

Best Practices in Support Levels for Students with Prader-Willi syndrome
By Jennifer Bolander, PWSA (USA) Special Education Specialist

One of the three main goals of the Individuals with Disabilities Education Act [IDEA] is to promote independence. For the child who is developing neurotypically, who does not have a medical diagnosis or health issue which affects their brain function, increased independence which culminates in their fully caring for themselves and making independent life decisions is a logical goal. Most students with Prader-Willi syndrome, however, require an adjusted understanding of and expectations for appropriate school environments and independence. There are at least four areas or situations where close support of the student with PWS is often a necessity and imperative in order for that student to benefit from their education:

- **Academics:** Students with PWS have diagnosis-based, ongoing, academic challenges. Slowed processing speed, short-term memory challenges, and being easily distracted mean that the student will possibly require prompts and redirection frequently, especially when placed in a highly distracting classroom without appropriate support. Classrooms with a large number of students (18 – 25) are settings where students can easily become distracted and lose learning opportunities, leading to frustration. Increased frustration often leads to increased behavior problems, which also decrease the student's learning time.
- **Food security:** The intense interest in food experienced by those with PWS is a manifestation of the diagnosis and is not something they can control. For most individuals with PWS, the only factor preventing them from accessing extra food or going into trash cans within the school setting is the arm's-length proximity of the trained aide. Simply having other school staff in the classroom is not adequate prevention, especially in a general education classroom which will have 18-25 students (several of whom may also have IEPs and need assistance). Thus, the provision of close support for the student with PWS will allow that student to function successfully in their classroom and throughout the school environment where there is food in multiple areas. Exposure to unauthorized food can be life threatening for the student due to the risk for choking and stomach rupture. It also causes the student to feel hopeful that they will get access to unauthorized food, which in turn increases their anxiety and increases the potential for behavior problems. When food is secure and there is no exposure to unauthorized food, the student's anxiety is reduced and they are better able to focus on the academic program to the best of their ability.
- **Physical security:** Students with PWS can potentially be "runners", meaning that for reasons which sometimes are clear only to them at that moment, they may take the opportunity to run out of a classroom and even out of the school building. This is a problematic situation for the student and staff, and can also become a safety issue if the student moves quickly enough to leave school property. There are multiple running triggers in each and every school day for the student with PWS. As mentioned with food security above, often the only factor preventing a student from using running as a coping option is the arm's length presence of a staff person who is trained to recognize the student's agitated state and potential for running and redirect the student appropriately.
- **Behavioral support:** People with PWS have mild to severe intellectual impairments. Some behavioral and academic challenges can be prevented or managed with proper programming and support. Many students with PWS have functional behavior assessment [FBA] data and a positive behavior intervention plan [PBIP] attached to their IEP. Often the key to the successful implementation of a PBIP is the consistent presence of an aide, teacher, or school staff person who is trained in "PWS best practices", has gotten to know the student from prolonged daily contact, and has an understanding

of how the brain functions for the student with PWS. They can assist the student in processing and managing their feelings of anxiety, rather than the student turning to perseverating, or engaging in escalating controlling and disruptive behaviors, in an attempt to manage the anxiety on their own.

It is important to note, that “independence” and the support needs of each student with PWS will vary, and will change depending on each specific setting in school. The times and situations in the school day when additional close support is generally necessary (i.e. not negotiable) for the student include (but are not limited to) coming into the school and exiting the school at the beginning and end of the day, getting to their classroom, transitioning between classrooms, and during any food-related situations (lunches, snack times, parties). At the same time, when the school staff and IEP team members have been in close communication with each other and have gotten to know the student, it will be apparent what other parts of the day can be times of check-in support. Supervision needs can change but they should be an area of constant collaboration and observation by all members of the IEP team.

It is also important to note that we encourage the concept of “supervised” or “perceived” independence, where the student is taught and encouraged to do as much for themselves as they can **safely** do. It is crucial that all aides, paraprofessionals, or school staff working with the student throughout his/her educational years keep a focus on long-term capabilities and functional goals. While it is common for individuals with PWS to transition into supported living after completing their education, and most parents will pursue legal guardianship of their son/daughter, it is also true that the student’s overall self-esteem and self-confidence will depend a great deal on their ability to function independently in as many areas as possible. The child’s parents and IEP team members should keep in constant and productive communication so that all are fully informed about the student’s individual needs for varying levels of support.

Lastly, we strongly encourage all school districts to fully train all school staff personnel working with students with PWS, **including aides and paraprofessionals**. Aide/para support staff will be working closely with the student and will need to know the student’s behavior plan, the student’s signs of growing frustration/agitation, and all of the “PWS best practices” known by the teachers. Aides/paraprofessionals should also be present for team meetings held to create and review the child’s behavior plan, so that they are fully informed of which behaviors the team is working to encourage, and which behaviors are non-preferred and how to respond to them.

Ultimately, each student with PWS will need some variety of supervision during their school day. For some students, dedicated 1:1 paraprofessional support from 1-2 consistent staff people is an absolute necessity. For other students, proximal or check-in support for some times of the day is possible. Food security for those who are food-seekers, physical security for students who elope, and behavioral support are needs inherent to the PWS diagnosis, and the IEP team should communicate closely regarding the student’s other individual needs.

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Prader-Willi Syndrome Association (USA)
8588 Potter Park Drive, Suite 500, Sarasota, Florida 34238
800.926.4797