

## All Behavior is Communication

## All Communication Affects Behavior



**Challenging behaviour**, also known as **behaviours which challenge**, is defined as "culturally abnormal [behaviour](#)(s) of such intensity, frequency or duration that the physical [safety](#) of the person or others is placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to the use of ordinary community facilities". "Ordinarily we would expect the person to have shown the pattern of behaviour that presents such a challenge to services for a considerable period of time. Severely challenging behaviour is not a transient phenomenon."<sup>[1]</sup>

### Who Decides When a Behavior is Challenging?

**Hint: Usually, it is the adult in charge.**

In her book, "Brain-Body Parenting", Mona Delahooke, Ph.D. tells us that behaviors are "communication of an unmet need (75)" and that self-regulation is "intentional control of one's thoughts, emotions, and behavior (95)."

In her book, "Interoception The Eighth Sensory System", Kelly Mahler, MS, OTR/L draws a distinct line between Interoceptive Awareness and Self-Regulation.

She tells us that "The interoceptive system drives the development of self-regulation from infancy (43)," and that "Individuals with poor Interoceptive Awareness may have difficulty controlling emotions because they don't know what the emotion is (44)" and that "...without good Interoceptive Awareness, good self-regulation cannot exist."

In his book, "Uniquely Human", Barry Prizant, Ph.D. tells us that building trust in others to offer understanding and support and the realization that the world is a safe place is necessary to reduce the anxiety that can result in challenging behaviors. He encourages us to follow his "simple advice: Listen, observe, and ask 'Why?' (51)."

In their book, “Autism and Difficult Moments”, Brenda Smith Myles, Ph.D., and Ruth Aspy, Ph.D. discuss the general inability of ...”people with HF-ASD to indicate in ways that are meaningful to others that they are under stress or having difficulty coping...these signs of stress often go unnoticed by others in the environment (12).” Their conclusion is that:

“without training and/or experience – that is, without knowing the connections between meltdowns and ASD – the neurotypical person observing a meltdown may draw uncharitable conclusions. As a result, meltdown behaviors may result in rejection, punishment, fear, or judgment.”

When a neurotypical person without training attempts to intervene or control the behavior of a neurodiverse individual, they are often doing their best in a difficult situation with the knowledge that they currently have. It is important for them to know that:

- Meltdowns do not occur without warning
- Challenging Behaviors are rarely exhibited “just to get attention”
- Support Persons must realize that their own behaviors may interfere with a person's ability to regain self-regulation in a challenging situation
- Understanding the cause of “challenging” behavior can result in positive intervention and teachable moments

In her book, “The Way I See It”, Temple Grandin, Ph.D. tells us that:

“Behavior never occurs in a vacuum; it is the end result of the interaction between the child and his or her environment, [including] the people in it.” To bring about positive change in the behavior of the child with ASD, adults need to first adjust their own behaviors [and beliefs].”

All good advice from all good researchers and therapists. How can we take their advice and move forward to benefit ourselves and those individuals that we support?

Changing the way we view “Challenging Behaviors” could be a first step to helping those we support to learn self-regulation in positive ways, without rejection, fear, or punishment.

**[Video – “The Square Hole”]**

<https://www.youtube.com/watch?v=cUblkNUFs-4>

## **Changing Challenging Behaviors IS possible.**

With kindness, understanding, compassion, patience, and learned skills.

