Developing Your Child’s Preschool IEP  
Guiding Question and Sample Statements

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**Overarching Question:** *How can I describe my child’s PWS-related needs in a way that is relevant to classroom functioning and access to instruction?*

Present Levels of Performance (Academics and Learning):

* Beyond academic readiness skills, how do attention and language (both understanding and expressive) skills impact the student’s ability to fully engage in the classroom learning environment?
* Potential areas of impact: Speech; Language; Attention; Ability to participate in adult-directed tasks
* Sample statement:
* It is important to ensure that Noelle is attending to instructions, either by getting her attention prior to giving directions or asking afterwards if she understands what is expected.

Present Levels of Performance (Social Development):

* In addition to social engagement, how does PWS impact engagement in the classroom, ability to cope with frustration and emotional functioning?
* Potential areas of impact: Ability to cope with frustration; Emotional regulation/ lability; Food anxiety; Perseverative behaviors; Rigidity; Need for structure, routine and consistency; Social interactions/ play
* Sample statements:
* Noelle is generally an affectionate and easygoing little girl. She loves to be a helper and enjoys engaging with peers. She tends to “mother” other children by pointing out behavioral
* expectations. Expressive language difficulties can interfere with her ability to communicate with peers and adults, even those familiar with Noelle.
* Noelle can be rigid in her approach to tasks and will refuse to engage in tasks or activities if pushed into a power struggle. She responds well to routine and is quick to point out when there is variation in that routine. If an activity or reward has been planned or promised, Noelle will be insistent that it occur. Consistency is essential when working with Noelle. Behavioral expectations should be clearly stated, as Noelle responds best when she understands expectations and consequences.
* A component of the food issue for Prader-Willi is anxiety. Having food available/ visible or being uncertain as to when food might be available can be extremely stressful for Noelle. When Noelle is in an environment where she knows she will be able to eat, what she will be able to eat, and that all food is out of her reach, she is typically focused and behaved. She will not evidence food seeking behaviors. However, if there is food available to her or she believes that she can get someone to make food available, Noelle will attempt to get something. She has gone to extreme lengths to obtain food, such as going into the garbage or in other student’s backpacks. In situations where Noelle is unsure of when she will eat or if she thinks she may be put in a situation where food may be available to her, she may become unfocused on school and only focused on the food (for example, asking repeatedly if it is time to eat, when it will be time, what she will have, etc.) This sort of obsessive/ perseverating behavior is indicative of anxiety for her.

Present Levels of Performance (Physical Development)

* In addition to motor skills, how does the syndrome impact energy levels and endurance for tasks? What should staff be aware of medically?
* Potential areas of impact: Motor skills/ motor planning; Signs of illness; Daytime sleepiness; Scoliosis; Thick saliva/ drinking; Hyperphagia/ food seeking; Reduced metabolism; Sensory processing; High pain threshold; Gastrointestinal issues; Temperature regulation; Skin picking
* Sample statements:
* Noelle has been diagnosed with Prader-Willi Syndrome. Hallmark characteristics of this syndrome include food seeking behaviors, in combination with a slowed metabolism. As a result, Noelle’s caloric intake is carefully monitored.
* Noelle has issues with skin picking (typically picking at bug bites or her lips, or chewing around her nails). She typically responds well to prompts to stop, but may occasionally need to be given something to keep her hands busy. We often provide her with a band aide to cover it up.
* Noelle does not run fevers and rarely vomits (most children with PWS have no gag reflex). If her behavior seems "off", you notice an increase in her food seeking, or she blanches suddenly, these are your best signs that she is not feeling well. She also has a relatively high pain threshold.

Present Levels of Performance (Management Needs):

* In comparison to most students, what is different about how the classroom needs to be organized/ structured or interventions provided?
* Potential areas to consider: Supervision; Consistency between adults (including communication with substitutes); Use of food in instruction (manipulatives or rewards); Special events; Communication with home
* Sample statements:
* Noelle should not be allowed to eat anything other than what is provided from home or has been previously approved by her parents. Noelle responds well if reminded that she has her own special food rather than simply being told that she cannot have something else.
* Food cannot be used as a reward for Noelle, or even for others in her group. Noelle can be distraught that other people are given food, and will become visibly upset (her face gets red, she shakes a little and she cries). Rewards should be in the form of non-edible items, such as stickers or special privileges.
* All food items in a classroom setting should be secured in a location out of Noelle’s reach. During snack and meal times, Noelle needs to be carefully monitored to ensure that she does not beg or take food from her peers. The disposal of left-over food should also be monitored, as Noelle will eat food off someone else’s plate or out of the trash on occasion.
* If a craft/ art project involves food items, an adult should monitor her work and hand individual items to her as she completes the project, in order to prevent her from having the opportunity to eat the materials. The use of typically non-edible items that could be mistaken as edible (such as Play-Dough) should also be monitored.
* Noelle needs her syndrome explained to all adults working with her, including transportation. She needs to be supervised throughout her day. A note to a substitute teacher should read something similar to this: “Noelle has a genetic syndrome that makes it necessary to restrict her food intake. She need to be watched when the class is eating or food is around, as she cannot have anything other than what was sent from home. She needs this structure both for health and behavioral reasons. Any questions should be directed to one of the adults working with her.”
* Any upcoming celebrations involving food need to be addressed with Noelle's parents ahead of time.

Remember to utilize the present levels of functioning as the basis for the   
remainder of the IEP:

* What goals should be prioritized, with those goals aligning with the student-specific needs outlined in the present levels?
* How will you know when the student has achieved those goals?
* What services, modifications and supports for school personnel are needed to help the student meet their goals?
* While the goal is to be in the least restrictive environment, where will the student’s progress toward their goals be best accommodated (i.e., participation with non-disabled children)?

Compiled 5/2020

Medical Overview for School Nurse and Medical Support Staff