Catholic Charities Disabilities Services	
Agency Standard and Procedure	
Standard Category	Residential
Standard Title	Prader-Willi Syndrome Programming
Regulations	
Original Issue Date	11/12/2025
Latest Revision Date	09/15/2026
Number of Pages	2
Attachments	Memorandum of Understanding For PWS Residential Services
Approved by: Paula Warika, Executive Director	Paula Warika

Standard:
In order to support people who have Prader Willi Syndrome (PWS), the agency is committed to the principle of "No hope, No doubt, No disappointment" and will maintain PWS specific supports for the people who receive residential services from CCDS and have this diagnosis.

Individuals or their guardian/advocate, will be informed of these expectations and consent to them through the MEMORANDUM OF UNDERSTANDING FOR PWS RESIDENTIAL SERVICES upon intake and annually.

Procedure:

1. Food Security & Menu Planning
    a) Kitchens are locked at all times. Only staff have access to the keys.
    b) Staff will prepare and distribute all meals following prescribed recipes and amounts.
    c) Whenever possible, meals should be "homemade" from fresh ingredients.
    d) Processed and prepared foods should be avoided.
    e) The Dietician will meet with each individual on a regular basis to review the menu.
    f) Menu substitutions must be approved by the Dietitian.
    g) Calories from unauthorized food consumption are reduced from daily intake as directed by the Dietician.
    h) Daily caloric intake prescribed by physician and menus developed by the agency Dietitian. A prescribed menu will be set into place upon admission until a menu can be developed.

2. Access to money
    a) Individuals do not have unsupervised access to money, unless otherwise outlined in their Individual Plan of Protective Oversight (IPOP).
    b) Individuals will only carry money when accompanied by a staff person, unless otherwise outlined in their IPOP.
    c) A representative payee must be appointed.

3. Staff Supervision
    a) Staff will provide continuous care to the individuals within the Prader-Willi program, 24 hours a day, and 7 days a week.

b) "Alone time" may occur, but must be discussed with the interdisciplinary team through the individual service planning process. "Alone time" guidelines will change based on the needs of the individual as approved by the interdisciplinary team.

4. Individualized Supports
    a) Exercise, as prescribed in the residential habilitation plan, is mandatory.
    b) Room and bag searches will be completed as outlined in the IPOP.

5. Family Support
    a) Coordination of services and communication with the individual's family is essential. Family and friends must be aware and adhere to the guidelines of the Memorandum of Understanding for PWS Residential Services.
    b) Family will check bags of individual before they leave their homes to return to the residence and remove all food items, money, credit cards, and other unauthorized items.
    c) If bag checks are not done during the visit, they should be done at the residence with the family member(s) present and unauthorized items taken by the family member(s).
    d) Family will follow exercise guidelines as much as possible when therapeutic leave occurs.
    e) Daily caloric intake expected to be followed on therapeutic leave, vacations, holiday gatherings, etc.
    f) Therapeutic leave will be communicated to the Residential Site Supervisor and/or Director of Residential Services, or designee, as early as possible to plan for appropriate staffing.
    g) Physician's appointments will be made by the Supportive Health Services team.
    h) If caloric intake must be adjusted for an event, such as family party, wedding, etc. requests to the Dietician to have calories adjusted should be made one week prior to the event.
    i) Family members should communicate schedule changes, requests, concerns directly to Residential Site Supervisor, and/or Director of Residential Services, or designee.
    j) Upon return from therapeutic leave, staff and family should have an open and honest discussion about the visit.

6. All rights restrictions will be part of a Comprehensive Behavioral Support Plan developed by the individual's interdisciplinary treatment team. That plan must be consented to by the individual and/or their legal guardian. The plan is also approved by an agency human rights committee and is reviewed on a semi-annual basis. All PWS guidelines will be reviewed in the IPOP as safeguards.

CATHOLIC CHARITIES DISABILITES SERVICES

MEMORANDUM OF UNDERSTANDING FOR PWS RESIDENTIAL SERVICES

Food Security & Menu Planning

- Kitchens are locked at all times except meal preparation times, only staff have access to the keys.
- Staff will prepare and distribute all meals following prescribed recipes and amounts.
- Meals should be "home made" from fresh ingredients whenever possible.
- Processed and prepared foods should be avoided.
- The dietician will meet with participants individually on a regular basis to review the menu.
- Menu substitutions must be approved by dietitian.
- Calories from unauthorized food consumption are reduced from daily intake as directed by the dietician.
- Daily caloric intake prescribed by physician and menus developed by agency dietitian. A prescribed menu will be set into place upon admission until a menu can be developed.

Access to money

- Participants do not have unsupervised access to money.
- Participants will only carry money when accompanied by a staff person.
- Agency Executive Director authorized as representative payee.

Staff Supervision

- "Alone time" can be granted but must be approved by the interdisciplinary team through the individual service planning process. "Alone time" guidelines will change based on the needs of the individual as approved by the interdisciplinary team.
- Provision of care specifies 24 hour / 7 day a week

Individualized Supports

- Exercise as prescribed in the residential habilitation plan is mandatory.
- Room and bag searches done with participant present and two staff members as authorized in the individual protective oversite plan.

Family Support

- Coordination of services and communication with the individual's family is essential. Family and friends must be aware of and agree to any dietary or behavioral guidelines that are part of the individual service plan.
- Family will check bags of individual before they leave their homes to return to the residence and remove all food items, money, credit cards, and other unauthorized items.
- If bag checks are not done at home, they should be done at the residence with the family member(s) present and unauthorized items taken by the family member(s).
- Family will follow exercise guidelines as much as possible when home visits occur
- Daily caloric intake expected to be followed on home visits, vacations, holiday gatherings, etc.
- Home visits will be communicated to the site supervisor and/or program manager at least two weeks in advance to plan for appropriate staffing.
- Physician's appointments will be made by or in conjunction with the residential RN of the program.
- If caloric intake must be adjusted for an event, such as family party, wedding, etc. requests to have calories adjusted should be made one week prior to event.
- Family members should communicate schedule changes, requests, concerns directly to site supervisor, and/or program manager.
- Upon return from home visit, staff and family should have an open and honest discussion about the home visit.

* All right's restrictions will be part of a behavioral support plan developed by the individual's interdisciplinary treatment team. That plan must be consented to by the individual and / or their legal guardian. The plan is also approved by an agency human rights committee and is reviewed on a semi-annual basis. All PW guidelines will be reviewed in the individual protective oversite plan as safeguards.

_____ _____

Individual Served - Signature Date

_____ _____

Family Member - Signature Date

_____ _____

Agency Representative - Signature Date