NEW FEDERAL RULES IMPACT YOUR FUTURE:

NEW TOOLS TO KEEP YOUR LOVED ONE SAFE

Presented by Lisa Graziano, M.A., LMFT
Chair, PWCF Home & Community-Based Services Task Force

2019 CONVENTION

1

IMAGINE…

Imagine a world where people with disabilities live in their own home, have the freedom to control their own schedule, activities and people with whom they interact.

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 are paid the same wage.

Imagine a world where the wishes, dreams and goals of every disabled individual are respected above all else.

2

• This is the world imagined by the Centers for Medicare & Medicaid Services (CMS), the federal agency that funds programs and services for persons with physical disabilities, developmental disabilities, and mental illness.

• CMS wrote new Home and Community-Based Services Rules and Regulations to create this world, to “deinstitutionalize” people with disabilities, “integrate them in the community to the same degree as nondisabled individuals” to ensure they live in dignity in their own home, recreate in their own neighborhood, and work for an employer who doesn’t only hire disabled people.

Sounds wonderful, right!!

3
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 INCLUDING...**

- Nowhere Safe to Live
- No Job
- No Day Program
- No Recreation
- Boredom
- No Income
- No Income
- No Transportation
- No Physical Activity
- INCREASED UNWANTED BEHAVIORS
- Food-Related Illness or Death

**HOW COULD HEALTH AND SAFETY BE JEOPARDIZED?**

Because one of HCBS’s Rules mandates that:

“**Individuals... have access to food at any time.**”
THIS PRESENTATION

HCBS’s Unintended Consequences and how to address them are the focus of this presentation.

- Provide a brief introduction of the new HCBS Rules & Regulations as they may impact persons with PWS
- Introduce tools created by Prader-Willi California Foundation’s HCBS Task Force designed to eliminate or mitigate these unintended consequences and keep your loved one – of any age – safe.

HCBS TASK FORCE OVERVIEW

- PWCF established the HCBS Task Force in 2016.
- Task Force members worked with CMS’s Director and Deputy Director of Long-Term Services and Supports and other high-ranking officials, California’s Department of Developmental Services, California’s Licensing agency, and various PWS specialists.
- Task Force members: Lisa Graziano, M.A., LMFT (Chair) • Emily Dame • Diane Kavrell • Tom McRae • Austin de Lone • Jonah Steinhart
- Task Force continues to meet monthly to assess impact of HCBS Rules and how we can help families and professionals respond to them.
- All tools created by PWCF’s Task Force have been shared with PWSA (USA) to share with families and professionals.

WHAT ARE HCBS RULES & REGULATIONS?

- HCBS Rules and Regulations establish mandatory requirements for the qualities of homes and community-based settings: residential settings, day programs, work programs, recreational programs.
- If a setting does not meet the new HCBS requirements, it will not receive Federal funding. State agencies rely on Federal funding.
- Requires Person-Centered Planning.
- Originally drafted in January 2014, the final deadline for all States to comply is March 17, 2022.
WHO DO HCBS RULES APPLY TO?

• Everyone in the U.S. whose services are funded in any way by CMS:
  
  • **Residential Settings** including certified and licensed homes (group homes, supported living / independent living agency providers, etc.)
  • **Day Programs**, recreational programs, other day-type services
  • **Employment Sites**, workshops, volunteer sites

WHY SHOULD WE CARE ABOUT THE NEW RULES?

Because…

• Some Rules are unhealthy and potentially dangerous to persons with PWS:
  
  ▶ “Individuals are able to have visitors of their choosing at any time.”
  ▶ “Individuals have the freedom and support to control their own schedules and activities, and have access to food at any time.”

• If there is no appropriately documented exemption to a Rule, the provider is legally mandated to follow the Rule.

WHY SHOULD WE CARE (CON’T)…

And because…

• If any setting is deemed to be “institutional” it will not be funded:
  
  • **Residential settings** that serve more than 4 persons may be judged “institutional” and close unless they receive a Heightened Scrutiny Waiver. As the PWS populations grows, finding appropriate housing will become more challenging.
  • **Day programs and employers** may not serve “too many” disabled people. In CA, programs have already changed or closed. People who used to earn an income in their day program now volunteer and earn nothing or stay home.
  • **Transportation services** will be challenged to keep up with increased individual transportation needs. In CA services assist paid employees first, leaving “less employable” persons with no transportation services.
  • There is no distinction between someone with a physical disability and someone with a developmental disability.
WHAT DOES THIS MEAN?

