



When Autistic Children Are Aggressive or Self-Injurious: Medical Causes and Best Practices for Support

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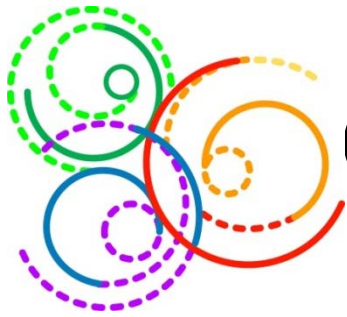
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In people with cognitive or communication differences....

- Illness presents as a change in behavior or function
- Communication is the key to success
- All people communicate



Challenging Behavior

Dear, you are a diamond in my heart.
But right now you are annoying me.





Caregiver Assessment

- Change in resilience or coping?
- Competing responsibilities?
- Maximizing your potential?
- Social support?
- Respite?
- Training?
- Equipment?



Meltdown vs Tantrum

- Overwhelmed
- Reactive mechanism
- Continues without attention
- Safety may be compromised
- Fatigue
- Not goal dependent
- May need assistance to gain control
- Want directed
- Goal/Control Driven
- Audience to perform
- Checks engagement
- Protective mechanisms intact
- Resolves if goal is accomplished



Challenging Behavior—Old Model

- Pathology inherent in the individual
- Remove from society
- Control the person
- Physical and mechanical restraint
- Chemical restraint with psychoactive medication
- Seclusion/aversives
- Psychological surgery



Challenging Behavior—New Model

- To change people's life circumstances for the better, not manage behavior in the context of unacceptable lifestyles.
- Trauma informed principles
- Skill development
- Knowledge
- Full and active inclusion
- Improve quality of life

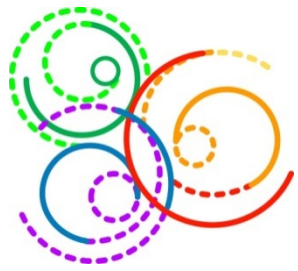


Health Status of Youth and Adults with DD

- A third have a sensory difference
- Most have multiple chronic medical problems
- About 20% have seizure disorders
- A third have a diagnosable psychiatric disability
- Medical problems are causing or contributing to behavior *most of the time*
- Challenging behavior very common—it doesn't last forever!

1. Croen LA, Ousseny, Z., Qian, Y., Massolo, M.L., Rich, S., Sidney, S., Kripke, C. The health status of adults on the autism spectrum. *Autism research and treatment*. Apr 24 2015.

2. 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.



Managing a Behavioral Crisis

The S.C.A.R.E.D. method

- Safe
- Calm
- Affirmation
- Routine
- Empathy
- Develop intervention plan



Sample Meltdown Plan

“Respect me when I have a meltdown. I have meltdowns periodically. Don’t overreact. I will pull myself together faster if you have patience in the moment, not hard words. Not nice to make me feel bad about it. Only touch me if I have said you are someone who can. Respect my space in the moment. My not saying it is caused by certain words is that it will happen anyhow. I have trauma from being underestimated, so I melt down often because of my trauma. It isn’t your fault.”



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

1. Collect/review baseline data
2. Interview caregivers
3. Do an observation
4. Physical exam
5. Ask the patient



What is the first step to sorting out a change in behavior or function?

1. Collect/review baseline data
2. Interview caregivers
3. Do an observation
4. Physical exam
5. **Ask the patient!!—Don't skip this step. With support, non-verbal people can communicate a lot.**

A person with no language communication skills (does not speak or type or use sign language, etc.) keeps hitting him/herself on the side of the head. The caregivers are concerned that this may cause an injury. The first thing you should try is:

1. Punish with something mildly aversive like a burst of static noise, whenever you see the head-hitting behavior.
2. Explain why head-hitting is a bad idea, and remind them by saying "Stop!" or "No!" each time they hit themselves
3. Ignore the behavior and hope it goes away
4. Praise or reward the person for increasingly longer periods of not hitting themselves.
5. Hold the person's hands down gently every time they try to hit themselves, until they stop trying.
6. Try to give them something else to do with their hands, like handing them a favorite object, every time they start hitting themselves.
7. Presume there is a reason and when calm, ask and systematically search for the trigger.

