



# Office of Developmental Primary Care

Improving outcomes for people with developmental disabilities

## Understanding Autism, Aggression and Self-Injury: Medical Approaches and Best Support Practices

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Dr. Kripke's presentation on medical and trauma-informed practices was part of a [panel on Understanding Autism, Aggression, and Self-Injury at Support for Families in San Francisco](#). She spoke alongside Brent White and Lindsey Anderson. The transcript of the talk was posted originally on August 16, 2016 at: <http://www.thinkingautismguide.com/2016/08/when-autistic-children-are-aggressive.html>

I'd like to give everyone a big group hug. Regardless of who you are, if you experience meltdowns, if you are a parent or professional trying to support someone through meltdowns, this is hard on everybody. We need to treat each other gently.

### CHANGES IN BEHAVIOR OR FUNCTION DUE TO ILLNESS

For people who have cognitive and communication differences, illness frequently presents as a change in behavior or function instead of a patient complaining of a sign or symptom. For example, a broken bone is not usually a hard diagnosis to make. A person comes in and says, "I fell, and I think I broke my ankle." Their doctor does an x-ray and sure enough, you broke your ankle. But in situations where people are unable to effectively communicate the cause of their distress, it's amazing how easy it is to miss something as obvious as a broken bone. If it is hard to notice a broken bone, imagine how easy it is to miss something such as a headache or heartburn?

Whenever there's a change in behavior or function, it's important to think that it could be a medical problem.<sup>1</sup>

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<sup>1</sup> Guinchat V, Cravero C, Diaz L, et al. Acute behavioral crises in psychiatric inpatients with autism spectrum disorder (ASD): recognition of concomitant medical or non-ASD psychiatric conditions predicts enhanced improvement. *Res Dev Disabil*. Mar 2015;38:242-255.

## THE IMPORTANCE OF COMMUNICATION

Communication is the key to success. All people communicate. That's an assumption we have to have, even if people are non-speaking, even if people communicate in a variety of ways, even if they don't have a formal communication system: our job is to try to figure out how that person communicates best, and partner with them.

It's also important to recognize that communication is a two-way street. We can't say, "That person doesn't communicate." Communication is a relationship between two people. Both people have a really important role — the person who's trying to get something across, and the person who's trying to receive the message. If communication is breaking down, it's not a function of one person; it's a function of a relationship between two people.

"DEAR, YOU'RE A DIAMOND IN MY HEART BUT RIGHT NOW YOU'RE ANNOYING ME":  
CHALLENGING BEHAVIOR

Challenging behavior is not a patient complaint. Nobody has ever come to me and said "Doctor, I have challenging behavior. Can you please help me?"

They might say, "I'm anxious."

They might say "I'm in pain."

They might say "I'm being abused."

But no one says "I have challenging behavior."

"Challenging behavior" is a caregiver complaint, a complaint for someone who's supporting someone else.

When anyone comes in with a complaint of challenging behavior, my first question is "Who is being challenged, and why?" The same behavior may be a problem for one person, but not for another. It may not be the behavior that is changed, but a change in a caregiver's capacity to cope. For example, if someone is extremely active, it might have been ok when their caregiver was in good shape, but not OK when their caregiver starts having back problems or has an injury and can't keep up anymore.

The solution is not to make the person being supported move less, but to figure out a practical solution for the caregiver's change in physical ability, to support them, and possibly relieve them of some of their caregiving responsibilities. Has there been a change in the caregiver's ability to cope? Do they have new, competing responsibilities, such as work, or care for a sick or disabled parent?<sup>2</sup>

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<sup>2</sup> Hutchinson LM, Hastings RP, Hunt PH, Bowler CL, Banks ME, Totsika V. Who's Challenging Who? Changing attitudes towards those whose behaviour challenges. *J Intellect Disabil Res.* Feb 2014;58(2):99-109.

People with disabilities have the right to maximize their potential, and we should be working on that — but so do caregivers. If people are feeling like their caregiver responsibilities are interfering with their ability to pursue their own dreams and get their own needs met, that's a problem that also needs to be solved — they need to be better supported.

