Supporting Learners with Autism Spectrum Disorders and Co-Occurring Mental Health Diagnoses (and their teams!)

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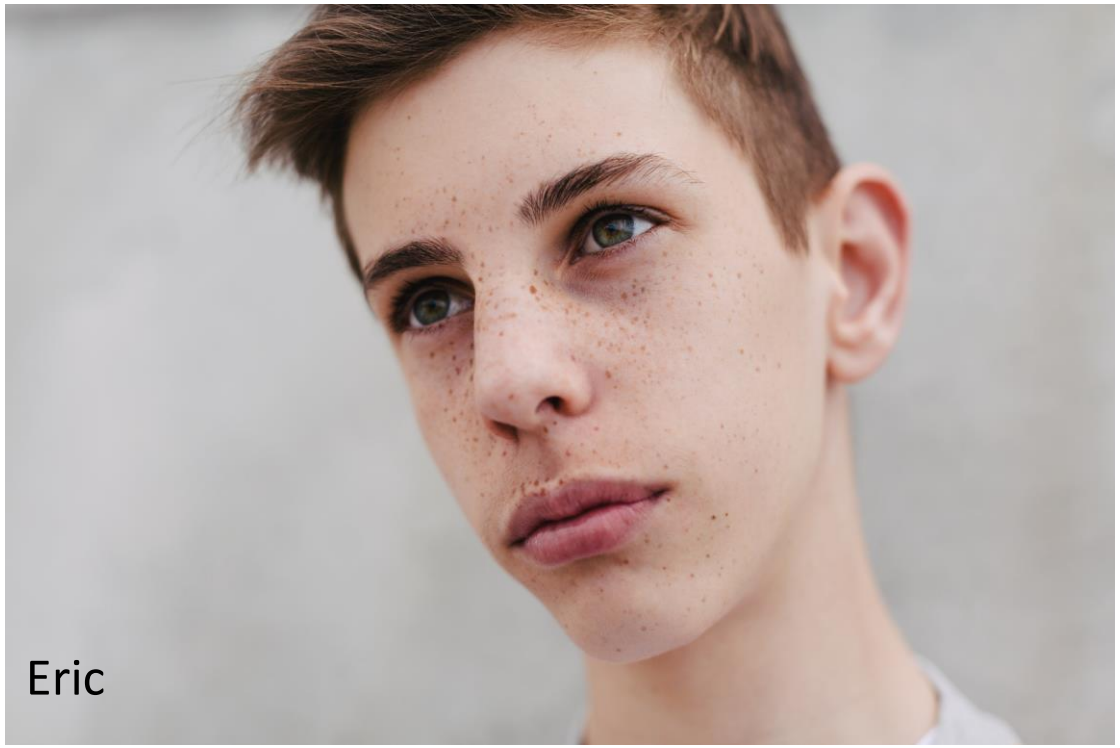
Objectives

1. Participants will be able to identify changes in the conceptualization of mental health needs for individuals with ASD/autistic individuals and common co-occurring conditions.

2. Participants will gain insight into the therapeutic principles to enrich their work with autistic individuals/individuals with ASD, such as self-determination.

3. Participants will be able to identify strategies to support effective collaboration with other members of an intervention team (parents, teachers, aides, and administrative personnel).