Thanks to Aiyana Bailin

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Think Medical

- ***H*ead**: migraines, hearing, vision, dental, injury
- ***U*rinary tract**: stones, infection, and obstruction
- ***R*eflux and gastrointestinal problems**
- ***T*h thyroid and Trauma**
- ***S*eizures and Side Effects of Medication**



Behavior can also signal....

- Abuse (often unintentional or well meaning)
- Escape or avoidance of demands
- Increase in arousal or self-stimulation
- Means of accessing preferred activity or objects
- Need for social attention
- Psychiatric disability
- Psychosocial stressors
- Pursuit of power and control
- Reduction of arousal and anxiety
- Sensory sensitivities
- Substance abuse



Baseline Documentation

- Collect Assessments
- Chart
 - Medications/Treatments
 - Behavior
 - Bowel Movements
 - Diet
 - Daily Living Skills
 - Seizures
 - Vital Signs
 - Periods

*forms available at <http://odpc.ucsf.edu>



Functional Behavior Analysis

What happened before? (antecedent)

What was the behavior?

What happened after? (consequence)

What may have been the function of the behavior?*

*Behavior can be easily misinterpreted in people with impulsivity, obsessions, or movement problems



What changed?

- Ability to communicate
- Activity level
- Behavior
- Confusion/Orientation to time, place and person
- Diet
- Mood
- Movements
- Sensitivity to sound, sight or touch
- Skills
- Strength, steadiness, energy
- Skin
- Sleep
- Stool or urine
- Vital signs



Atypical pain behavior

- Sensory integration
- Communication
- Atypical affect
- Understanding how to get help
- Learned helplessness
- Difficulty identifying sensation as pathological
- Social understanding problems leading to delay in communicating to appropriate person in appropriate timeframe



Some changes make caregiving easier

- No periods
- Hard stools
- Vision/hearing problems
- Decreased activity levels
- Depression/Thyroid



Respecting Agency

1. Hurt vs. injury
2. Hazard vs. risk
3. Unusual vs. violates of rights of others
4. Respect natural movements and behaviors
5. Interpret behavior neurologically
6. Interpret behavior developmentally



Decreasing Behavioral Disabilities

- Improve body functions and structures
- Increase activities and participation
- Improve in the social environment
- Improve the physical environment



Prevention

- Teach communication
- Person centered planning
- Healthy lifestyle
- Consider health, social and physical environment
- Plan transitions carefully:
 - Person
 - Place
 - Activity

What is the biggest risk factor for sexual abuse?



Prevention

- Teach communication
- Person centered planning
- Healthy lifestyle
- Improve the social and physical environment
- Plan transitions carefully
 - Person
 - Place
 - Activity

What is the biggest risk factor for sexual abuse? **Compliance Training.**
Make sure people have communication tools and support to set boundaries—not just request.



Psychoactive Medication

- Goal is quality of life and function--not to behave “normally”
- Goal should be developmentally appropriate
- Make a diagnosis before prescribing (challenging behavior is not a diagnosis)
- First explore improving participation, inclusion, social and physical environment
- Treat the caregivers
- In people with intellectual disabilities without mental illnesses, placebo is more effective than psychotropics
- Psychotropics frequently used as chemical restraint



How do you monitor the effects of therapy?

- Research past therapeutic trials
- Define objective measures with a clear timeline and milestones
- Define parameters in advance to stop treatments that aren't working.
- Make sure entire team is on board (e.g. day program, caregivers, case coordinator, primary care)
- Take data across settings
- Keep good notes on failed therapy



Summary

- Illness presents as a change in behavior or function
- Don't get so distracted by trying to stop the behavior that you forget to ask *why*
- Don't forget to ask the person, even if communication skills are limited!
- Interpret behavior neurologically and developmentally
- Improving quality of life improves behavior
- Take care of caregivers
- Don't panic—challenging behavior gets better!