One example is respite — evidence shows we can reduce hospitalizations of autistic people by increasing funding for respite hours. Usually when we think about doing interventions to make people healthier and keep them out of the hospital, we're usually not thinking about supporting caregivers — but that's often the best solution.<sup>3</sup> Caregivers need training and social support. The evidence is that caregiver wellbeing has very little to do with the support needs of the people they support.<sup>4</sup> It has more to do with the social support that they receive;<sup>5</sup> the attitudes they take towards their caregiving;<sup>6</sup> and the services and supports that they can access.<sup>7</sup>

Sometimes additional adaptive equipment such as augmentative communication equipment,<sup>8,9</sup> hooyer lifts, or home modifications can make a big difference.

## MELTDOWNS VS. TANTRUMS

I want to talk a little bit about meltdowns versus tantrums and the difference between them. The solution is different, depending on what's going on.

Meltdowns are more like the blue-screen-of-death on your computer. It is as if “my brain is overloaded so it's going to shut down temporarily.” If someone is having a meltdown, they're overwhelmed. It is a reactive mechanism to being overwhelmed. It can be triggered by sensory things, being fatigued, too many changes or social pressures or something that is going on in their life. It continues even if it doesn't get the person any attention. Safety may also be compromised during a meltdown.

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<sup>3</sup> Mandell DS, Xie M, Morales KH, Lawer L, McCarthy M, Marcus SC. The interplay of outpatient services and psychiatric hospitalization among Medicaid-enrolled children with autism spectrum disorders. *Arch Pediatr Adolesc Med*. Jan 2012;166(1):68-73.

<sup>4</sup> Roth DL, Haley WE, Hovater M, Perkins M, Wadley VG, Judd S. Family Caregiving and All-Cause Mortality: Findings from a Population-based Propensity-matched Analysis. *Am J Epidemiol*. Oct 3 2013.

<sup>5</sup> Hsiao Y-J. Pathways to mental health-related quality of life for parents of children with autism spectrum disorder: roles of parental stress, children's performance, medical support, and neighbor support. *Research in Autism Spectrum Disorders*. 2015;23:122-130.

<sup>6</sup> Bekhet AK. The Mediating Effects of Positive Cognitions on Autism Caregivers' Depression and Their Children's Challenging Behaviors. *Arch Psychiatr Nurs*. Feb 2016;30(1):13-18.

<sup>7</sup> Weiss JA, Tint A, Paquette-Smith M, Lunsy Y. Perceived self-efficacy in parents of adolescents and adults with autism spectrum disorder. *Autism : the international journal of research and practice*. May 27 2015.

<sup>8</sup> Walker VL, Snell ME. Effects of augmentative and alternative communication on challenging behavior: a meta-analysis. *Augmentative and alternative communication*. Jun 2013;29(2):117-131.

<sup>9</sup> Hutchins TL, Prelock PA. Using communication to reduce challenging behaviors in individuals with autism spectrum disorders and intellectual disability. *Child and adolescent psychiatric clinics of North America*. Jan 2014;23(1):41-55.

Meltdowns are not goal-oriented. It is not a way to get someone else to do something. The person may need help regaining control.

A tantrum is a completely different thing; it's more want-directed. It's about trying to control someone else's behavior. For example, "I want the gum out of your purse, and I'm going to sit here and cry and kick until I get the gum out of your purse." People having tantrums check to see if their behavior is working. If they get ignored, they might escalate, or give up. During a tantrum, your protective mechanisms are intact and you are not likely to hurt yourself. You are in control, and trying to manipulate. If the goal is accomplished, the tantrum will stop. If it works, it also means that you may use that strategy to get what you want.

It's important to know whether the behavior you're observing or trying to support someone through is a meltdown or a tantrum, because the strategies will be different. In a meltdown there's no goal. The person can't process at that time. Reasoning and lecturing won't work. Reasoning or bargaining might work with a tantrum, but it's not going to work with a meltdown. Behavioral methods help manage tantrums, but they may further stress and traumatize people having meltdowns.