Unintended Consequences:
- Reduction of housing options
- Reduction of workshops and other employment site options
- Loss of earning any wage
- Reduction of day programs
- Lack of transportation services
- Lack of daytime activity ➞ boredom ➞ increased unwanted behaviors

The Most Serious Unintended Consequences:
- Unrestricted access to food leading to:
  - Severe behavior problems
  - Morbid obesity
  - Death

HOW DO WE PROTECT OUR LOVED ONE AGAINST UNINTENDED CONSEQUENCES?

- It all starts with the Person-Centered Plan (PCP).
- The PCP is designed to ensure the Individual's hopes, dreams, wishes and goals are respected and that everything is done to help the Individual achieve his or her goals.
- Some States may call their plan something different (e.g., Individual Program Plan) but the Federal language is PCP and all states are required to use Person-Centered Planning.
- Document and detail all health and safety needs and all desired daily activities in the PCP.

WHAT IS PERSON-CENTERED PLANNING?

- A meeting with the State representative, the disabled Individual, and people chosen by the Individual to create the person-centered plan that details what and how services will be provided. Think of the PCP as a contract.
- Occurs when and where it's convenient to the Individual.
- The Individual directs the process to the maximum extent possible.
- Includes individually identified goals and preferences related to relationships, community participation, employment, income and savings, healthcare and wellness, education, etc.
- Offers choices to the Individual regarding services and supports the Individual receives and from whom.
- Services can only be provided if they are written in the PCP.
- If it's not in the PCP it can't happen.
WHAT INFORMATION IS REQUIRED IN A PCP?
The written PCP must:
• Reflect the Individual's strengths and preferences;
• Include the Individual's clinical and support needs;
• Include goals and desired outcomes;
• Document the Individual's residential setting as chosen by the Individual and ensures it is integrated in and supports full access to the community;
• Document opportunities to seek employment and work in competitive integrated settings;
• Document opportunity for the Individual to engage in community life, control personal resources, and receive services in the community to the same degree of access as individuals not receiving Medicaid HCBS;
• Document providers of services including unpaid supports provided voluntarily in lieu of waiver or state plan HCBS;
• Document risk factors and measures in place to minimize risk;
• Document individualized backup plans and strategies when needed.

INFO REQUIRED IN A PCP (CONT')
The written PCP must also:
• Document people who are important in supporting the Individual;
• Use plain language and be understandable to the Individual;
• Document who is responsible for monitoring the plan;
• Document informed consent of the Individual in writing;
• Contain the signatures of all individuals and providers responsible;
• Be distributed to the Individual and others involved in the plan;
• Include purchase/control of self-directed services;
• Exclude unnecessary or inappropriate services and supports;
• Document any modifications from HCBS setting requirements;
• Be reviewed and updated every 12 months, or when the Individual's circumstances or needs change significantly, or at the request of the Individual.

NEW TOOL: PERSON-CENTERED PLAN (PCP) CHEAT SHEET
PCP MEETING SUGGESTION

• To ensure a productive, detailed, accurate PCP, have the Individual with PWS participate in the beginning of the meeting. Gather their hopes, wishes, dreams and goals. Discuss their strengths and preferences for home, work, recreation, education, relationships and socialization, etc. Avoid discussing anything that could be perceived as critical or disappointing, including past behavioral challenges, as this will likely lead to unwanted behavior and disrupt and prolong the meeting.

• Excuse the individual from the meeting and continue with the meeting, integrating the individual’s hopes, wishes, dreams and goals.

• Provide copy of PCP to the Individual later, review it, and obtain signature.

CALL AND Q & A WITH CENTERS FOR MEDICARE & MEDICAID SERVICES

CMS Q & A: FOOD SECURITY AT GROUP HOME OR 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 PWS does not mean the Individual’s PCP will automatically allow restricted access to food to avoid obesity or death.

• There must be appropriate documentation in the PCP to justify any attempt to reduce an Individual’s right to direct their life.

CMS Q & A: WHAT IS “APPROPRIATE DOCUMENTATION”?

What is the appropriate documentation to justify a reduced calorie diet and restricted access to food?

• The management of each symptom caused by PWS must be addressed and documented in the PCP on an individual, case-by-case basis.

• A clear description of the condition or symptom(s)

• A clear description of the assessed need

• A description of all things previously tried but were not successful.

Would something like a Physician’s Note serve this purpose?