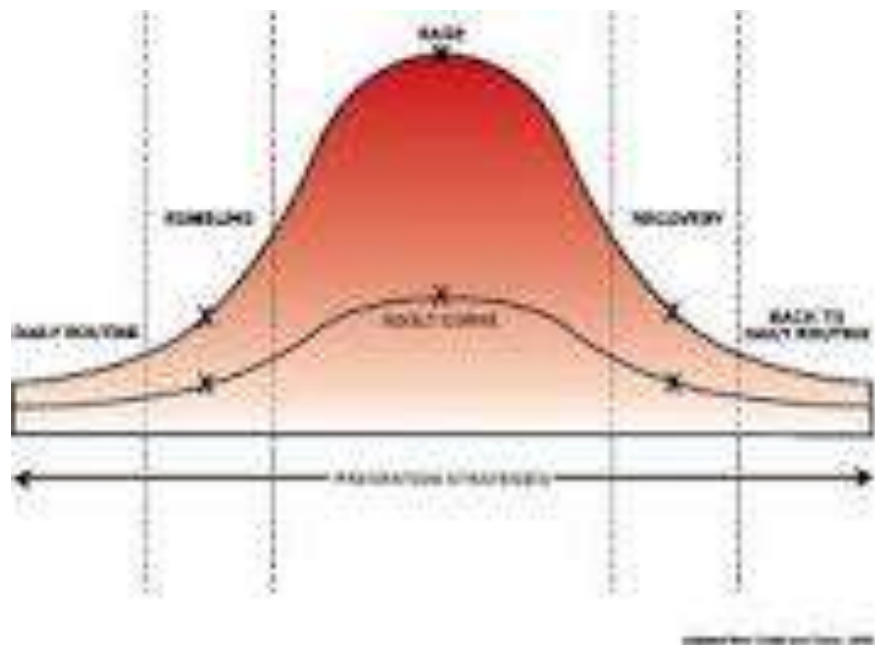
### **MELTDOWNS DO NOT OCCUR WITHOUT WARNING: SYMPTOMS**

- Biting lips or nails
- Lowered voice
- Tense muscles
- Tapping foot
- Grimacing
- Appearing disengaged
- Complaints of not feeling well
- Withdrawing socially
- Threatening others
- Questioning rules of authority
- Becoming argumentative or verbally challenging
- Physical aggression

## COMMONLY IDENTIFIED “CHALLENGING BEHAVIORS” (Myles/Aspy)

- Being Disinhibited
- Acting Impulsively
- Emotional
- Explosive
- Destroying Property
- Self-injurious
- Screaming
- Biting
- Hitting
- Kicking
- Experiencing Internalized Behavior
- Desk throwing
- Elopement

These “challenging behaviors” can be seen during the “Rage” portion of the “Rage Cycle” Identified by Brenda Smith Myles and Jack Southwick (1999).



The most important take-away from this illustration is that teachable moments are at the end of each curve and are the ONLY times a new skill can be learned.

## **Support Person Behaviors that Can Escalate a Crisis (Myles/Aspy)**

- Raised voice or yelling
- Making Assumptions
- Preaching
- Backing the student into a corner
- Saying "I'm the boss here"
- Pleading or bribing
- Insisting on having the last word
- Bringing up unrelated events
- Using tense body language
- Generalizing i.e., "you guys are all the same"
- Being sarcastic
- Attacking the individual's character
- Making unsubstantiated accusations
- Nagging
- Holding a grudge
- Acting superior
- Throwing a temper tantrum
- Using unwarranted physical force
- Mimicking the individual with ASD
- Drawing unrelated persons into the conflict
- Making comparisons with the behavior of other people
- Insisting on being right
- Having a double standard "Do what I say, not what I do"
- Commanding, demanding, dominating
- Rewarding the individual for unacceptable behavior
- Using degrading, insulting, humiliating, or embarrassing putdowns

## **Effective Support Person Behavior (Myles/Aspy)**

- Control “flight-or-fight” tendency
- Remember that “less is more”
- Remain calm and quiet
- Remain neutral
- Do not take behaviors personally
- Disengage emotionally
- Be conscious of your nonverbal cues
- Take deep breaths
- “Walk don’t talk”

**[Video – “These Kids I Taught”]**

**<https://www.youtube.com/watch?v=WnoqhiRdjw8>**

### **ALL BEHAVIOR IS COMMUNICATION**

### **BUT WE DON’T ALL SPEAK THE SAME LANGUAGE**

Most of us learn how to communicate in our family of origin and we expect the communication skills we have learned to serve us well in our interactions in society. Usually they do. But what if we decided to join a different society? A different religion, a different country with a different language and customs, a different lifestyle? Our learned communication skills will need to be re-learned to fit the new circumstance.

