

**NEW FEDERAL RULES
IMPACT YOUR FUTURE:**

**NEW TOOLS TO KEEP
YOUR LOVED ONE SAFE**

Presented by PWCF's Home & Community-Based Services Task Force

Imagine...



- Imagine a world where it's the law of the land that people with disabilities work in their community side by side with people without disabilities and that they are paid the same wage.
- Imagine a world where people with disabilities live in their own home and have the freedom to control their own schedules and activities.
- Imagine a world where the wishes, dreams and goals of every disabled individual are respected above all else.

CMS HCBS Rules & Regulations

- This is the world imagined by the Centers for Medicare & Medicaid Services, the federal agency that funds programs and services for persons with physical and developmental disabilities, and mental illness in the U.S.
- The goal of CMA's new HCBS Rules & Regulations is to “deinstitutionalize” people with disabilities, ensure they are independent and integrated in their community -- living in dignity in their own home, recreating in their own neighborhood, and working for an employer who doesn't *just* hire disabled people.



Utopia





But what happens when there are
UNINTENDED CONSEQUENCES
that decrease quality of life and
jeopardize the health and safety of
our loved one with PWS?

Unintended Consequences



No Physical Activity

Food Death

No Income

NO JOB

No Day Program

No Recreation

Boredom

INCREASED UNWANTED BEHAVIORS

No Transportation

NOWHERE SAFE TO LIVE

This Presentation:

These **Unintended Consequences** are the focus of PWCF's HCBS Task Force

- Provide a brief introduction of the new HCBS Rules & Regulations that impact persons with PWS
- Introduce new tools to eliminate or mitigate these unintended consequences to keep your adult safe today and your child safe tomorrow.
- The Breakout Session will provide greater detail answer questions in depth.

PWCF HCBS Task Force

- Task Force members work with Centers for Medicare & Medicaid Services, Department of Developmental Services, Community Care Licensing, PWS specialists
- Task Force members meet monthly to develop new tools to help families and professionals
- Task Force members:
 - Lisa Graziano, M.A. (Chair) | Emily Dame, M.Ed.
 - Diane Kavrell | Tom McRae | Austin & Lesley de Lone
 - Former members: Paula Watney | Chris Patay, Esq.

What Are HCBS Rules & Regulations?

HCBS Rules regulate what services will be provided and how they will be provided

- The intent of the new HCBS Rules is to “deinstitutionalize” people, “integrate them in the community to the same degree as nondisabled individuals.” Group homes cannot house “too many” disabled people. Employers may not employ “too many” disabled people.
- HCBS Rules “optimize, but **do not control, individual initiative, autonomy, and independence in making life choices**, including but not limited to daily activities, physical environment, and with whom to interact.”
- **“Individuals** have the freedom and support to control their own schedules and activities, and **have access to food at any time.”**

Who Do HCBS Rules Apply To?

- Everyone in the United States who is funded directly or indirectly by CMS through the Regional Center, Medicare, Medi-Cal, and every other agency funded by CMS
- Residential settings including group homes, supported living service providers
- Day programs, recreational programs, and all other day-type services
- Employment sites, sheltered workshops, volunteer sites

Why Should We Care About the New Rules?

- If a service is in any way paid for with federal dollars it *must* comply with the new HCBS Rules & Regulations.
- If a service does *not* comply with the new HCBS Rules and Regulations there must be written documentation confirming the exemption waiver.
- If there is no exemption waiver, the provider *legally must* adhere to HCBS Rules.

What Does This Mean?

Unintended Consequences:

Fewer PWS-specific residential options

Elimination/reduction of workshops and other employment sites

Loss of *any* wage

Elimination/reduction of day programs

Lack of transportation

Lack of daytime activity, boredom, unwanted behaviors

The Most Serious Unintended Consequences:

Unrestricted access to food

Morbid obesity

Death

How Can We Protect Our Loved One Against Unintended Consequences?