Mild Intellectual Disability

- Keeping roommates up at night
- Yelling at roommates and shoving them
- Declining physical therapy



Cure by increasing participation

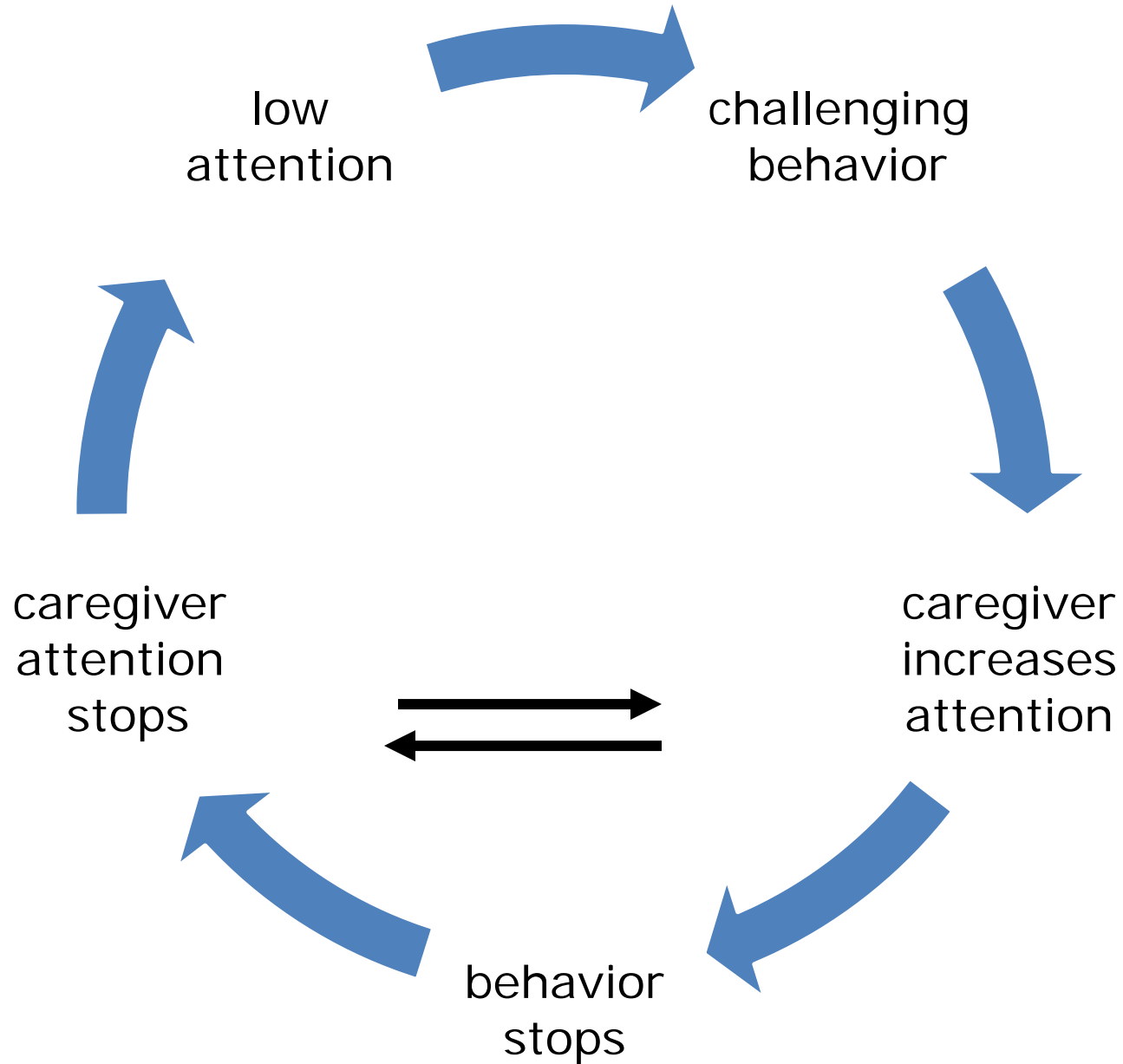
- Get him to day program so he doesn't sleep all day
- Reschedule physical therapy so it doesn't conflict with day program

