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 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.
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
- No Recreation
- NO JOB
- No Transportation

Food Death
- No Income
- No Day Program
- Boredom

Increased Unwanted Behaviors

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.
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
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, ensuring you have all the information you need or may wish to include in this critical document.

For more information or assistance, contact us:
www.PWCF.org | info@pwcf.org | 800-496-5934 in CA

SERVICE PLAN FOR:
[Name]

MEETING DATE:
[Date]

ABOUT CLIENT:
[Description of client]

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

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

CIRCLE OF SUPPORT:
[Description of support network]

HOPES AND DREAMS FOR THE FUTURE:
[Description of goals and aspirations]

LONG RANGE GOALS:
[Goals and objectives]

PERSONS WHO HELPED WITH THE PLAN:
[Names of individuals who contributed to the plan]

LIVING OPTION:
[Description of living options]

[Additional sections and details as necessary]
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.
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

### PWS Hypothalamic Hypogonadism
- **Symptoms:** Reduced sexual drive, reduced fertility, reduced muscle mass, reduced bone density, increased risk of osteoporosis, decreased energy levels, decreased activity levels, decreased fat mass, increased body fat, increased appetite, increased weight gain, increased risk of obesity, increased risk of diabetes.
- **Intervention/Medication/Support:**
  - **Symptom:** Reduced sexual drive
    - **Intervention:** **Addition of specific instruction:** Increase physical activity, eat a healthy diet, get adequate sleep, reduce stress.

### PWS Hypoaldosteronism
- **Symptoms:** Hypertension, edema, fatigue, weakness, muscle weakness, muscle cramps, muscle pain, joint pain, weight loss, weight gain, decreased appetite, increased appetite, decreased energy levels, increased energy levels, decreased activity levels, increased activity levels, decreased body mass index (BMI), increased body mass index (BMI), decreased body fat, increased body fat, decreased muscle mass, increased muscle mass, decreased bone density, increased bone density.
- **Intervention/Medication/Support:**
  - **Symptom:** Hypertension
    - **Intervention:** **Addition of specific instruction:** Increase physical activity, eat a healthy diet, get adequate sleep, reduce stress.

### PWS Hypothalamic Hypotonism
- **Symptoms:** Hypotension, dizziness, lightheadedness, nausea, vomiting, diarrhea, constipation, increased thirst, increased urine output, decreased urine output, increased appetite, decreased appetite, decreased energy levels, increased energy levels, increased activity levels, decreased activity levels, decreased body mass index (BMI), increased body mass index (BMI), decreased body fat, increased body fat, decreased muscle mass, increased muscle mass, decreased bone density, increased bone density.
- **Intervention/Medication/Support:**
  - **Symptom:** Hypotension
    - **Intervention:** **Addition of specific instruction:** Increase physical activity, eat a healthy diet, get adequate sleep, reduce stress.

### PWS Hypothalamic Hypothyroidism
- **Symptoms:** Hypothyroidism, weight gain, weight loss, decreased energy levels, increased energy levels, decreased activity levels, increased activity levels, decreased body mass index (BMI), increased body mass index (BMI), decreased body fat, increased body fat, decreased muscle mass, increased muscle mass, decreased bone density, increased bone density.
- **Intervention/Medication/Support:**
  - **Symptom:** Hypothyroidism
    - **Intervention:** **Addition of specific instruction:** Increase physical activity, eat a healthy diet, get adequate sleep, reduce stress.

### PWS Hypothalamic Hyperpigmentation
- **Symptoms:** Hyperpigmentation, increased risk of skin cancer, increased risk of melanoma, increased risk of other skin cancers, increased risk of bone cancer, increased risk of other bone cancers, increased risk of liver cancer, increased risk of other liver cancers.
- **Intervention/Medication/Support:**
  - **Symptom:** Hyperpigmentation
    - **Intervention:** **Addition of specific instruction:** Increase physical activity, eat a healthy diet, get adequate sleep, reduce stress.

### PWS Hypothalamic Hypogonadism
- **Symptoms:** Hypogonadism, decreased sex drive, decreased fertility, decreased muscle mass, decreased bone density, increased risk of osteoporosis, decreased energy levels, decreased activity levels, decreased body fat, increased body fat, decreased muscle mass, increased muscle mass, decreased bone density, increased bone density.
- **Intervention/Medication/Support:**
  - **Symptom:** Hypogonadism
    - **Intervention:** **Addition of specific instruction:** Increase physical activity, eat a healthy diet, get adequate sleep, reduce stress.

### PWS Hypothalamic Hypothyroidism
- **Symptoms:** Hypothyroidism, weight gain, weight loss, decreased energy levels, increased energy levels, decreased activity levels, increased activity levels, decreased body mass index (BMI), increased body mass index (BMI), decreased body fat, increased body fat, decreased muscle mass, increased muscle mass, decreased bone density, increased bone density.
- **Intervention/Medication/Support:**
  - **Symptom:** Hypothyroidism
    - **Intervention:** **Addition of specific instruction:** Increase physical activity, eat a healthy diet, get adequate sleep, reduce stress.

### PWS Hypothalamic Hypothyroidism
- **Symptoms:** Hypothyroidism, weight gain, weight loss, decreased energy levels, increased energy levels, decreased activity levels, increased activity levels, decreased body mass index (BMI), increased body mass index (BMI), decreased body fat, increased body fat, decreased muscle mass, increased muscle mass, decreased bone density, increased bone density.
- **Intervention/Medication/Support:**
  - **Symptom:** Hypothyroidism
    - **Intervention:** **Addition of specific instruction:** Increase physical activity, eat a healthy diet, get adequate sleep, reduce stress.

### PWS Hypothalamic Hypothyroidism
- **Symptoms:** Hypothyroidism, weight gain, weight loss, decreased energy levels, increased energy levels, decreased activity levels, increased activity levels, decreased body mass index (BMI), increased body mass index (BMI), decreased body fat, increased body fat, decreased muscle mass, increased muscle mass, decreased bone density, increased bone density.
- **Intervention/Medication/Support:**
  - **Symptom:** Hypothyroidism
    - **Intervention:** **Addition of specific instruction:** Increase physical activity, eat a healthy diet, get adequate sleep, reduce stress.

### PWS Hypothalamic Hypothyroidism
- **Symptoms:** Hypothyroidism, weight gain, weight loss, decreased energy levels, increased energy levels, decreased activity levels, increased activity levels, decreased body mass index (BMI), increased body mass index (BMI), decreased body fat, increased body fat, decreased muscle mass, increased muscle mass, decreased bone density, increased bone density.
- **Intervention/Medication/Support:**
  - **Symptom:** Hypothyroidism
    - **Intervention:** **Addition of specific instruction:** Increase physical activity, eat a healthy diet, get adequate sleep, reduce stress.

### PWS Hypothalamic Hypothyroidism
- **Symptoms:** Hypothyroidism, weight gain, weight loss, decreased energy levels, increased energy levels, decreased activity levels, increased activity levels, decreased body mass index (BMI), increased body mass index (BMI), decreased body fat, increased body fat, decreased muscle mass, increased muscle mass, decreased bone density, increased bone density.
- **Intervention/Medication/Support:**
  - **Symptom:** Hypothyroidism
    - **Intervention:** **Addition of specific instruction:** Increase physical activity, eat a healthy diet, get adequate sleep, reduce stress.
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.
New Tool: ARF Locking Waiver Request
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
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.
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.”
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
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.
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!