

Most children and adults with PWS are highly motivated to have friends, but for most, friendships don't come easily, if at all. More often than not, our loved ones don't quite fit squarely into the Special Needs World, nor do they fit entirely in the Typical World. Our loved ones often live with one foot in each world; constantly, precariously straddling and balancing both. This balancing act expends a lot of energy.

At first glance, social media looks to be an excellent way for persons with PWS to connect with and enjoy the company of others. Whether through Facebook, X (formerly Twitter), Instagram, Snapchat, or TikTok, reachable by computers, smart phones, and gaming systems, some platform is always readily available for our loved one to connect, share, and interact with someone in some virtual community somewhere in the world.

The challenge is that most kids and adults with PWS lack the skills required to use social media responsibly and safely. Let's first look at why this is true, and then let's look at what it takes for them to engage appropriately on some social media platforms.

How does PWS interfere with using social media appropriately?

To varying degrees, PWS interferes with executive functioning skills and social functioning skills. The loss of these skills makes using social media not just challenging, but potentially dangerous.

Executive Functioning Skills include:

- Good judgment
- Adequate impulse control, self-control
- Ability to shift thinking, adjust plans
- Ability to see another's perspective
- Ability to experience the passage of time, estimate time, manage time
- Ability to self-monitor, self-regulate, and manage emotions

Social Functioning Skills include:

- Effective communication skills
- Effective ability to read non-verbal cues
- Empathy
- Listening skills, paying attention, understanding, and showing the speaker they are heard
- Emotional regulation
- Ability to resolve conflict
- Cooperation and teamwork
- Assertiveness by clearly stating needs, wants, and rights without aggression or passivity
- Social awareness including understanding and following unwritten social rules and customs (e.g., don't pick your nose in public, etc.)

Consider the scenario where the individual with PWS receives a communication requesting a photo of their private parts in exchange for friendship. The strong desire for friendship coupled with a lack of judgement and impulse control may become problematic. If the individual with PWS is age 18 or over and the other party is a minor, we are now in some serious legal territory.

Or consider the individual with PWS who interprets a conversation benignly when in fact, the other is engaging in bullying behavior. Without ability to see things from another's perspective and without ability to resolve conflicts effectively and amicably, there could be seriously hurt feelings, or worse. On the other hand, I've seen individuals with PWS brutally bully others, engaging in manipulative or intimidating behavior in attempt to achieve food, objects, relationship, or perceived higher social status.

We know from PWS specialists Janice Forster, M.D. and Linda Gourash, M.D. that core features of PWS include cognitive rigidity and an excessive drive for reward, not just for food. Because the brain's "brakes" don't work properly, the brain's pleasure center tend to run on overdrive. "Enough" is *never* enough whether it's food, talking, asking questions, dispensing soaps, using toilet paper, electronics time, collecting things – including collecting "Friends" on Facebook by admitting *everyone* without discernment. I can't tell you how many sexually provocative photos of "Friends" on Facebook I've deleted from my son's account over the years.

For many with PWS, if it was seen, read, or heard on social media, then it *must* be true. Often, no amount of rational argument will persuade a change of mind. This cognitive inflexibility, coupled with the need for things to be the way the individual *wants* them to be, not as they *are*, plus a degree of gullibility, naivete, and inability to see things from another's perspective can lead to inability to accurately assess hostile, risky, or dangerous intent or consequences.

So how do we as parents and care providers help our loved one safely access social media?

First, we need to understand that our loved one *needs* support in order to use social media safely. Higher IQ has little impact upon managing oneself more safely. We need to provide supports for social media and smart phone use in much the same ways we provide supports in general.

- **Provide supervision at all times**, the same way we do with food. We restrict our son's access to electronics to when we are in the same room, and we have also learned (the hard way!) to position him in front of us so that we can see his screen, lest he wander to unauthorized sites.
- **Regularly review all social media platforms** by checking history, communications, etc.
- **Use Parental Controls on all Internet-connected devices and social media platforms.**
- **Place limits – boundaries – around how much time may be spent on electronic devices.** Remember to use Preferred Choices when determining time limits: "Let's establish some time limits. Do you want to use Insta for 20 minutes or 25 minutes today/each day?"