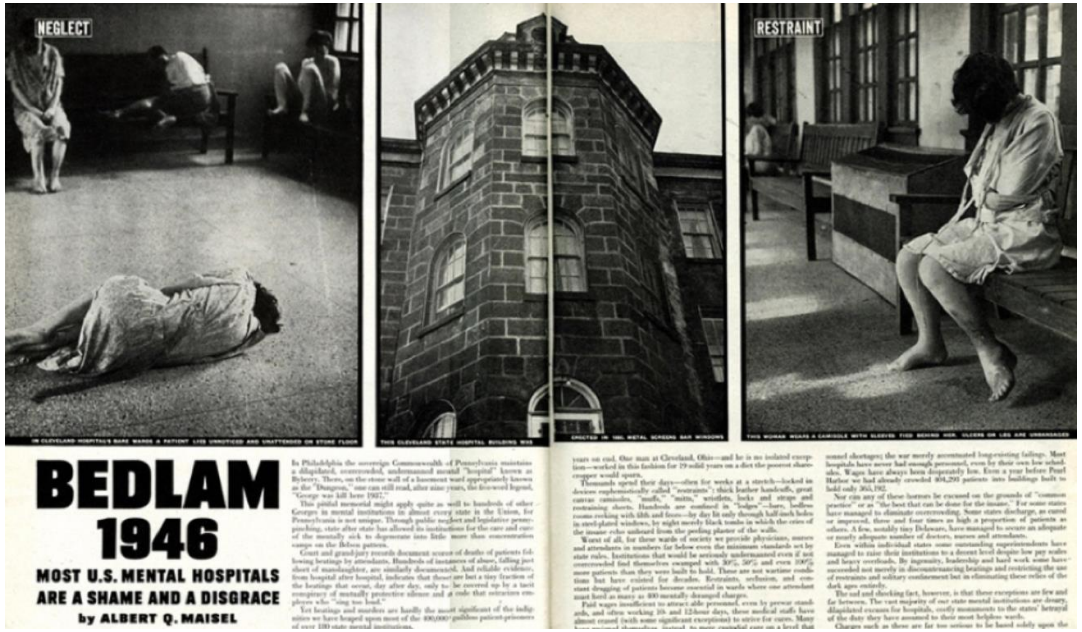
Why we are here



Historic Context

Historically, it was believed that people with Intellectual/Developmental Disorders could not have a psychiatric illness and that behavioral issues were entirely related to intellectual functioning.

- This school of thought was taught/believed well into the 50s/60s
  - Supported the view of institutionalization that prevailed at the time in the US…this view continues to remain in other parts of the world
  - Impacted how behavioral practitioners were trained (and practiced) well beyond those years

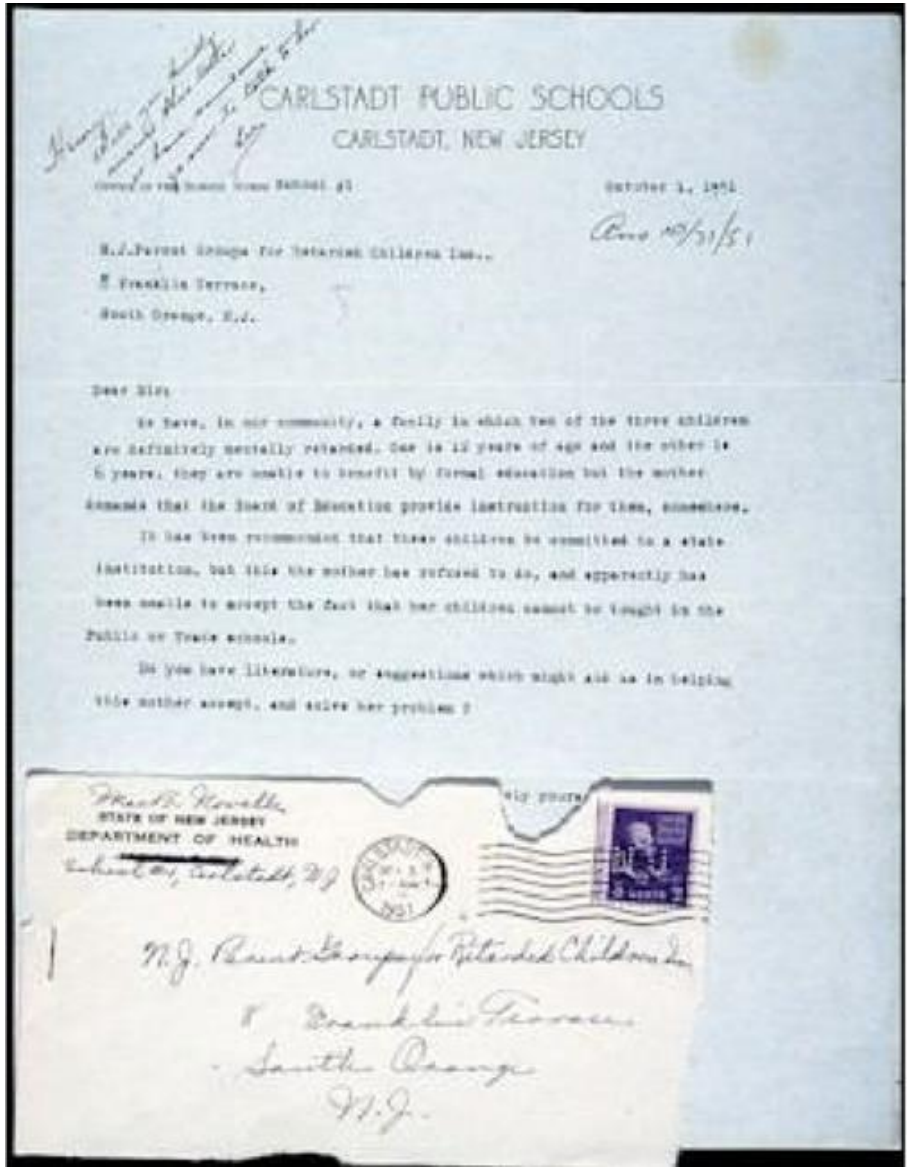


1951: A letter that was sent from Carlstadt, New Jersey Public School #1 to the New Jersey Parent Groups for Retarded Children.