- It all starts with the Individual Program Plan, the “contract” between the disabled individual and the State.
- Services are only provided if they are written in the IPP
- If it’s not in the IPP, it didn’t happen.
- If it’s not in the IPP it *can’t* happen.
- **Document and detail all health and safety needs in the IPP**

Person-Centered Planning & the IPP

- All IPPs must be written using a Person-Centered Planning approach
- Intent of Person-Centered Planning is to ensure that the individual's hopes, dreams, wishes, and goals are respected and that everything is done to help the individual achieve their goals.

New Tool: Person-Centered IPP Cheat Sheet



Person-Centered - Individual Program Plan Cheat Sheet

This document will help guide you in the creation of your loved one's IPP, showing you what information you should or may wish to include in this critical document.

For more information or for assistance contact us
www.PWCF.org | info@pwcf.org | 800-400-9394 In CA

SERVICE PLAN FOR:
DOB:
MEETING DATE:

ABOUT CLIENT:

There should be a section that describes the many positive qualities and characteristics of your loved one.

There should be a section that describes the activities that your loved one enjoys, including with whom he or she enjoys doing them.

CIRCLE OF SUPPORT:

There should be a section that describes the individuals who are a support system to your loved one.

HOPES AND DREAMS FOR THE FUTURE:

This section is the "heart and soul" of a Person-Centered Plan. This section should describe your loved one's wants, wishes and dreams for today and into the future. This section's intent is not limit or edit your loved one's stated wishes but to simply reflect them.

You may wish to include language that reflects, "While Name prepares for his goals, he will continue to reside in his current home to utilize the benefits of this structured, safe environment."

LONG RANGE GOALS:

This section should include obtainable long range goals. For persons with PWS, obtainable goals do not include independent living, unsupervised access to food or learning to control food intake.

- 1.
- 2.
- 3.
- 4.

PERSONS WHO HELPED WITH THE PLAN:

This section should list everyone who participated in writing the Person-Centered Individual Program Plan.

LIVING OPTION:

This section should describe the residential options for your loved one and/or the current residential option. It should include: "To continue to reside in a safe, comfortable home that

's PCP-IPP Cheat Sheet

Client's residential care (if living outside the family home).
The Prader-Willi California Foundation as needed/requested by
Staff will maintain the home's schedule, consistency and fairness,
de-stressing techniques that work for Client.
Expense from the RSP to budget for and make small purchases with P&I
two family vacations per year if determined to be necessary. This
implemented accordingly.

should include:

Client uses the symptoms hyperphagia and insatiable appetite. Client
at any time, despite any and all expressed desires in the
Prader-Willi syndrome; more information may be found at

ide:

but needs assistance with completing them. H/she is capable of
is not able to pick out appropriate clothing and dress self.
needs encouragement to eat within a reasonable time frame.
ease independence in as many areas of self-care as possible.

ability for taking care of his own hygiene, laundry, and personal
of Name's self-care needs will be completed daily.
monitor Name's progress quarterly and as needed.

Cheat Sheet

include:

including: "Temper tantrums, Emotional outbursts,
Fabrications/lying, Non-Compliance, Being rude to
or summarize any behavioral incidents since last IPP

Client has symptoms hyperphagia and insatiable appetite. Client should
state any and all expressed desires in the moment. See
include a statement in the PCP-IPP that stipulates,
drawer without staff authorization. Include a signed

essential setting can lock exits and/or install delayed
mentation to justify the need for each progressive
in the PCP-IPP that states, "Client has a prior
but authorization. He/she may not have access
individual with PWS - Elopement." Include a signed

adaptive behaviors with more appropriate wa

needed
address each behavior
sent/incentive program
environment that fosters trust and heal
reports.

IPP Suggestion

- To ensure a productive, detailed, accurate PCP-IPP, have the individual with PWS participate only in the beginning of the meeting. Discuss only the wonderful things the individual is doing. Gather their hopes, wishes, dreams and goals.
- Then excuse the individual from the remainder of the meeting and continue the PCP-IPP process.

CMS Answers: Food Security at Group Home/Supported Living Site

What specific information needs to be included in which specific document(s) to ensure that food is locked at all times and there is restricted access to unauthorized food in residential facilities serving someone with PWS?