The old, outdated model is to think of challenging behavior as a problem with the person who's having the behavior. They're a bad person because they're having this behavior. They are sick or having some disability-related problem. The old solution was to try to control the person who's having the problem, to restrain them — either with medicines or physically. If that couldn't be done, the solution was to remove them from society, or to seclude them. In the past people even resorted to medical procedures like surgery on the brain. That's the old model. We know better now.

A newer model is to change people's life circumstances for the better. We cannot manage behavior in the context of unacceptable lifestyles. If someone's situation, their social environment, the activities they're doing, the people they are with or their physical environment is unacceptable to them, then that is the problem that we need to fix. For example, if they can't be in a room because the air conditioner is too loud, and causing them such discomfort that they feel like they're going to melt down, the solution isn't to punish them, to yell at them, or to tell them they'll be strapped to that chair if they don't stop their behavior — the solution is to turn off the air conditioner, or, if that's not possible, to move to a different environment. The problem isn't always obvious. Often, it isn't anybody's fault.

#### WHAT DOES "TRAUMA INFORMED PRACTICES" MEAN?

Trauma informed practices means that, when someone is having a problem, we don't ask "what's wrong with you?" but "what happened to you?" It's about being empathetic, and assuming that there's a reason for the problem.<sup>10</sup>

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<sup>10</sup> Keesler JM. A Call for the Integration of Trauma- Informed Care Among Intellectual and Developmental Disability Organizations. *Journal of Policy and Practice in Intellectual Disabilities*. Mar 2014;11(1):34-42.

We need to focus on skill development: caregiver skill development, as well as skill development for the person who is stressed. This might be learning a new communication technique, learning better ways to get your needs met, or learning strategies for self-calming (or how to help someone else to calm). It's about practicing mindfulness, skill development, knowledge, full and active inclusion. It is about giving people opportunities to do things they want to do, and that other people have the opportunities to do, and overall improving quality of life.

I am not trying to diminish how challenging some of these situations can be, how stressful, or even how dangerous. But escalating those situations through harsh language, reacting emotionally, restraining, or using other "old" methodologies, only makes it worse. In general, and keeping in mind that every situation is unique, we want to de-escalate.

We're not going to eliminate meltdowns. And most of us, if we're honest with ourselves, whether we have disabilities or not, have meltdowns on occasion. It's more a matter of frequency, intensity, and what they look like.

#### CONSIDER MEDICAL CAUSES FIRST

Meltdowns often happen because of physical complaints, or because of illnesses that are under-treated or have not been diagnosed. How many of us have gotten unreasonable when we don't feel well?<sup>11, 12</sup>

One-third of people with developmental disabilities also have vision, hearing or sensory integration problems; most have multiple chronic medical problems, about 20% have seizure disorders, about one-third have a diagnosable psychiatric disability. When people have meltdowns, medical problems are contributing to or causing the problem most of the time.<sup>13, 14</sup>

If you're supporting someone who has a challenging behavior or meltdowns, and you just guessed that it had to do with their health, you would be right 75% of the time. \*\*You should always think about medical causes first.\*\* Think about them before you think about other reasons for behaviors.

When I talk about the frequency of medical conditions causing behaviors, I'm taking that from a

<sup>11</sup> Charlot L, Abend S, Ravin P, Mastis K, Hunt A, deustch C. Non-psychiatric health problems among psychiatric inpatients with intellectual disabilities. *J Intellect Disabil Res*. February 2011 2011;55 part two.

<sup>12</sup> Guidelines for Supporting Adults with Challenging Behaviors in Community Settings. 2005. [https://mn.gov/mnddc/positive\\_behavior\\_supports/pdf/guidelines\\_supporting\\_adults\\_challenging\\_behaviors1.pdf](https://mn.gov/mnddc/positive_behavior_supports/pdf/guidelines_supporting_adults_challenging_behaviors1.pdf)

<sup>13</sup> Croen LA, Zerbo O, Qian Y, et al. The health status of adults on the autism spectrum. *Autism : the international journal of research and practice*. Oct 2015;19(7):814-823.