“Dear Sir: We have, in our community, a family in which two of the three children are definitely mentally retarded. One is 12 years of age and the other is 6 years. They are unable to benefit from formal education but the mother demands that the Board of Education provide.

It has been recommended that these children be committed to a state institution, but this the mother has refused to do and apparently has been unable to accept the fact that her children cannot be taught in the Public or Trade schools.

Do you have any literature, or suggestions which might aid us in helping this mother accept, and resolve her problem?"


CARLSTADT PUBLIC SCHOOLS
CARLSTADT, NEW JERSEY

October 1, 1951

N.J.Parent Groups for Retarded Children Inc.,
8 Franklin Terrace,
South Orange, N.J.

Dear Sir:

We have, in our community, a family in which two of the three children are definitely mentally retarded. One is 12 years of age and the other is 6 years. They are unable to benefit by formal education but the mother demands that the Board of Education provide instruction for them, somewhere.

It has been recommended that these children be committed to a state institution, but this the mother has refused to do, and apparently has been unable to accept the fact that her children cannot be taught in the Public or Trade schools.

Do you have literature, or suggestions which might aid us in helping this mother accept, and solve her problem ?

STATE OF NEW JERSEY
DEPARTMENT OF HEALTH

N.J. Parent Groups for Retarded Children Inc.
8 Franklin Terrace
South Orange
N.J.

Kansas Council on Developmental Disabilities

- 1960s- Behaviorists begin expanding work beyond animal models,

applying operant conditioning principles to work with children

- 1975- IDEA/Education for All Handicapped Children

PRESIDENT GERALD FORD SIGNING A NEW LAW

Parents with handicapped children are optimistic about this change.

On Nov. 29, 1975, then President Gerald Ford signed into law the Education for All Handicapped Children Act (Public Law 94-142). With the adoption of this act, Congress opens public school doors for many children with disabilities and sets the foundation of the country's commitment to ensuring that children with disabilities have opportunities to develop their talents, share their gifts, and contribute to their communities.

Skagen, February 2005

What we know now…

- Up to 85% of individuals with ASD have a co-occurring psychiatric diagnosis…
  - Depression*
  - Bipolar Disorder
  - Anxiety *
  - ADHD*
  - Psychosis/Schizophrenia
- High level of genetic overlap between Autism Spectrum Disorders and other psychiatric conditions
  - ADHD
  - Schizophrenia and Bipolar Disorder are found to more commonly co-occur in family systems with ASD and to likely share genetic links
  - What this means as children age
- In general, mental disorders are prevalent, increasing, and undertreated

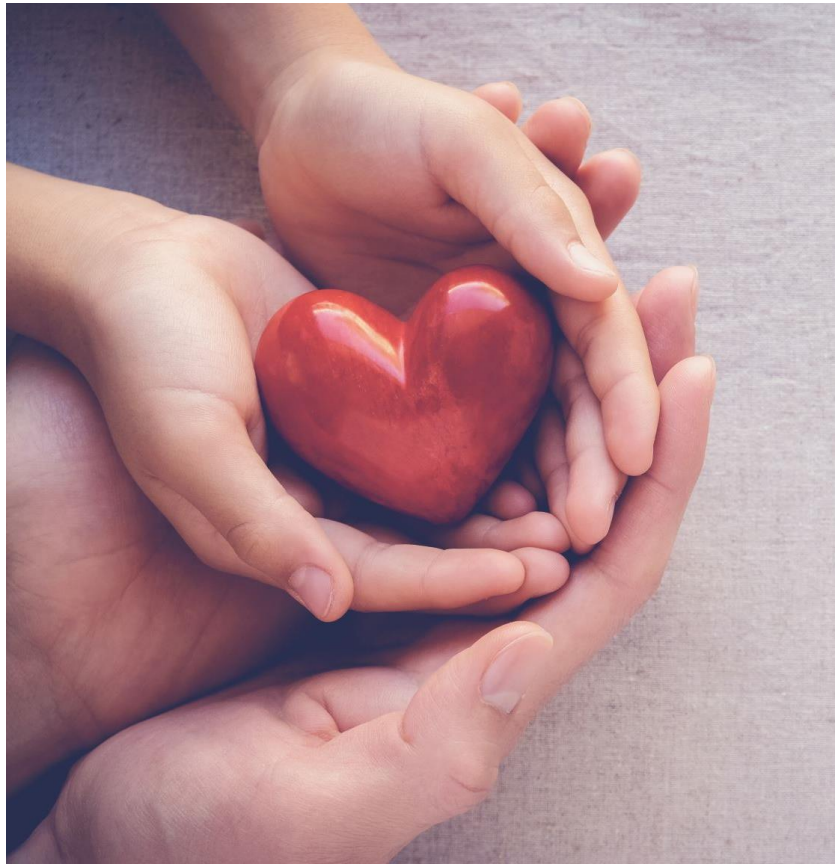
NINDS, 2018; Pinals et al. 2022; Harvey & Gumport, 2015

