



## What is Prader-Willi syndrome?

Prader-Willi syndrome is a disorder of chromosome 15 Prevalence: 1 : 12,000-15,000 (both sexes, all races) Major characteristics: hypotonia, hypogonadism, hyperphagia, cognitive impairment, challenging behaviors Major medical concern: morbid obesity

The majority of adults with Prader-Willi syndrome work in sheltered workshops. The remainder are in transitional employment, supported work programs, entry level competitive jobs, and volunteer work. Most perform short-cycled repetitive tasks found in the areas of production work, light duty, clerical work, laundry service, outdoor maintenance, day care, \* and pet care\* (\*feasible if access to food is restricted).

Supervision and consistency are the keys to success. Like all workers, each individual with Prader-Willi syndrome brings unique skills and abilities to the workplace. Most thrive in a structured workplace where expectations are clearly defined and maintained. When expectations, work instructions, and manner of supervision are consistent, behavioral difficulties can be minimized.

Employers and supervisors who understand the unique aspects of Prader-Willi syndrome may then be able to increase the success of individuals with the syndrome in the world of work.

Prader-Willi syndrome is a birth defect resulting in a dysfunction of the brain, which creates insatiable appetite, chronic preoccupation with food, and extreme, potentially life-threatening, weight gain on what for others is normal caloric intake. **The food compulsion makes constant supervision necessary.** Motor skills and cognitive abilities may vary, as well as levels of behavioral and social functioning. Due to individual differences, not all characteristics are always present. Also, the degree of severity of these characteristics will vary.

### Common Cognitive and Behavioral Characteristics may include:

- Insatiable Appetite
- Food Stealing
- Hoarding Possessions
- Tantrums
- Stubbornness / Rigidity
- Limited Attention
- Perseveration (repetitive thoughts and words)
- Non-compliance
- Sleepiness
- Skin Picking

The Prader-Willi Syndrome Association | USA was formed in 1975 in order to provide a vehicle of communication for parents, professionals and other interested citizens. It is an organization dedicated to the sharing of experiences in how to cope and work with the syndrome. Chapters of PWSA | USA are located in most states and are available for support, education and advocacy.

An annual national conference, a bimonthly newsletter entitled *The Gathered View*, which incorporates contributions from members as well as professional advice, and a wealth of other written materials and publications on Prader-Willi syndrome are all part of the PWSA | USA's effort to carry out its mission.

PWSA | USA is supported solely by membership fees and donations. Our agency has made a difference in the lives of many families and individuals affected by this unique syndrome. **YOU TOO CAN HELP.** Donations and membership applications may be sent to the address below.

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*We hope you find these materials helpful and that you consider a donation to PWSA | USA to assist in developing more good work(s) like this. Please see our website, [www.pwsausa.org](http://www.pwsausa.org).*

## Management of PWS in the Work Setting



### A Guide for Employers and Supervisors



# Persons with Prader-Willi syndrome can be motivated and productive workers



## Communication and Planning Employer / Staff Education

It is imperative that all personnel be trained about the syndrome.

Training should include a description of Prader-Willi syndrome, dietary management, special behavioral difficulties, behavioral interventions or approaches, cognitive strategies, and specific rules / instructions for the work area.

## Family / Care Provider Involvement

Involvement of care providers in behavioral planning and assigning responsibilities is vital for the consistency and structure needed by the worker.

Team planning and negotiation are essential in developing consistent and effective behavioral approaches, and firmly establishing responsibilities of employer and care provider.

## Work Skill Development

Workers can learn simple tasks and multiple-step procedures.

Directions should be presented a few at a time in simple terms, since many have difficulty understanding complex concepts.

Additional time and repetitions may be required to learn new tasks. One training may not be enough.

Visual models are more effective than verbal directions. Demonstrating and hands-on examples are effective learning tools.

Close monitoring during the learning process helps to insure that instructions are followed.

## Behavioral Management

**Be generous with verbal praise** for good work and appropriate behavior.

**Identify rewarding work incentives**, e.g., assisting a supervisor with a special task, spending break time with a specific co-worker or supervisor, participating in a special activity, earning an additional low-calorie snack (pre-approved by guardian), or receiving points / tokens to be used for later rewards.

**Restrict access to food at all times.** Persons with Prader-Willi syndrome will go to extremes to seek food. Careful supervision in the work setting is necessary as well as lunch and break areas and trips to the restroom.

**Define off-limit areas.** Selected monitors should direct the person back to an appropriate area and notify the supervisor.

**Provide strict monitoring if it is necessary for a person to bring money to workplace.**

**Have workers bring lunches and snacks pre-packed.**

**Specify a key person to whom the worker should address work-related concerns or problems.** Identify the method(s) for addressing these concerns before the worker begins the job.

**Prepare persons for changes in routine which lead to frustration and difficult behavior.** Inform the individual of changes in advance. Daily written work schedules may be helpful, if they can be followed. Support / counseling may be beneficial for adjustment to major changes.

**Include the individual in planning to increase his / her motivation.** Structuring / limiting choices can help decision-making and avoid frustration.

**Avoid arguing.** Limit excessive question asking.

**Allow an appropriate area and time period for venting frustration and regaining composure, when needed.**

**Have key personnel readily available if physical intervention is needed.**

**Require the person to return or replace items broken or taken without permission, when possible.**

## Use of Cognitive / Behavioral Strategies

Cognitive strategies are useful in aiding new learning memory, organization, planning, problem-solving, and self-monitoring for quality and accuracy.

Possibilities include: using simple written directions, note taking, verification, clarification, checklists, and schedules.

Accommodate for slow processing of information, limited ability to understand, previous knowledge, distractibility, and level of functioning.

Demonstration, additional time for practice, and repetitions are often required.



Strategic placement of the work area and / or materials diminishes the likelihood of stealing / hoarding materials and decreases environmental distraction and inappropriate social interactions.

Many workers lack the ability to self-monitor adequately. Providing supportive feedback in a non-accusatory manner may decrease argumentativeness and perseveration.

Establish and discuss specific standards and expectations prior to beginning work tasks.

Incorporate picture schedules and / or visual timers that may assist smoother transitions or task completion throughout the workday.