<sup>14</sup> Nicolaidis C, Kripke CC, Raymaker D. Primary care for adults on the autism spectrum. *The Medical clinics of North America*. Sep 2014;98(5):1169-1191.

study of people who got as far as consulting a specialty psychiatric service. For someone to get referred to a developmental psychiatrist for a formal evaluation means they typically tried quite a few things before they got to that point. Most of those people had talked to primary care doctors. Even in that population, 75% of the people who are experiencing problem behaviors had an undiagnosed or untreated medical condition. The medical causes are not easy to diagnose or detect.<sup>15, 16</sup>

Also, while challenging behaviors are extremely common, they don't tend to last forever. Meltdowns last minutes to an hour or two. The more dramatic ones tend to be shorter. It doesn't feel like a short time when you're going through it. But people tire. Also, when you're with someone who is going through a difficult period, like puberty, a change in their routine, or when they are developing a medical problem, it can feel like the meltdowns and challenges will never end. Whenever you're in the middle of it--head banging, chewing on skin causing infections, having episodes in public places--time moves so slowly. There's a lot of fear and emotion that get associated. Remind yourself that it doesn't last forever. Even if you do nothing, data shows that challenging behavior tends to get better with time.

#### MANAGING CRISES USING THE S.C.A.R.E.D. METHOD

I got this acronym and strategy from Deborah Lipsky, who's an autistic first responder. Her book is called "Managing Meltdowns." I highly recommend it for anyone who is working with people who have behavioral crises of various sorts. She describes what meltdowns are like from the inside, and gives a very easy-to-read and clear explanation of what to do.

The S.C.A.R.E.D. method is to do the opposite of what you feel like doing. Most people's impulses, including my own, are to get upset, to lecture or to yell, to be embarrassed, and to try to control the situation. When I see someone who is upset, who is at risk of hurting others, or at risk of hurting themselves; someone getting themselves in trouble or getting me in trouble, my own anxiety levels increase, and I get worked up myself. This isn't helpful. It's really important to take care of yourself, so that when this situation comes up, you can go to your calm place. If you have those impulses, like I do, try to control them. Keep the lid on them.

-SAFE: If you're not in a safe place when a meltdown happens, then it's important to get into a safe place. If you are supporting someone who is flailing in a way that someone nearby could get hit, or if there are objects nearby that could be thrown, don't focus on trying to control the person; instead focus on getting people and objects out of the way and getting the person to a safe place. If the person is in the middle of the street, get them to the sidewalk. If it's happening in the classroom, either help them leave the classroom, or help other people leave. Keep a safe distance away.

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<sup>15</sup> Ryan R, Sunada K. Medical evaluation of persons with mental retardation referred for psychiatric assessment. *Gen Hosp Psychiatry*. Jul 1997;19(4):274-280.

<sup>16</sup> Checklist of nonverbal complaints and clues. Ruth Ryan. <http://dimagine.com/page66.html>

-CALM: Simple instructions, not lectures. This is not the time to talk about feelings. Keep it to simple words such as “Jane, stop.” or “Jane, here.”

-Use AFFIRMATIONS (positive words).

-ROUTINE: If you know what that person’s safe routines are in general, try getting them into one of their safe routine activities or patterns to work through it.

-EMPATHY: They’re not the enemy; your approach should be trauma-informed: “What happened to you,” not “What’s wrong with you.”

-DEVELOP an intervention plan: This is not something you can do in the moment, but hopefully you’re not entering these situations without a plan in place. If you don’t have one, then as soon as the episode is over, is a good time to start developing a plan for what to do next time.

### Sample Meltdown Plan

Here is a meltdown plan that was written by an autistic, non-verbal person who uses augmentative communication:

1. Respect me when I have a meltdown.
2. I have meltdowns periodically — don’t overreact. I’ll pull myself together faster if you have patience in the moment, not if you have hard words.
3. It’s not nice to make me feel bad about it.
4. Only touch me if I’ve said you’re someone who can — respect my space in the moment.
5. I have trauma from being underestimated so I melt down often because of my trauma — it’s not your fault.

When trying to figure out why meltdowns happen, think about what precipitated it. How can we in the future reduce the frequency? If that’s not possible, how can we reduce the meltdown’s intensity or length? Also think about the conditions that may have reduced the person’s capacity to cope such as fatigue, hunger, too much sensory stimulation, too many people, or too many demands.