When Disability is a Disguise (2015)

- Very well-intentioned folks in an individual's life (caregivers, providers) often overlook potential mental health needs because the individual's existing disability overshadows or leads to misinterpretation of behaviors
  - Eric's teacher

    "He could manage this if he wanted to."
  - Administrators at King's school

    "He just likes to fight."



Hogg Foundation for Mental Health, University of Texas

What would I look for?

Signs that warrant further investigation:

- New behaviors that fall outside of a person's general repertoire
- Anxiety: *many of the behavioral symptoms of ASD overlap with common signs of anxiety (pacing, meltdowns, repetitively asking questions, rigidity surrounding changes in schedule)
  - Excessive worry, restlessness, school avoidance/refusal, disruptive behaviors surrounding certain triggers (e.g., classroom)

"Anxiety can also make kids aggressive. When children are feeling upset or threatened and don't know how to handle their feelings, their fight or flight response to protect themselves can kick in — and some kids are more likely to fight. They might attack another child or a teacher, throw things, or push over a desk because they're feeling out of control." Child Mind Institute

- Depression: Substantial changes from a person's baseline in terms of interest in favorite activities, sleep, appetite, becoming increasingly withdrawn—but can also look like irritability/being on edge
- Self-reported concerns**

Clinical Needs Assessment: Mental Health

- Importance of awareness and recognition of possibility of co-occurring psychiatric symptoms in each individual
  - Allows targeting of the comorbid condition for intervention that can improve behavior, functioning, and outcome
  - Allows better understanding of behavioral symptoms (sometimes not an environmental function)
  - Identification can be done through review of previous evaluations, new evaluation, use of questionnaires and/or interviews with caregivers and other members of the treatment team
    - Examples: NIH toolbox (brief, validated questionnaires), the M.I.N.I. (Mini International Neuropsychiatric Interview)
- Variability in risk and functioning is wide
  - Particularly for those with multiple disabilities, for example individuals with ASD + IDD will likely have different needs and risks for comorbidities than someone with ASD or IDD alone, such as higher rates of self-injurious and repetitive behaviors and possibly a poorer prognosis

Clinical Needs Assessment: Trauma

A 2013 report found that **70% of respondents with disabilities reported that they had been a victim of abuse** and of those **90% had experienced such abuse on multiple occasions**

- Potential for traumatic life events is high
  - Individuals with developmental disabilities are more likely to be personally victimized, particularly those with moderate to severe intellectual impairment (neglect, sexual abuse, emotional abuse, physical abuse)
  - If trauma occurs, higher risk of developing psychiatric symptoms (e.g., PTSD) due to difficulty processing the events
  - Beyond individual trauma, individuals with developmental disabilities experience exposure to environmental stressors (e.g., violence, poverty, social rejection) at higher rates than those without developmental disabilities…exposure to negative life events lowers resilience and exacerbates traumatic response
  - "T"rauma versus "t"rauma– letting each individual define for themselves, incorporating supports as needed
- Need to include questions to assess for trauma at intake or incorporate use of questionnaire (e.g., ACEs)
  - Importance of sensitive delivery/space when asking
- Eric: Trauma from repeated negative interactions with isolation, seclusion, and restraint procedures used within his behavior plan in school since he was in middle school
- King: Negative life events that have led to increased anxiety and hypervigilance (car accident, near drowning)

