

Practical implementations overcoming household barriers to achieve total food control in Prader-Willi syndrome

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I. Introduction

Ironically households dealing with Prader-Willi Syndrome (PWS) thrive when total physical control over food exists despite the prevailing concept of least restrictive environments (1). PWS is a complex genetic disorder characterized by symptoms such as hyperphagia, a condition in which affected individuals experience constant hunger and a lack of satiety after meals, leading to overeating (2). Despite years of household training and understanding of what should be done, the reality is most families struggle an adequate level of food control. Total food control has been shown to reduce anxiety of PWS individuals among other symptoms (1). We endeavor to identify barriers to achieving household food control and practical implementations that can then enable PWS families to make the necessary changes.

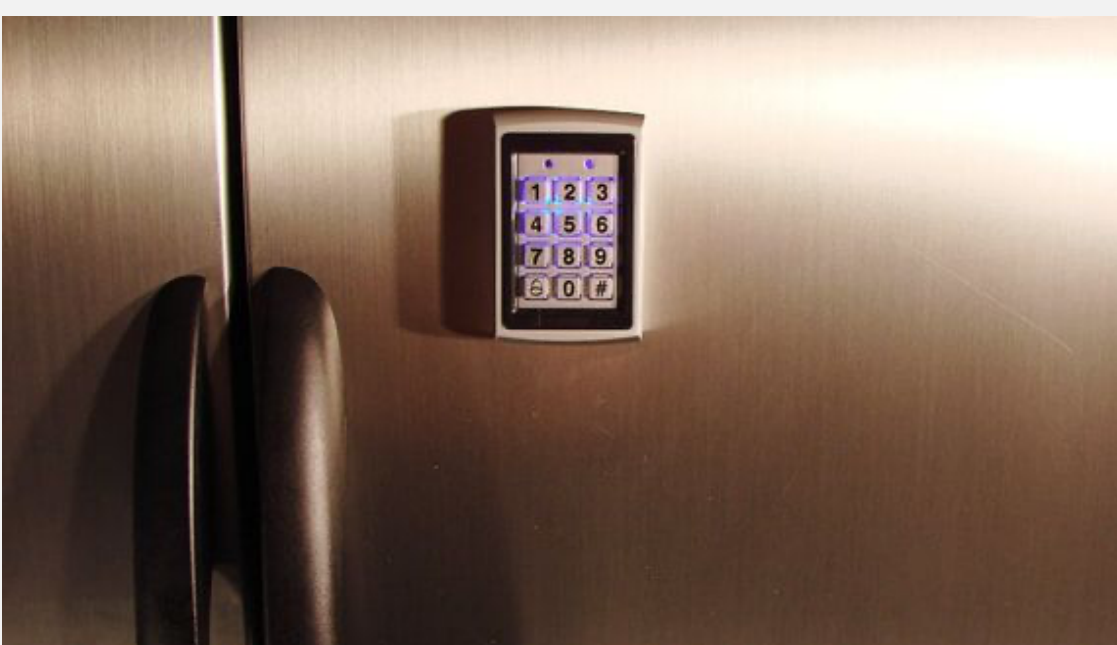


Figure 1 – A device designed to prevent unlimited access to the fridge by use of self locking mechanisms.

Figure 2 – A self-locking door handle that safely secures the pantries, bedrooms, storage rooms, etc.



II. Methods

- We conducted an in-depth review of existing literature and current practices used by families to understand the state of food control for individuals with PWS.
- We created a survey and administered it to families in Utah to identify their current food control strategies, status and needs.
- To assist families in acquiring these food control devices, we secured funding to support the purchase of commercially available self-locking devices.
- We hired personal to identify appropriate food control devices for the family home and trained families and/or personnel to install these devices.

III. Results

- Consistent food and personal security play a crucial role in reducing anxiety and ensuring the safety of individuals with PWS and their families.
- Recognizing the value of total food control, we developed a survey for families with PWS.
- We surveyed 35 families from Utah and found assistance is needed to achieve adequate physical security, including recommendations, installation, and training.
- Factors contributing to security failures include distractions, such as phone calls, and devices that are too cumbersome.
- Many families start implementing security measures too late, which may lead to preventable issues.
- Protecting items that may appear like "food," including non-edible substances like cleaning chemicals, art supplies, and medicine, is essential.
- **Only two families claimed to have everything secure regarding food control (See Figure 3).**