- **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.**
- **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 condition or symptom(s), a clear description of the assessed need, and a description of things tried previously but not successful. The management of each symptom caused by PWS must be addressed and documented on an individual, case-by-case basis. **A Physician's Note would serve as appropriate documentation.**

New Tool: Physician's Note—Symptom & Treatment Checklist

Physician's Note - Symptom & Treatment Checklist

_____ DoB _____ has a diagnosis of Prader-Willi syndrome, type _____
 ICD 10: F07.0 Personality change secondary to a medical condition - PWS) and requires individualized supports and services that are unique to this diagnosis.

Prader-Willi syndrome (PWS) is a rare, complex, life-threatening medical disorder. Symptoms are believed to be caused in part by a defect in the brain's hypothalamus, an important supervisory center that controls the release of hormones that regulate growth, muscle strength, body temperature, sexual development, appetite, metabolism, the regulation of the sleep-wake cycle, the expression of emotions, and many more functions of the body.

The following supports and services are necessary for the health and safety of the individual you are serving:

Symptom Name	Symptom Description	Intervention/Medication/Support	Additional/Specific Instructions
Hyperphagia	<p>PWS hyperphagia is a life-threatening, uncontrollable genetic drive to eat that is not satiated regardless of the quantity of food consumed.</p> <p>PWS hyperphagia includes preoccupation with food; food seeking; foraging; manipulation; sneaking; hiding; and hoarding food; and eating unusual food-related items (e.g. sticks of butter, pet food, mouthwash, rotten food taken from trash).</p> <p>PWS hyperphagia causes food-related anxiety that frequently results in dangerous behaviors (e.g. verbal aggression; physical aggression; elopement; burglary; theft; self-injury; lack of regard for personal safety).</p> <p>There is no learning to control PWS hyperphagia. Treatment consists of restricted access to food and continuous supervision. No currently known medication reduces or eliminates this life-threatening symptom. PWS hyperphagia has caused fatality from a single food hoarding incident.</p>	<p>Frequently, very low calorie diets are needed to achieve or maintain a healthy weight (e.g., 800 – 1000 kcal/day if the patient is not treated with growth hormone). Adjust diet to patient requirements, following weight closely. Patient should be provided with a food secure environment that includes:</p> <ul style="list-style-type: none"> • Food should be locked at all times. • Menus for breakfast, lunch, dinner, and snack should be posted (patient should be aware in advance of what meals/snacks will consist of). • Meal/snacks should be consistently offered at the same time throughout the day, every day. • Adult supervision should be provided during all snack and meal times. • Registered dietician trained in PWS should provide specific outline/amounts/ types of food offered for meal plan. 	<ul style="list-style-type: none"> • Patient should receive a maximum of _____ calories per day consisting of _____% Protein _____% Carb
Anesthesia & Medication	<p>Individuals with PWS can safely undergo anesthesia. Risks are related to their general health before and after the procedure. Priority of</p>	<p>Only a physician familiar with the patient and their individual medical needs should make medical decisions. Patients undergoing general anesthesia should be monitored by a</p>	

Intervention/Medication/Support	Additional/Specific Instructions
<p>Essential (when attempts to implement Management of chronicotropic should be prescribed to the patient).</p> <p>Sleep Study: (CPAP) or airway pressure.</p> <p>Sleep Study: (CPAP) or airway pressure.</p> <p>Consider to return to clinic if symptoms may be helpful.</p> <p>Intensive behavior therapy (available: applied behavior analysis and language skills therapy and sensory integration) may be helpful for PWS-specific treatment. A treatment plan for persons with PWS should be developed for persons with PWS. A treatment plan for persons with PWS should be developed for persons with PWS.</p> <p>Supplements (vitamin D and calcium supplements), hormonal replacements (testosterone), and</p>	

