

## Key Components 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 schools across the country to create more effective learning environments for students with Prader-Willi syndrome.

### Key Components:

- A. Structure and Predictability
- B. Staff Competencies and Commitment
- C. Supervision
- D. Food Security and Controls

#### 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 (4) 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 inedibles
- 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