

HCBS Rules & Regs: Health and Safety Tools for Residential & Other Professionals Serving Adults with PWS

The 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 or employees with PWS. These tools – in the Yellow Box to the right – will help you keep your residents with PWS safe both at your home and throughout their day.

- **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** 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.

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.

2017 HCBS Task Force Members:

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