• Yes, a Physician’s Note would serve as appropriate documentation.
NEW TOOL: PHYSICIAN’S NOTE – SYMPTOM & TREATMENT CHECKLIST

PHYSICIAN’S NOTE SYMPTOM LIST INCLUDES:

- Hyperphagia
- Anesthesia & Medication Sensitivity
- Anxiety
- Apnea
- Attentional Deficits
- Autism Spectrum
- Behavior Management Deficits
- Bone Mineral Deficiency
- Cognitive Deficits
- Developmental Delays
- Diabetes Type II Mellitus
- Elopement
- Epilepsy
- Gastroparesis
- Growth Hormone Deficiency
- Hypotonia
- Kyphoscoliosis
- Lying, Confabulation
- Metabolic Abnormality
- Obsessions, Perseverations
- Pain Sensitivity
- Reflux
- Saliva Disorder (dry mouth)
- Skin Picking
- Slow Bowel
- Temperature Regulation Disorder
- Theft
- Thyroid Disorder
- Unreliable Self Reporting
- Vitamin Deficiency
- Wandering
- Blank areas for physician to add additional symptoms or diagnoses

PHYSICIAN’S NOTE IS FOR PERSONS WITH PWS OF ALL AGES

- Documentation for applications for State and County services
- Documentation for school-based services
- Documentation for all physicians and therapists on your child’s Treatment Team
CMS Q & A: 
FOOD SECURITY AT GROUP HOME OR SUPPORTED LIVING SITE

CMS suggests:
• It would be helpful to include in the PCP an agreement signed by the Individual regarding limited access to food.
• Include a statement to the effect that they “do not waive their Agreement even if they’re dealing with their symptom [e.g., hyperphagia causing unwanted behavior] and that the Agreement can only be changed at the PCP.”

NEW TOOL: AGREEMENT REGARDING FOOD AND LOCKS

CMS Q & A: 
WHAT ABOUT PLANNED COMMUNITIES?

How can an individual protect his or 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 programs; multiple persons with disability living/working together)
• In March 2019 CMS issued its Heightened Scrutiny guidelines to permit a planned community or congregate housing / employment / day program to operate if it is appropriately documented that the setting integrates all individuals into the general community and does not isolate or restrict their access to the greater community.
NEW TOOL: ADULT RESIDENTIAL FACILITY LOCKING WAIVER REQUEST TEMPLATE

CMS Q & A:
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.
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 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.

CMS Q & A: ELOPEMENT (CON'T)

It would be helpful to include in the PCP 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."

NEW TOOL: AGREEMENT REGARDING ELOPEMENT AND LOCKS
CMS Q & A: HOW TO MANAGE CONFLICT BETWEEN INDIVIDUAL AND CONSERVATOR/GUARDIAN

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 PCP?

• 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 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 Q & A: 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.

NEW TOOL: CONSERVATORSHIP FAQ
CONSERVATORSHIP IS CRITICAL TO PROTECT YOUR ADULT'S HEALTH AND WELFARE

7 Potential Powers of a Conservator:

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

NEW TOOL: FACTS ABOUT PWS THAT CONSERVATORSHIP ATTORNEYS NEED TO KNOW

NEW TOOLS FOR FAMILIES
All tools are posted on PWCF's website at www.PWCF.org

1. HCBS Questions with CMS Answers
2. Person-Centered Planning Individual Program Plan Cheat Sheet
3. Physician’s Note Symptom & Treatment Checklist
4. PWS Brief Overview Educational Video
5. Agreement for Individual with PWS re: Food
6. Agreement for Individual with PWS re: Elopement
7. FAQs About Limited Conservatorship for Adults with PWS
8. Facts About PWS that Conservatorship Attorneys Need to Know
NEW TOOLS FOR PROFESSIONALS

1. All tools are posted on the website
2. Template to Request Waiver to Residential Licensing Agency
3. List of Local Residential Services Licensing Offices (only in CA)
4. PWS Overview Educational Training Video
5. HCBS Questions with CMS Answers
6. Physician’s Note Symptom & Treatment Checklist
7. Agreement for Individual with PWS re: Food
8. Agreement for Individual with PWS re: Elopement
9. Facts About PWS that Conservatorship Attorneys Need to Know

FOUR THINGS YOU NEED TO DO NOW

1. Incorporate the words “health and safety” into your vocabulary
2. Obtain Guardianship (Limited Conservatorship in CA) so that you have the legal ability to protect your adult’s health and safety.
3. Provide the Physician’s Note Symptom Checklist to your child or adult’s “main” physician to document all needs.
4. Create a detailed, PWS-Specific PCP that documents your loved one’s health and safety needs including:
   - Restricted access to food in all settings (and restricted access to money which can be used to purchase food)
   - Supervision in all settings at all times
   - Individual Agreement(s) re: Restricted access to food, Elopement
   - Structure and routine to reduce anxiety, reduce unwanted behaviors
   - Signed Physician’s Note, updated annually

FOR MORE INFORMATION

Read the HCBS Rules & Regulations Final Ruling
www.medicaid.gov/medicaid/hcbs

Download all Tools
www.PWCF.org | Parents tab | School Age Years or Adult Years

Contact Lisa Graziano, M.A., LMFT
LisaG@pwcf.org

Keep Informed!
Stay Connected with PWSA (USA)!