

## 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

- Use logical sequence of events throughout the day

##### 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