We could expect to feel confused, anxious, fearful, frustrated, unhappy, maybe angry.

Like how I felt when I visited Greece with my sister, I asked to use the toilet at a restaurant where we had lunch. The server pointed to the inside of the bar area – which was not currently serving. Inside the bar, I found no signs or indications of a restroom, I came out, looked around, went back in and eventually realized that that initials “W C” were painted in 3 foot high letters on a door – leading to

the restroom. My year of college French helped me to recognize this as the “water closet” or restroom, (not to be confused with “La Salle De Bain” which is the Salon of the Bath or the room with a bathtub).



It was possible for me to recognize the restroom because I had some prior learning.

When a learner is neurodiverse and the support person is neurotypical, communication will be difficult, especially without prior learning or pre-teaching to connect them.

In essence, we need to learn each other’s language. Each family has its own native culture, and outsiders are often alien to that culture. As professionals, we

need to rely on the insiders of that family: parents, children, other family members, to explain or interpret the language, be it verbal or non-verbal.

It can be hard for us to recognize that our people may be responding to something in ways that are appropriate, if unfamiliar, to us. Once we learn each other's language, communication becomes possible and sometimes easy.

## **Where To Begin?**

Barry Prizant tells support people to :

- Listen – to what is being communicated
- Observe – how it is being communicated
- Ask Why – they are communicating

Not 3 simple steps to be undertaken in a 10 minute bi-weekly OT session.

This is a process that is undertaken over time to build trust and reduce anxiety.

Trust is built carefully over time with kindness, respect, and compassion. Most professionals don't have a dedicated 50 minutes or more each week with a person they support, like I do. But repeated, positive exposure to a person, place, or situation, will result in trust over time. The 10 minute semi-weekly OT visit may serve only to build trust for the first school term. Progress may not be made until the second or third, school term – provided the professional is the same person in the same place.

If the person or place changes, foreshadowing the change is vitally important to keep the level of trust intact.

### **[Share story of Janna and sexual abuse.]**

I met Janna when she was about 6 yrs old. She had significantly sexually abused in a day care center. The perpetrators had been charged and imprisoned, the day care center closed, but the trauma created problems for Janna in all aspects of her life.

Janna and I spent approximately 150 hours of individual, face-to-face therapy together in the same office before she was able to trust me. She sang and danced, drew pictures, played games with me, but didn't share her history of abuse in that childcare setting until we had been in therapy together for 3 years. She was always my 4:30 appointment on my late day and one day it was just time to share and she did, for 2 ½ hours. I later considered that all the music, dance, and games was her way of presenting the best parts of herself to me so that when she shared the worst parts, the trauma, I would still like her.



Pop psychology would have us believe that everybody, neurotypical or neurodiverse, needs to be able to trust someone to reveal their true selves, “warts and all”.

In this instance, Pop psychology is right.

### **How Do We Build Trust?**

- Acknowledge attempts to communicate, try to respond appropriately
- Practice shared control – offer choices, listen to their 'voice'
- Acknowledge emotions – an emotionally dysregulated person may appear to be disruptive or inappropriate. Consider their emotions, how can you help?
- Be dependable, reliable, and clear – Do what you say you will do when you say you will do it. Be clear and transparent in your communication.  
Consider using Hidden Curriculum or similar materials to explain expectations in specific situations when pre-teaching social skills and foreshadowing.
- Celebrate Successes!

When a child begins to trust their support team, they can begin to trust the world.

### **Acknowledge attempts to communicate, respond appropriately**

What does your person's communication look like?

- Verbal
- Verbal – verbally aggressive, keening
- Non-verbal (sign)
- Non-verbal – Assisted Technology
- Physical – body movements, showing or pointing
- Aggressive – pushing or shoving
- Distracting
- Refusal
- Shutting down
- Withdrawal

All of these types of communication are valid, although sometimes inappropriate.