### DETERMINING WHY BEHAVIOR CHANGES HAPPEN

What is the first step to sorting out the cause of a change in behavior?

- 1) Collect/review baseline data
- 2) Interview caregivers
- 3) Do observation
- 4) Do physical exam

## 5) Ask the patient

All these strategies are important, but I always start with asking the patient — even if they're non-verbal, even if they don't have a formal communication system, even if I'm not sure whether I'm going to get a meaningful response. When I try; when I give people the opportunity; when I support them, I'm amazed by the useful information I get in return. Here's a story:

I had a patient who was brought in by her sister. Her sister didn't know her very well, because she'd been living with her mother and the mother had just passed away. She thought something was wrong but she didn't know what. I didn't know the patient at all. The sister was insisting that the patient was non-verbal and couldn't provide me with any history, but I said, "Let's try. We have no idea what's going on here. It can't hurt." So I started trying things: I sat her down in front of my computer to see if she could type. She did type letters but nothing I could interpret. I got out pictures of anatomy and bodies to see if she might point to something, or one of the pictures might get a reaction. I gave choices like "show me how you say 'yes,' show me how you say 'no.'" That didn't work.

Then I said, "touch hurt." She took my hand, and put it on the right upper part of her tummy. I ordered a sonogram. She had gallstones. That is a *\*really, really\** hard diagnosis to make without someone giving you a hint, and telling you where they have pain — there's nothing that shows up elsewhere on their body to indicate they have gallstones. Without her hint, I would not have been able to make her diagnosis until she was sick enough to be in the hospital. The *\*only\** way I made that diagnosis was because of the information she provided.

Trying this kind of strategy doesn't always yield useful results, but it does often enough that it's always worth trying. It also sets the person thinking, "They're trying to work with me on this; I'll try a little harder to communicate with them; I'm going to try to figure out a strategy to get my needs across, because they're really listening." All of us shut down if we think people aren't listening to us, and we don't try to get our communication across. A lot of time people can communicate better than you think they can, but they don't try because they think people don't listen. Giving people the impression that you are listening to their verbal and non-verbal cues will increase how hard they try.

Another case I use with thanks to Aiyana Bailin: A person with no language communication skills, who does not speak or type or use sign language, keeps hitting herself on the side of the head. The caregivers are concerned that this could cause an injury.

Should they:

- 1) Punish with something mildly aversive, like some static noise, whenever you see the behavior.
- 2) Explain why head-hitting is a bad idea, and say "no" or "stop" when they do it.

- 3) Ignore the behavior, and hope it goes away.
- 4) Praise or reward the person when they have longer periods of time without hitting themselves.
- 5) Hold the person's hands down gently every time they try to hit their head until they stop trying.
- 6) Give themselves something else to do with their hands, like giving them a favorite object every time they start trying to hit their head.
- 7) Presume that there's a reason, and when they're calm, ask, and systematically search for the trigger.

1 through 6 are primarily old-school thinking. When someone's having an alarming behavior, if you don't know why, and if they're at risk of hurting themselves or other people, ninety percent of the time, the primary focus is on getting that behavior to stop. People are eager to do whatever it takes, because otherwise something bad will happen.

I don't want to minimize people's stress and fear, because the consequences of these behaviors can be really significant. But it's important to take your time to figure out why it is happening. I know of someone who wouldn't stop chewing on his thumb. Eventually the thumb got gangrene and fell off. That's a really significant behavior. So after trying everything else they could think of, his doctors decided to try a physical restraint. They built a brace that would allow him movement but not allow him to get his hand into his mouth. He broke his own arm getting his mouth to this thumb.

Another story: In the middle of a meltdown, a patient was banging his head against the wall. His caregivers were alarmed that he might get a head injury, so they put their hand between his head and the wall. What do we do in the middle of a meltdown? Back off, stay calm, remove things that could be dangerous. It might have been OK to come up from the side, and slide some sort of pad between his head and the wall. But they put their body between the person who was out of control and something hard. This was not good. The patient bit the caregiver. Another staff tried to help the caregiver because he was getting bit. He tried physical restraint by holding the patient's arm. The patient's arm snapped and was broken. He ended up in the hospital with complications, and now has a permanent physical disability.

