

## Braden on Behavior Public or Private?

Including people with handicaps in our communities poses significant challenges. While inclusion helps increase normalization, it also increases vulnerability to community risks and hazards. How do we prepare children and adolescents to access their communities without running the risk of their being exploited, or showing affection in inappropriate ways, using sexual language that may be misconstrued, or touching body parts that could bring legal action or at the very least a disgruntled public?

If we simply advocate for opportunities to be included and leave it at that, we are not fulfilling our obligation to those who do not automatically develop or naturally demonstrate prosocial behavior. We teach academic skills in a systematic fashion, skill-streaming the ones we feel are most salient for each level of functioning. Why then do we assume matters of prosocial behavior will develop without direct instruction?

People with FXS experience a unique social dilemma because on the one hand they express a desire to be social, but when given the social opportunity, they can become so hyperaroused that they retreat and prefer to watch from a distance. This approach-avoidance behavior can become a deterrent to acceptance and experiences of social reciprocity. I have discussed this phenomenon in a prior column with respect to the role that anxiety plays in social integration. This article, however, is focused on teaching more prosocial behaviors, absent anxiety.

In 1981, two very brave female professors at Portland State University began to discuss and write about how people with disabilities need prosocial and sex education training. At that time many people believed that persons with disabilities belonged in institutions and that to even fathom social/sexual relationships among those with mental or physical challenges was perverted and taboo. I was fortunate enough to have known those women, and I benefited from their mentoring. Twenty-five years later we can truly say, "We've come a long way baby." But we have further to go.

Strategies to reduce the anxiety provoked in social venues are certainly important in our quest to foster more natural social interaction. There are, however, other important skills to becoming more accepted in a very discerning social society. Teaching children at an early age how to discriminate between public and private provides a rule-based strategy that can use visual supports. This process begins early so that the child comes to understand the concept of public and private places, people and behaviors. It also can lay the groundwork for responding to more abstract social dilemmas that present throughout the life span.

For example, a very young child may be allowed to remove his pajamas and underwear in preparation to dress for the day while watching his favorite cartoon in the family room. As the child grows older, this standard becomes less appropriate, yet the behavior has become so embedded into his daily routine and schedule that it becomes difficult to change. It is also hard for the child, as he gets older, to understand why the behavior is now inappropriate and no longer tolerated.

Another example is when as an adolescent, a boy chooses to unzip his pants to tuck in his shirt. That behavior is considered private, allowed only in a private setting such as the bedroom or bathroom. If that lesson is not learned early and the behavior takes place in public, it might be construed as a sexual act or as pre-perpetration behavior.

Training to distinguish clearly between public and private can also be critical to a child's avoiding exploitation. Knowing that touching and hugging is a private behavior that should only be demonstrated with private people such as family members and *not* strangers may provide a safety net and subsequent protection. Learning a concrete rule-based structure eliminates any guessing or evaluative process in situations that might result in an exploitive relationship.

Teaching prosocial behavior works best using real life photographs and video vignettes that demonstrate appropriate social interactions using the private and public context. The structure of this type of program provides reinforcement so that when similar real life situations are encountered, the learned skills can be applied and the behavior corrected in a safe and caring environment.

Teaching to discriminate between private and public behaviors and then matching those behaviors to public and private places and people provides a simple, concrete method to shape safe behavior. It also allows for immediate redirection from a parent, caregiver or school staff when unsafe behavior occurs. If, for example, when the person with FXS engages in behavior that should be demonstrated only in a private place, the parent can say, "Stop, that's private," and redirect him to a private place like a bathroom or bedroom.

The chart below is an example of a matrix of behaviors identified as either private or public, along with corresponding people and places used in this program.

---

## BEHAVIOR

---

### Public Behavior

---

- Blowing your nose
  - Holding hands
  - Talking on the telephone
  - Dancing
  - Shaking hands, high-fives
  - Hugging or being hugged
  - Pats on the back
  - Kissing on the cheek
  - Eating
  - Riding public transit
  - Smiling at another person
  - Giving compliments
- 

### Private Behavior

---

- Wearing pajamas
  - Urinating, having a bowel movement
  - Masturbating
  - Dressing and undressing
  - Changing underwear, Depends
  - Flatulating
  - Kissing
  - Taking a bath or shower
  - Intimately touching others (private areas)
  - Cursing
  - Zipping and unzipping pants
  - Changing tampon or sanitary napkin
  - Closing bedroom door
  - Standing very close to someone
  - Keeping a secret
  - Brushing teeth
  - Putting on deodorant
  - Giving out address or phone number
  - Insulting others
  - Writing in a diary
- 

---

## LOCATIONS

---

### Public Places

---

- Public restrooms (school, church, restaurant)
  - Theaters
  - Restaurants
  - Living rooms; common rooms
  - Buses and public transportation
  - Library
  - Classrooms and playgrounds
  - Automobiles, trains, airplanes
  - Stores, shopping malls
  - Church, synagogue
  - Public park, amusement park
  - Museums
- 

### Private Places

---

- Bathroom at home
  - Bedrooms
  - Hotel rooms
  - A private place with a door closed
  - Doctor's office/examining room
  - Airplane bathroom
-