Intervention/Medication/Support	Additional/Specific Instructions
<p>Early intervention therapies including physical therapy, infant stimulation therapy, and growth hormone therapy may be initiated < age 2 years may improve cognitive functioning. Assessment of adequacy of vitamin and mineral intake by a dietitian, and prescription of appropriate supplementation, is indicated. Supplements that may provide cognitive benefit but for which there are no controlled studies include Coenzyme Q-10, fish oil, certain B vitamins, and acetyl-L-carnitine.</p> <p>Traditional psychotherapies, such as Cognitive Behavior Therapy, may not be helpful due to lack of insight necessary for progress, and symptoms of contamination (story-telling). Psychotropic medications may be necessary to decrease symptoms.</p> <p>Early intervention therapies including physical therapy, infant stimulation therapy, oral motor therapy, and speech and language therapy.</p> <p>Treat as in the general population. Diet compliance is a significant concern. Weight loss is important, and the diabetes may resolve with significant weight loss in these patients. Monitor blood sugar levels and keep them at goal set by physician, and combination of diet, exercise and medication.</p> <p>Treat underlying cause. Medication is often necessary.</p> <p>Continuous monitoring. Alarms on all exits including windows and doors for people with a prior history of elopement.</p> <p>Treatment includes medications to control seizures. For some, the ketogenic diet can help, however this diet requires medical supervision.</p> <p>Chronic condition. Serve smaller sized meals, provide cooked rather than raw vegetables, avoid</p>	

CMS Answers: Food Security at Group Home/Supported Living Site

- It would be helpful to include in the PCP/IPP an **agreement signed by the Individual** regarding limited access to food 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.”

New Tool: Agreement Regarding Food

Agreement Regarding Food and Locks

To the best of my ability I understand that I have a medical disorder. The name of this medical disorder is Prader-Willi syndrome.

To the best of my ability I understand that two of the symptoms of this medical disorder are an insatiable appetite (hyperphagia) and the inability to feel full or recognize feeling full.

To the best of my ability I understand that for my own health and safety, my food must be managed properly.

authorized meals and snacks.

New Tool: ARF Locking Waiver Request



Prader-Willi California Foundation
Supporting People with Prader-Willi Syndrome

pwcf.org

Written Request for Waiver or Exemption

This template is designed for residential providers' use to request that Community Care Licensing (CCL) issue a waiver to authorize restricting access to food with locks. Copy this template on to your stationary, enter the applicable CCL Regional Office address, and edit as needed. If you need assistance contact Evelyn Schaeffer, CCL Assistant Program Administrator, at (916) 653-9272.

Date

Name of Community Care Licensing Regional Office

Address
City, State Zip

RE: Request for Waiver or Exemption for Consumers' Health and Safety Needs for facility to serve persons with Prader-Willi syndrome
ICD-9: 759.81 Prader-Willi syndrome
ICD-10: F07.0 Personality change secondary to a medical condition - PWS

Dear xx:

My name is xx and I am the owner and operator of xx, an **Adult Residential Facility / Supported Living Agency**. I write to request a Waiver to securely lock at all times my home's refrigerator, cupboards, and anything that contains food and beverages. I request this waiver to ensure the health and safety of my home's residents, all of whom have Prader-Willi syndrome (PWS) as confirmed by a physician's report.

Ordinarily we do not restrict our residents' access to food. However, we are serving residents who have a diagnosis of PWS and therefore require that their access to food (and money which could be used to purchase food) be restricted with locks.

PWS is a life-long and life-threatening medical disorder which causes substantial deficits and functional limitations in all major areas of life including:

- (1) Self-care
- (2) Receptive and expressive language
- (3) Learning
- (4) Mobility
- (5) Self-direction
- (6) Capacity for independent living
- (7) Economic self-sufficiency

There are significant medical symptoms of PWS which necessitate a Waiver authorizing us to lock our food sources which include but are not limited to:

Hyperphagia : A hallmark symptom of PWS is the physiological, unrelenting biochemical drive to eat coupled with a lack of feeling satiated, or full, or even discomfort despite the quantity of food consumed. Medication controls or even reduces the PWS hyperphagia food drive symptom, which should be. My residents with