I'm not trying to underestimate the significance of the behaviors. But restraint, punishment, focusing on the behavior instead of what's causing it simply doesn't work. It gets people hurt—both people who are struggling, and those trying to help. We need to get through these episodes safely, and then focus on why they happen. If we don't understand why the behaviors happen, we are less likely to be successful in stopping them, and we'll mismanage them.

#### WHEN PEOPLE CAN'T COMMUNICATE ABOUT A SIMPLE MEDICAL CONDITION

Here is another story about why we need to presume there's a reason for behaviors, and systematically search for those reasons: A person was going around doing really challenging

things, like going up to law enforcement and grabbing them, laying down in front of cars, a whole variety of things that are quite alarming and dangerous. He was losing his housing, because his caregivers didn't feel they could keep him safe. He'd also seen multiple doctors. Then a primary care doctor did a really careful physical exam, from head to toe — and they found a little toy bead in his ear, removed it — and the behaviors stopped.

Imagine, like this man, having even a very simple condition — like a yeast infection, an itch you can't scratch, conjunctivitis, or constipation. Now imagine you can't tell anyone about it or help yourself. Sometimes people try to get your attention by doing things that can appear to be aggressive, but they're really saying, "I have a problem, and I need help." That's why this patient was going to authority figures and trying to get their attention — it looked aggressive, but he was actually asking for help.

Another story: a patient was going up to people and punching them in the chest. That was viewed as scary and aggressive. It turned out he was having heart pain. He was trying to tell people that he needed help with a medical problem. If we had simply given him medication to calm him down, we would have completely missed the point, and also missed a major medical problem.

Another situation: A patient started to throw chairs at caregivers. She was having increasingly severe meltdowns. It turned out, she was being hit by a caregiver. The caregiver was well-intended; the patient had behaviors that she feared were going to get her in trouble, and was handling it in the way it had been handled in her childhood, which is with very tough love. She was disciplining her by saying firmly, "You're not doing that!" and giving her a slap. She wasn't trying to hurt the person, but was trying to manage things in the way she knew how. Nevertheless, the person was being abused, and that's where the behavior was coming from. When the staff was fired, the behavior stopped.

## WORKING THROUGH POSSIBLE CAUSES

How do you systematically think through a patient's possible medical needs? I use a mnemonic, "H-U-R-T-S." It doesn't include everything that could possibly be wrong medically. But if you work through it, more often than not, it will give you a hint that will lead to the answer.<sup>17, 18</sup>

- Head — Migraines are a very difficult diagnosis to make if someone can't tell you that

<sup>17</sup> Office of Developmental Primary Care. Evaluation of Behavior Change. Available at: [http://odpc.ucsf.edu/sites/odpc.ucsf.edu/files/pdf\\_docs/Evaluation%20of%20Behavior%20Change\\_1.pdf](http://odpc.ucsf.edu/sites/odpc.ucsf.edu/files/pdf_docs/Evaluation%20of%20Behavior%20Change_1.pdf) . Accessed 8/10/16.

<sup>18</sup> Zelenski, SG. Evaluation for and use of psychopharmacologic treatment in crisis intervention for people with mental retardation and mental illness. In: Hanson R, Wieseler K, Lakin C, Braddock DL, eds. Crisis: Prevention & Response in the Community. Washington, DC: American Association on Mental Retardation; 2002:243-256.

they have a headache. Hearing or vision change — caregivers are really poor at recognizing these problems; people can be totally blind or deaf and caregivers may not notice, especially if they have other motor challenges. Dental problems are really common, and caregivers and doctors often don't think about it. Consider the last time you had a toothache or gum problem and how painful that was. Other unrecognized injuries are also possible.