All communication deserves respectful response.

All respectful responses can help to develop a trusting relationship.

Above all, the support person needs to remain calm, neutral, and professional

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### **Examples of inappropriate behaviors**

I met Peter when he entered 7<sup>th</sup> grade. I had actually received a written 'warning' from his case manager at his middle school when I requested records. At our first appointment, he focused on my gold desk clock, wanting it for himself. When I refused to let him have it, he left the session without permission and began keening in the outer vestibule, disrupting my suitemates. *(insert clock photo here)*.

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I met Janie when she was in 3<sup>rd</sup> grade. She was a "behavioral problem" in her parochial school, not yet toilet trained, had no friends, and was unable to read. She wanted to make friends, so she and I began to work on social skills and behaviors. When I tried using written materials with her, she complained of feeling tired or tried distracting with questions about me. I didn't realize that her reading skills were significantly below 3<sup>rd</sup> grade level.

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I met Kenny at age 12, he refused to communicate with me, sitting inside his hoodie and remaining mute. His primary care physician had suggested he was ODD. His previous therapist had discharged him as "noncompliant with therapy."

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I met John at age 16 – he was addicted to video games. I suggested a break from video games and he attacked me physically until his father pulled him off of me.

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All of these communications were valid, some inappropriate or dangerous, but valid.

My job as a support person is to build the trust that needs to be in place to allow my clients to accept me and to engage meaningfully with me to facilitate their successful communication with me and with others.

By remaining calm, neutral, and professional in these challenging interactions, my person recognized the environment in my office as a safe space, a place to grow.

## **How do we Begin?**

### **Practice Shared Control**

In Janie's case, we had established rapport and it had resulted in a trusting relationship.

However, her poor reading skills, low functional IQ, and receptive language disorder created problems for us when trying to use printed materials. I defaulted to Jed Baker's picture books for social skills training and, when she was older, Laufenberg's Social Skills video programs, both of which were remarkably successful for her.

WE took control her of her learning style through visual communication and shared the control of her sessions. After transferring to the public school system, She did learn to read at the 4<sup>th</sup> grade level, graduated high school, succeeded in Project Search and works part time as a dietary aid in an assisted living facility.

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In Kenny's case, we established a trusting relationship by me allowing him to take the necessary time to become familiar with my office and comfortable with me. I didn't wrestle with him for control of the situation. I let him know that we would spend 50 minutes together each week and that I would respect his need for peace. I only invited him to share when ready, which he was eventually able to do. I never saw the symptoms of ODD suggested by the primary care provider, only the ASD and Anxiety, which we acknowledged and he was able make progress in both areas.

### **Acknowledge Emotions**

In John's case, we had not established rapport or trust. I mistook his agreeable presentation as a willingness to work with me through therapy. His parents asked advice, I asked appropriate questions, and gave my best advice.

John attacked me physically he was tall and broad-shouldered, he put his hands on my shoulders and his chest on my head and began to push down with force— he obviously wasn't communicating his dissatisfaction with the session until that time. He was angry, his parents were shocked and I was fearful and somewhat injured. I responded professionally, but not well, repeating that he was hurting me and to to let go of me.

A better choice would have been for me to allow John to talk about his "gaming addiction" and for me acknowledge John's emotions related to this passion before suggesting interventions.

## **Be Dependable, Reliable, and Clear**

In Peter's case, I explained the 'office rules' for a session and he agreed to those rules. But my clock hadn't been addressed in the 'rules' conversation.

When I added the 'clock rules,' he refused to comply, and eventually left the session, keening in the vestibule and disturbing my suitemates.

My approach was to explain that keening wasn't appropriate communication for this situation. When he returned for a second session, we created A social story that was effective in controlling his verbal outbursts. Another social story was effective in controlling his desire to have my clock.

