include the following:

- Citation(s) of the regulation(s) in question;
- The rationale for the request;
- Sufficient supporting documentation to substantiate the rationale;
- An alternate method or plan by which the purpose of the specified regulation(s) will be carried out;
- Written placement agency input (e.g. copy of the individual services plan or other appropriate placement monitoring documents). For clients with no identified placement agency, the licensee should obtain written concurrence with the request from the guardian, authorized representative, or appropriate medical or professional personnel as warranted by the individual case.

For a waiver request to lock kitchen cabinets and prevent access to food, CCLD recommends addressing these additional questions in the request:

- How will the licensee ensure that other clients will not be adversely affected by granting of the waiver (i.e. provide adequate food to clients with PWS and other clients)?
- Is there sufficient documentation (e.g. a doctor’s or behavioral specialist’s recommendation, approval from the client’s placement agency, an Individual Program Plan or behavioral plan) that support this alternate method of care?

Abiding by these recommendations does not guarantee that a waiver will be approved because CCL evaluates each case on a case-by-case basis. CCL advises and reminds you to work closely with your LPA on these types of requests, as the LPA may request other specified information.

Thank you,

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