- Urinary tract infections, kidney stones, or urinary tract obstructions — not being able to pee.
- Reflux (heartburn) is really uncomfortable. It can present as insomnia. There can be other gastrointestinal complications, such as constipation.
- Thyroid problems, or traumas, such as broken bones or orthopedic injuries, or sprains. I've had patients whose injuries have presented in the form of "they [patient] slapped me!" when the caregiver was trying to help them up using their broken arm. They were defending themselves by slapping them away. People can behave very violently when they're being injured, even if it's unintentional.
- Seizures can present in very unusual ways. Not all of them present as the typical all-over body shaking. Any behavioral pattern that lasts about three minutes and looks the same each time could be a seizure. This could present as flailing that looks aggressive; you can have emotional lability—(e.g. they might start to laugh or cry out of context or very suddenly or inappropriately), but that's actually a type of seizure. Think about seizures because there can be some very uncommon seizure types. Also side-effects of medications can go unrecognized. That is really common.

Story about reflux: A patient has such bad insomnia that their parents were at their wits' end, and considering an out-of-home placement. But the insomnia was uncharacteristic; most of their life they'd slept just fine. So I started thinking why this person might not be sleeping, and worked through this H-U-R-T-S mnemonic. I got to reflux, and I thought, "When people lie down it usually makes their heartburn worse; why don't you just try some over-the-counter heartburn medicine and see what happens?" Two days later, the symptoms were done and the family was no longer thinking about out-of-home placement. It didn't solve all this person's problems, but again — simple medical problems can become big problems if you can't get the help you need.

## OTHER CAUSES OF BEHAVIOR

Behaviors can also signal:

- Abuse, even unintentional or well-meaning.
- Escape or avoidance of demands (can be mistaken for tantrums) — "e.g. a sound or light

in this room is bothering me; so if I become disruptive, then I'm going to get removed from this room — which is what I need.”

- Increase in arousal or self-stimulation. Sometimes people have sensory issues where they don't really feel their bodies, so hitting or tapping themselves can help them feel where their body is in space.
- A means of accessing preferred activities or objects.
- A need for social attention.
- It could be a sign of psychiatric disability; a lot of times when we don't understand why someone is doing something, it can look like it came out of nowhere, and it can be confused with hallucination or seem completely irrational. Not understanding why someone is doing something is not the same thing as there not being a reason. That being said, there is a fair amount of psychiatric disability in this population, there can be bipolar disorder, schizophrenia, anxiety, depression — and psychiatric disabilities need to be treated with psychiatric medication.
- Psychosocial stressors, like being stressed out because of social relationship issues, or pursuit of power, or control.
- A way to reduce arousal and anxiety.
- A way to manage sensory sensitivities.
- It could be substance abuse.

Story: A patient of mine was living in a group home that had recently had a budget cut, so they weren't doing that many activities. My patient figured out that if she threw things, she would get her preferred staff member to work with her, and she would get to do what she wanted to do — she was able to establish power and control through throwing things.

Sometimes Functional Behavioral Analysis can be useful: taking data on what happened right before the behavior and also what happened right after might help you start to see what's going on. You might start to see patterns. You can take data on what changed in their life: activity level, ability to communicate, behavior, diet, mood, etc.

The one caveat to functional behavior analysis: I used to teach that all behavior is communication, and I'm trying to undo that teaching now, as I've learned from autistic people that all behavior isn't necessarily communication — it can be a problem with impulsivity or motor control, and also sometimes people might be doing something because they have an obsessive/compulsive need to do it — they know it's wrong, but they can't stop themselves.

They might not have the body control to meet the expectation. “I know you want me to go over there. I’m trying to go over there, but I can’t get my body to initiate the movement — I’m not being defiant.”

#### INTERPRETING AND IDENTIFYING PAIN

Interpreting pain is also sometimes challenging. Sometimes I’ll ask a caregiver, “Do you believe this person is in pain?” And they’ll say, “No, I don’t think so.” And I’ll say, “How do you know?” They’ll say, “Well, they aren’t doing the things we’d usually expect from someone in pain.” They aren’t grabbing the part that hurts, or making groaning sounds, crying, or grimacing. But not everybody with a disability does those things — and frankly, non-disabled people don’t always, either. Those behaviors are usually a response to acute pain, like stubbing a toe. But if we have chronic pain, like the back pain I’ve had for the past three years, I don’t go around making those facial expressions and movements all day long.