When we shared control over the situation through social stories, which he helped to write, we were able to develop trust and work together for his success.

- Dependability is key in a trusting relationship.
- Reliability is defined as "being trustworthy, performing consistently well."
- Clarifying expectations and/or goals helps your person to succeed.

### **How we present to our people is more important than what we say.**

Regulating ourselves and kindly communicating that regulation through looks, touch (if appropriate), mood, and general disposition helps our people learn what appropriate self-regulation feels like, allowing them to mirror that regulation to us and to use it in present, as well as future, similar situations.

When we regulate ourselves, we can begin to use co-regulation with our people.

“Co-regulation is nurturing connection of another individual that supports regulation needs through the use of strategies, tools, and calming techniques in order to self-soothe or respond in times of stress. Co-regulation and self-regulation are part of the developmental process.

Co-regulation begins when we begin caring for our people;

we develop communication skills, shared language, and give and take in our relationship.

This takes practice, perseverance, trial-and-error, relationship repair, failure, and success.

Many of my clients are working on social skills and self-regulation as goals.

In those cases, helping them to self-regulate, feel at ease, in my office can be challenging. "Small Talk" doesn't typically work with people on the autism spectrum. Sometimes we begin sessions with a game, like Uno, or a 'talking game' or beginners yoga. These activities can help to open our connection and support self-regulation.

(Insert Photo of games here)

Using strategies such as these helps our people connect with us and become 'ready to learn'. We all know that even the best teacher will have difficulty teaching people who are poorly regulated. When we help our people self-regulate, we encourage effective learning.

Some of my clients have Alexithymia, or poor emotional awareness. Alexithymia makes it difficult for these individuals to identify and describe emotions. Rates as high as 65% among young people with ASD were noted by Berthoz & Hill (2005) and Bird & Cook (2013). It is important for us, as professionals, to recognize that these people are not without emotions, they have merely not learned to identify and share their emotions.

Kelly Mahler tells us that "without clear awareness of Interoceptive signals, effective self-regulation does not naturally develop and improve as we grow."

"Behavior can be changed in specific situations.

however, until the individual and their support team identify the underlying cause of Interoception Awareness, no generalization will occur."

Mahler has created a program called "IA Builders" which also utilizes visual supports and social narratives, to help increase interoceptive awareness to help improve self-regulation.

The Incredible 5 Point Scale by Kelly Dunn Buron and Mitzi Curtis is another excellent tool to help with self-regulation, as is When My Worries Get Too Big also by Kari Dunn Buron.

As professionals and carers for individuals with ASD, it is important for us to help those we support to identify their emotions and physical feelings to help them find effective ways to self-regulate.

Compassion and empathy for our people helps us teach them regulation skills and helps them trust us enough to learn and internalize this information.

## **What About an Emotional Regulation Plan?**

**Always necessary**

**Needs to be a collaboration between a person and the support team**

**(Insert DPI My Emotional Regulation Plan image here)**

**Almost every expert in the Behavioral field has a sample plan for us to use.**

**What will make a plan valuable is: how effective the plan is for the support person and the individual with ASD.**

### **Beliefs, Training, and Attitudes of the Support Team**

- When carers assume a child can self-regulate and the child can't, Mona Delahook calls it "The Expectation Gap."
- When we impose a "Behavior Plan", an "Emotional Regulation Plan", or any other catch phrase plan without collaboration, we risk "The Expectation Gap."
- I think we all have 'pushed' someone further than they can go at some time or other, and that person hasn't met our expectations.

*In graduate school, I had an excellent practicum mentor who used to ask us if our clients were "compliant" with treatment goals.*

*If we said they were non-compliant, he would ask us, "whose goals are you expecting them to achieve, theirs or yours?"*

Collaboration and planning, celebrating successes, rethinking failure, reformulating goals and redefining success helps our people

achieve their goals, builds a trusting relationship, and allows for continued success.

***Progress is impossible without change, and those that cannot change their minds cannot change anything.***

George Bernard Shaw

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