---

## PEOPLE

---

### Public

---

- Postal carrier, delivery person
  - Bus driver
  - Waitperson
  - Plumber
  - Teacher
  - Acquaintances
  - Policeman, fireman
- 

### Private

---

- Mom, dad, sibling, grandparents
  - Girlfriend or boyfriend
  - Spouse
  - \*Pastor, priest, rabbi
  - Close friend
  - Doctor, dentist, therapist
- 

\*Depending upon the context these individuals could be considered Private or Public

Providing good modeling and consistent intervention to distinguish public from private spheres must begin at an early age. Engaging the child in a structured program to teach these issues at a young age will pay off as a child matures, when acceptance is often determined by prosocial behavior. People with FXS have so much to offer. It would be a grave disservice to our society to limit their free access to communities due to inappropriate social behaviors. Yes, we've come a long way baby, but the best is yet to come!

## Braden on Behavior Reading, Writing & Behavior?

Now that school is back in session, I am reminded about the significance of appropriate educational supports. In my role as a consultant, I have encountered on numerous occasions a lack of understanding about how important the learning environment is to behavioral outcome. An interesting study by Symons, Clarke and Roberts (2001) concluded that engaging children of elementary age with FXS was strongly related to the environmental and instructional quality of teachers and classrooms. The authors found that the ways in which teachers structured and arranged the classroom environment was more important than were the specific aspects of the child's FX status such as severity of affectedness, medication usage or dual diagnosis.

This documents what we have experienced clinically for years. Best practice for those affected with FXS means providing a learning environment that allows them to access the curriculum in ways that minimize disruptive behaviors and even further, without a teacher being overly concerned about functional levels or complex diagnoses.

Even though the Fragile X community has worked very hard to include children with FXS with their typical peers, the educational systems often fall short in their mandate to provide a free and *appropriate* education. The issue of appropriate education has been debated through many due process hearings, culminating in a number of landmark special education decisions. In my view, an "appropriate" education requires accommodations and adaptations specific to a special education student's condition. For example, students with FXS have a keen sense of belonging, especially when they notice their level of performance is not on par with the typical peers surrounding them. This can have a significant impact on their behavior. Learning is contingent upon engagement. When a child is disengaged it becomes critical to assess any factors that contribute to that disengagement.

One antecedent that is often overlooked when assessing engagement is the curricula and lack of necessary adaptations. When there are students with FXS in a classroom, the curriculum must include adaptations that incorporate what we know about their learning style. If adaptations specific to FXS are not provided, the student may lack the skills to respond successfully.

It is not uncommon to observe students with FXS working hard to avoid curricular expectations, especially when their skill set is inadequate. The student with FXS may see no other option than to respond with some form of aberrant behavior in order to avoid the failure. Neglecting to account for this possibility when formatting an instructional model is a recipe for disaster. In addition, failing to consider the arrangement of the classroom and environmental adaptations may also contribute significantly to aberrant behaviors.

Too often, educators consider behavioral issues to be separate from the instructional program, making it easy to lose sight of the curricular factors that may be contributing to a problem behavior. With the reauthorization of the Individuals with Disabilities Education Act (IDEA), there is now an emphasis on

implementing interventions that are scientifically based. It is no longer acceptable to determine special education eligibility simply on the basis of student failure. Now, if the student fails, the intervention itself must be analyzed, along with the student's response to the intervention. This shift supports the need to implement appropriate intervention strategies that include remedies specific to the child's condition, and long before a behavior intervention plan is developed. It also highlights the need to look beyond the identified behavior and to address other factors that might be contributing to the behavioral response.

The tendency to focus on isolated behavioral episodes before considering the environmental, curricular and instructional methodology is no longer accepted. The evidence is clear, the mandate has been clarified, and the students will ultimately thrive within this new approach to behavior intervention. The simple take-away lesson is this: Before your child's teacher targets a specific behavior, he or she must carefully consider your child's level of engagement and how it might be enhanced through environmental adaptation and instructional design.

Addendum to  
 Braden on Behavior  
**Reading, Writing & Behavior?**

<b>Best Practice Supports for Students w/FXS</b>	
<b>Environmental Accommodations</b>	<b>Curricular Adaptations</b>
<ul style="list-style-type: none"> <li>● Provide structure and predictability of schedule</li> <li>● Provide opportunities to be included with normal peers</li> <li>● Reduce level of noise, proximity of other students and EA's</li> <li>● Use natural lighting whenever possible</li> <li>● Avoid crowded areas/help desensitize student to large crowded environments</li> <li>● Encourage opportunities to move</li> <li>● Remove stressful events</li> <li>● Provide support for transitions, i.e. transitional object, job or task to move from one location to another</li> </ul>	<ul style="list-style-type: none"> <li>● Use teaching triad (indirect instruction with another student)</li> <li>● Provide small group instruction</li> <li>● Provide visual supports such as charts, diagrams, pictures and color coding</li> <li>● Provide nonverbal feedback</li> <li>● Provide sensory intervention with an OT</li> <li>● Use hands on materials to teach math – understand it is a very difficult academic area</li> <li>● Teach reading using a visual approach</li> <li>● Provide alternative means of responding to written tasks</li> <li>● Use technology to augment writing</li> <li>● Enhance learning using high interest materials</li> </ul>