CDSS
WILL LIGHTBOURNE
DIRECTOR

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Counties: Colusa, Del Norte, Glenn, Lake, Lassen, Marin, Mendocino, Plumas, Shasta, Sierra, Siskiyou, Yuba

Prader-Willi Syndrome: A Brief Overview Created for Community Care Licensing

Prader-Willi California Foundation
An Affiliate of Prader-Willi Syndrome Association (USA)

514 N. Prospect Avenue, Suite 110-LL, Redondo Beach, CA 90277
Phone: 310-372-5053 | Toll-free in CA 800-400-9994
info@pwcf.org | PWCF.org | facebook.com/pwcf1



[Click Here to Access YouTube Video Presentation](#)

CMS Answers: Food Safety at Work Site or Day Program

What is the mechanism for documenting the need for securing food in the day program and work site?

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

CMS Answers: Elopement

What specific information needs to be included in which specific document(s) to ensure the health and safety of the individual when it conflicts with their right to freely come and go?

- 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 condition or symptom(s), a clear description of the assessed need, a description of things tried previously but not successful and these descriptions should state that the person is born with this disability and the symptoms are lifelong and will not diminish 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 "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 at the PCP/IPP."

New Tool: Agreement Regarding Elopement and Locks

Agreement Regarding Elopement and Locks

To the best of my ability I understand that I have a medical disorder. The name of this medical disorder is Prader-Willi syndrome.

To the best of my ability I understand that one of the symptoms of this medical disorder is elopement or running away. Sometimes I elope in search of food and sometimes I elope for other reasons.

I cannot control this symptom. I cannot stop myself from trying to elope or run away.

I understand this symptom can be very dangerous to me and threatens

CMS Answers: How to Manage Conflict Between Wishes of Individual and Conservator

What authority does a Conservator have when there is disagreement between what the conservator believes is in the best interest of the Individual, and what the Individual 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.
- 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 possible to meeting the Individual's wishes and goals without endangering their health and safety.

CMS Answers: What if the Individual Has No Conservator?

What if the individual has no conservator?

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

Conservatorship is Critical

- Legal ability to protect your adult child's health and welfare.
- 7 Potential Powers of a Conservator:
 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.

New Tools for Families

1. All new tools are posted on the website
2. Letter will be mailed or emailed to every active PWCF member outlining critical information and how to access tools
3. HCBS Questions with CMS Answers
4. Person-Centered Planning Individual Program Plan Cheat Sheet
5. Physician's Note Symptom & Treatment Checklist
6. PWS Overview Educational Training Video
7. Agreement for Individual with PWS re: Food
8. Agreement for Individual with PWS re: Elopement

New Tools for Professionals

1. All new tools are posted on the website
2. Letter will be mailed or emailed to every active PWCF Professional member outlining critical information and how to access tools
3. Request for Waiver Letter from ARF to Community Care Licensing Template
4. List of Local CCL Offices
5. PWS Overview Educational Training Video
6. HCBS Questions with CMS Answers
7. Physician's Note Symptom & Treatment Checklist
8. Agreement for Individual with PWS re: Food
9. Agreement for Individual with PWS re: Elopement

4 Things You Need To Do Now

- 1. Incorporate the words “health and safety” into your vocabulary**
- 2. Obtain conservatorship** so that you have the legal ability to protect your adult child’s health and safety.
- 3. Provide the Physician’s Note Symptom Checklist to your child or adult’s “main” physician.**
- 4. Create a detailed, PWS-Specific PCP-IPP with your Regional Center that documents your loved one’s health and safety needs:**
 - Restricted access to food (and money to purchase food) in all settings
 - Supervision in all settings
 - Physician’s Note
 - Individual Agreements
 - Structure and routine to reduce anxiety, reduce unwanted behaviors.

More Information

Read the HCBS Rules & Regulations Final Ruling

<https://www.medicaid.gov/medicaid/hcbs/>

Contact a member of PWCF's HCBS Task Force

310-372-5053 | 800-400-9994 | info@pwcf.org

Keep Informed! Stay Connected with PWCF!