Sometimes people never make those indications. Also bear in mind that we behave differently in a social environment, when people are watching, than we do when we’re alone. If I stub my toe and nobody is watching, I might not say much. If I’m in a room with people, I might make a bigger production. Maybe the person did make a facial expression, but it was quick, and nobody was watching at that moment. Often people with disabilities who don’t use speech to communicate are used to other people ignoring their communications, so they may not be trying very hard to communicate their pain.

Also be aware that some changes in behavior make caregiving easier. Caregivers tend to bring up problems that make caregiving harder. If something makes a caregiver’s life easier, they may not think to mention it. For example, they may not mention that a person stopped menstruating, or has stools that are little, hard, rocks that only come once a week, or that their activity level is decreased. But decreased activity level like sitting in front of the TV all day for a typically active person could indicate depression. It could indicate a thyroid problem. It could indicate illness. But because it makes the caregiver’s life easier, they might interpret it as the person just being “relaxed.”

#### TIPS FOR RESPECTING AGENCY

Respecting agency: When you talk about self-injurious behaviors, it’s important to react to what is actually happening, and not focus on fear of what *may* happen.

Hurt vs. Injury: Injury is bad. But we do things that hurt all the time. We play rugby. We pluck our hair. We get tattoos. We engage in things that aren’t going to cause any serious damage, but which are uncomfortable, like going camping. If it hurts, but isn’t injurious, try to lower your anxiety level. You may not need to intervene.

Hazard vs. Risk: I was supporting somebody at the child care area of the gym. The child kept

running into the gym through the alarm door. There was another alarm door that went into the street. The child care supervisor said, "This child can't be in the childcare area, because they keep running out the alarm door that goes into the gym, and therefore they \*could\* go out through the alarm door into the street," even though that had never happened before. The kid was interested in being in the gym, not outside. True, it is a risk. The kid could run in the street. But it is a small enough risk that it isn't a real hazard. The chances the kid is going to run out the door, into the street, and get hit by a car is low and doesn't justify excluding the child from the program.

Unusual or atypical behavior vs. behavior that violates the rights of others: it's important to respect people's natural movements and their natural behaviors, and not interfere if they're not hurting anybody. We need to interpret behavior developmentally, that is, if someone is a young child and they have an imaginary friend, we don't consider that psychosis. Some adults also manage loneliness or work out problems by talking to imaginary friends. Sometimes somebody might be doing something that's completely developmentally appropriate, like asking repeatedly, "When are we going to get there?" because they don't have much experience with travel or they have a short term memory issue. That is not a behavioral or psychiatric problem. It may just be developmentally appropriate. It needs to be tolerated and accommodated.

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#### Q& A Responses Regarding Managing Meltdowns

Meltdowns don't usually come out of nowhere; there's usually a buildup. It might start as a tantrum — but we usually know it's coming. If the thing that's contributing to the meltdown is not addressed, it's going to explode.

If the problem is a sensory issue, there's no "mindful" way to address it — you need to take care of that sensory issue, or remove the person from that sensory environment. Otherwise you're on the path to an inevitable meltdown.

I think it's a great strategy to teach people with intellectual disabilities mindfulness techniques, like a quiet mantra such as, "You're safe, you're loved, you're home."

You don't want to get into a power struggle. When someone's getting agitated, you don't want to come at them head-on — if you confront them like that, you could get hit, you could get hurt. Try to give them space. If you have to approach, be non-confrontational and give plenty of room and warning. Try not to trap someone and try not to position yourself so you are trapped.

If you do need to intervene, try to approach from the side, and be gentle. You usually don't need to abruptly stop them. You can just try to deflect them a little; to get them going in a slightly different direction. Try a light touch, or handing them something that you know is a

comforting stim object. Use kind words the whole time: "It seems like you're agitated. Here maybe this stim will help." Usually you don't need to make a huge change, just a slight change in direction. You can say, "We need to get you to the sidewalk instead of to the middle of the street." or, "If you give me a chance I'll just slide this little pad in so you don't get a bloody head."