Key Component for Success with a child with Prader-Willi Syndrome in a School Setting

These notes on working with children with Prader-Willi Syndrome in a school setting are taken from the presentation "Behavior Challenges in a School Setting," written by Mary K. Ziccardi. Ms. Ziccardi is an Executive Director with REM, OH and serves as a behavioral and educational consultant for the Prader-Willi Syndrome Association (USA) working with school across the country to create more effective learning environments for students with Prader-Willi Syndrome.

Key Component for Success with a child with Prader-Willi Syndrome in a School Setting
1. Structure and Predictability
2. Staff Competencies and Commitment
3. Supervision
4. Food Security

Structure and Predictability
- Use of written and/or picture schedules
- Limiting choices to two
- School personnel who provide assurance are a "safety net", providing a sense of security
- Predictability reduces overall anxiety

Staff Competencies and Commitments
- Must match personality, training, and desire…“it’s not for everyone”
- School staff require ongoing support and updated information
- Build a relationship of trust between home and school

Supervision
- There is no substitute for consistent visual and/or auditory supervision.
- School teams should identify and discuss particularly vulnerable situations (i.e. transportation, bathroom breaks, substitute teacher or aide) and have a pre-agreed plan.
- Building a relationship with and wanting to be with the student is preferable to just “watching” him/her.

Food Security and Controls
- Transportation
- Holidays, birthdays, special occasions
- Avoiding the "just this once" phenomenon

Four Challenging Behaviors and Solutions

Issue #1: Transitions
- Sudden change in routine or schedule, particularly around food
- Difficulty accepting the change, even if it is a "preferred" activity

Strategies
- Keep schedule and routine predictable
- Have a staff dedicated to the student in order to take the time necessary to work through the changes

Issue #2: Perseveration
- Repetitively asking the same question/saying the same phrase
- Talking about the same topic or event repeatedly
- Playing with the same toy or puzzle over and over again

First Analyze…
- Is the repetition soothing?
- Does it signal stress and/or an imminent meltdown?
- Is it disruptive?

Once these issues are addressed, then…
- Be certain the child does know and understands the answer/information
- Ignore when possible
- Write down/use a picture to affirm the answer
- Give the student the “last word” on the subject

Issue #3: Sleepiness and Trouble Paying Attention

Strategies
- Work with the school staff to
- Accept this characteristic as one you may have little influence over…but manage the environment by…
  - Presenting high and low movement/activity levels alternately
  - Use highly motivating rewards for particularly difficult times
  - Sit the student close to the teacher/center of activity

Issue #4: Food Management
- Searching for food that is not properly secured
- Seeking garbage and other in-edibles
- Trading/borrowing/swapping for food
- Being victimized for the promise of food

Strategies
- Keep all lunches out of sight and secured
- Do not use food in the classroom as reinforcers or teaching tools
- Agree with the school that your student only eats/drinks what is sent from home
- Monitor/secure all trash cans
- Discuss in advance and provide additional supervision for holiday parties