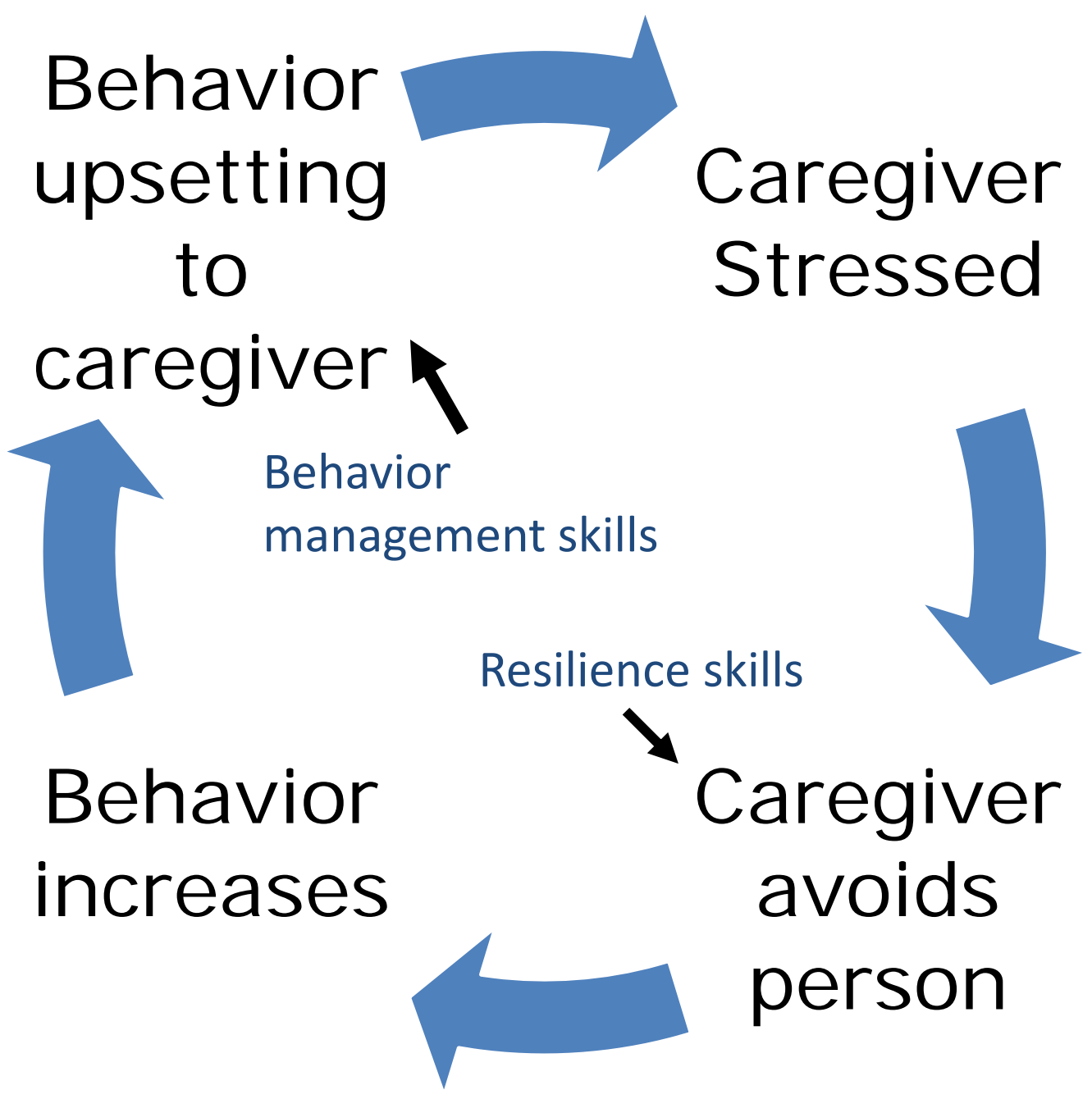


Ms. Autism

- Hitting caregivers
- Jealous of caregivers giving others attention

Change the Social Environment







Mr. Aspergers in ER

- Becomes non-verbal
- Behavioral melt-down
- Extensive medical evaluation normal
- Psych recommends electric shock treatment and medication



Change the physical environment

- Turn off the machine beeps
- Turn off florescent lights
- Find a private room
- One person talking



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