

## **1:1 Support for the Student with Prader-Willi Syndrome**

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The first instinct of any school district in terms of helping their students grow and develop into adulthood is to help the children become as independent as possible. 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.

The student with Prader-Willi syndrome, however, requires an adjusted understanding of and expectations for appropriate school environments and independence. When the IEP team is discussing the appropriate classroom setting for the student with PWS, there will be a goal to place the student in the “least restrictive environment” [LRE] with just the amount of direct support to allow the student to get through the day. Requests for 1:1 aide/professional support are often frowned upon by school staff because this type of support is viewed as restrictive for the student. There is also a concern that the student will become too dependent upon that staff person.

The reality for the student with PWS, however, is that 1:1 dedicated support from a trained aide/paraprofessional is often the key to the student’s ability to function successfully in any type of school environment and benefit from their educational program. These students need close support for the following reasons:

- **Food security:** 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 1:1 aide. Simply having other school staff in the classroom is not enough 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 1:1 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 the 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 their mind is free to focus on the academic program to the best of their ability.
- **Physical security:** Students with PWS are often “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 always escalates to 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 1:1 dedicated staff person who is trained to recognize the student's agitated state and potential for running and redirect the student appropriately.

- Behavioral support: Many, 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 the 1:1 aide/paraprofessional who is trained in "PWS best practices", has gotten to know the student from prolonged daily contact, and has an understanding of how the "PWS brain" functions. The aide can assist the student in processing and managing their feelings of anxiety, rather than the student managing by perseverating or engaging in escalating controlling and disruptive behaviors in an attempt to manage the anxiety on their own.
- Academic support: 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 require prompts and redirection much more frequently than can be provided by 1 teacher and 1 assistant in a classroom of 18-25 students. When placed in a highly distracting classroom without 1:1 support, the student will quickly and repeatedly lose focus, resulting in their falling behind and becoming increasingly frustrated in this setting. Increased frustration often leads to increased behavior problems, which also decrease the student's learning time.

Concerns about student dependence on the aide/paraprofessional:

It cannot be stressed enough that the student's parents want their child to be as independent as they can safely handle. Parents want their child to be appropriately challenged and engaged at school, and want their child to be encouraged to do things for themselves. However, given the cognitive delays inherent in the PWS diagnosis, and the hyperphagia food drive symptom, individuals with PWS always need supervision throughout their day, both in and outside of school. Thus the goal in the school environment is always "supervised independence" or "perceived independence"; the 1:1 aide/para can support this goal by providing proximal support in settings where they have observed (over time, from being in close contact with the student) that the student is secure in a particular activity. Ultimately, however, without effective 1:1 support, the student with PWS often finds that the highly-stimulating school environment combined with their own cognitive and behavioral challenges becomes restrictive, to the point where the student is unable to function. With 1:1 support, there is a behavioral, academic, food and physical safety net which makes attendance in the public-school setting, receiving educational benefit, and accessing a free-and-appropriate public education, possible for the student with PWS.

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