

Effective Communication with People with PWS

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This presentation focused on three critical areas impacting individuals with **Prader-Willi Syndrome (PWS): Executive Functioning Disorder (EFD), Sensory Processing Disorder (SPD), and Theory of Mind (ToM)**. Two interactive activities emphasized the importance of communicating in a way that supports success, speaking **low, slow, steady, and concise**.

Key Takeaways:

Executive Functioning Disorder (EFD):

- People with EFD **struggle to organize, plan, and retain instructions**, which is often mistaken for defiance or lack of understanding.
- **Impulse control** is compromised; emotional responses may be immediate and intense.
- **Attention span** is limited, structured environments with **frequent breaks** and **varied activities** help maintain focus.
- Clear, step-by-step instructions delivered slowly help minimize anxiety and confusion.

Sensory Processing:

- Many individuals with PWS have **slow processing speeds** and **heightened sensory sensitivities**.
- Rapid instructions overwhelm the individual. It is essential to **slow the pace** and **break down information** clearly and calmly.
- Individuals typically retain **only the last thing said** in a sequence, keep communication simple and focused.

Theory of Mind (ToM):

- Typically develops around ages 3-4 in neurotypical individuals.
- People with PWS often **do not naturally develop Theory of Mind**, affecting their ability to understand others' thoughts, feelings, and perspectives.
- The good news: **ToM skills can be taught**, using techniques like **modeling self-talk**, e.g., "I don't like pop music, but Jeremy does, maybe we can listen to Taylor Swift for him."

Practical Strategies & Insights:

- **Meet individuals where they are**, not where we want them to be.
- Use **individualized communication plans**, avoid complex vocabulary and unnecessary words.
- Promote **inclusive communication**, simple, respectful, and consistent.
- **Fantasies** are common and generally **harmless**. They can be **encouraged**, as long as they don't cause harm to self or others.