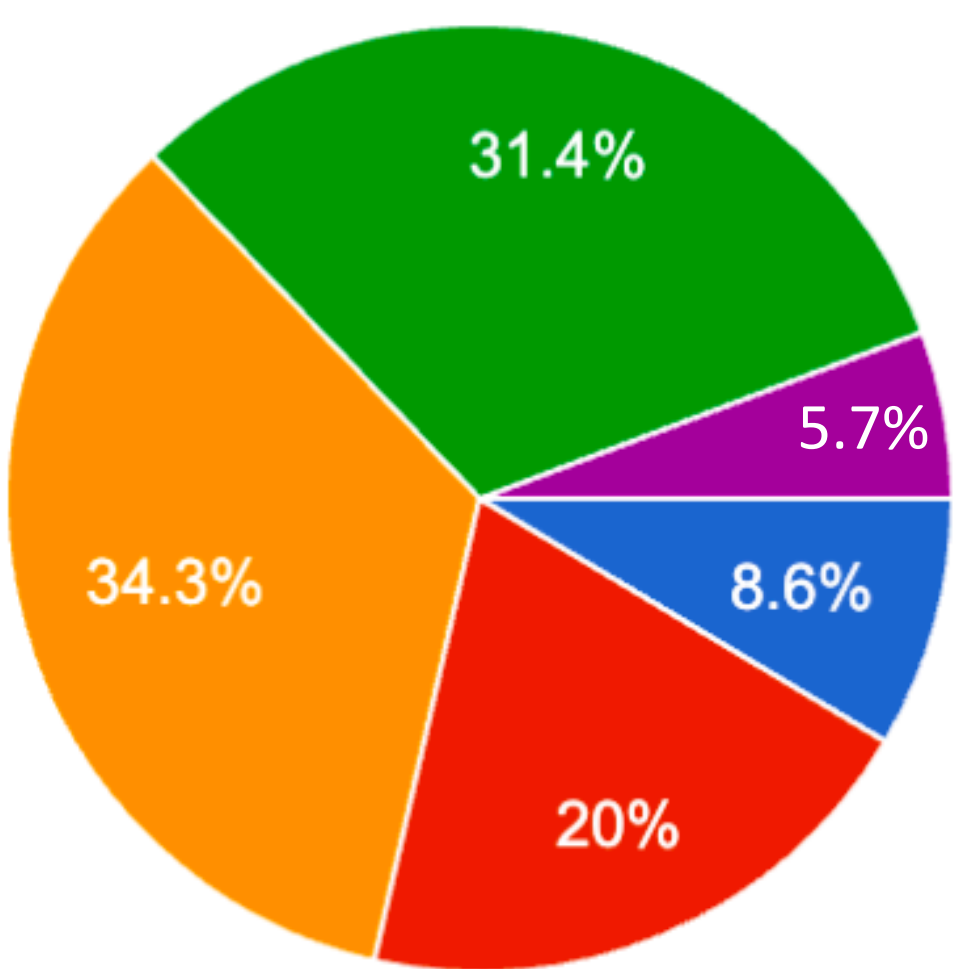
Based on our research, the following best practices have emerged, helping to eliminate human error and reduce family anxiety:

- Self-locking fridges and pantries.
- Self-closing and locking doors to rooms with food.
- Alarms and locking ice chests for travel.
- Securing parent and sibling rooms to protect personal property.
- Providing enabling equipment such as adult strollers, cameras, body cameras, and air tags, allowing attention to be diverted from protected areas to typical activities like outdoor exercise and yard play.

It is important to note that a single point of failure increases anxiety and the fear that the system will fail again for individuals with PWS. In busy households with multiple family members accessing controlled areas, distractions such as phone calls can contribute to security failures. Devices that are too cumbersome also pose challenges.

Consistent food control is crucial in ensuring the safety of individuals with PWS and their families. It is often observed that families start implementing physical control measures too late, believing they do not need to take precautions until the last minute.

Figure 3 – PWS Families when asked, “How is your current home security?”



- None - we are really struggling
- We have a few security measures in place, but we're still struggling
- We have a pretty good system in place, but we would be open to additional security.
- We have everything completely locked down and our system works great, but...
- We have everything under control and don't need any help with security.

IV. Conclusions

For the households in which we have intervened with security equipment, installation, and training, we observed an increase in their food control. We expect these interventions to continue in the coming months as new families are matriculated into the management. We plan to formally evaluate the effectiveness of our interventions in the next grant cycle. These evaluations would include the impact on BMI and anxiety levels and on the cultural understanding of exceptions to least restrictive environments.

References:

1. Forster, Janice L., and Linda M. Gourash. Prader-Willi Syndrome: A Primer for Psychiatrists Pittsburgh Partnership. 2005.
2. Prader-Willi Syndrome - Symptoms, Causes, Treatment | NORD. (n.d.). National Organization for Rare Disorders. <https://rarediseases.org/rare-diseases/prader-willi-syndrome/>

Acknowledgement

This work was supported by: The Utah Prader-Willi Syndrome Association; Utah Prader-Willi Syndrome Multidisciplinary Clinic; Marc C. and Deborah H. Bingham Foundation; UTAH DEPARTMENT OF HEALTH & HUMAN SERVICES CONTRACT

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