Clinical Needs Assessment: Race, Ethnicity & SES

- Critical to be aware and acknowledge how racial and socioeconomic biases affect identification, referral, diagnosis, and treatment of Autism Spectrum Disorders
  - Inherent biases in attribution of symptoms among professionals
    - "He isn't talking yet because you speak Spanish at home." ; "Black boys are just a little slower to develop."
  - Referral patterns; Later age at referral, if at all
  - More specialist appointments to achieve diagnosis & more severe presentation often required

> "Black parents in the study by Constantino et al. reported that the average age at which they first had concerns about their child's development was around 2 years. Nearly half of the children were evaluated by multiple providers before being diagnosed, and 14% were seen by at least 6 professionals before finally receiving a diagnosis. This resulted in costly delays, with children not receiving a diagnosis until, on average, over 3 years later. Similar findings have been reported with Latinx children who receive an ASD diagnosis after an average of 8 doctor visits." (Aylward, Gal-Szabo, & Taraman, 2021)

  - While national average for ASD referral is around 3yo, Black, Asian and Hispanic children, as well as children from lower socioeconomic backgrounds are often closer to 7yo when diagnosed.

- As providers, we must make space for impacts of systemic racism and/or racial trauma in conceptualization of concerns

“Do the best you can until you know better. Then when you know better, do better.”

Maya Angelou

Evidence-Based Treatments

Expanding our scope…responsibly

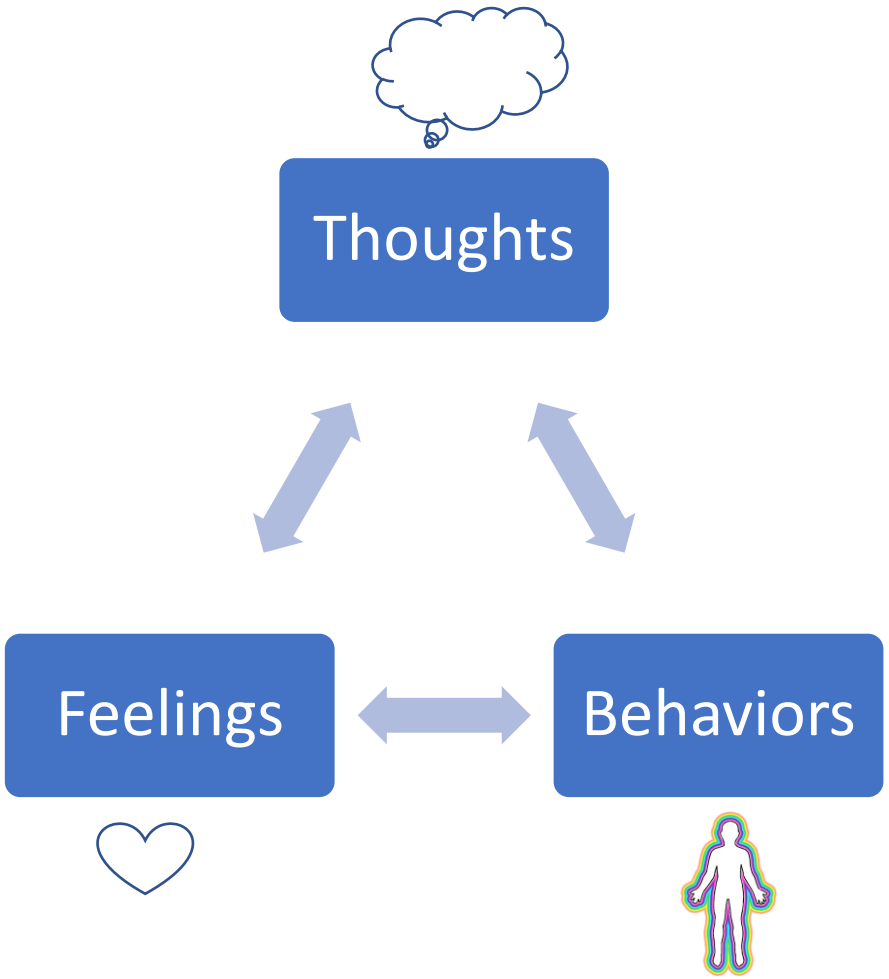
- Continued reliance on behavioral principles and understanding how approaches *work* in terms of behavioral principles
- Incorporating thoughts into practice
  - Thoughts as private verbal behaviors
  - Thoughts as temporary
  - Our mind does not control behaviors

grounding in behavioral learning principles & positive behavior supports remains relevant and important across all of the approaches we will discuss

-Practice of incorporating techniques from mental health therapy thoughtfully

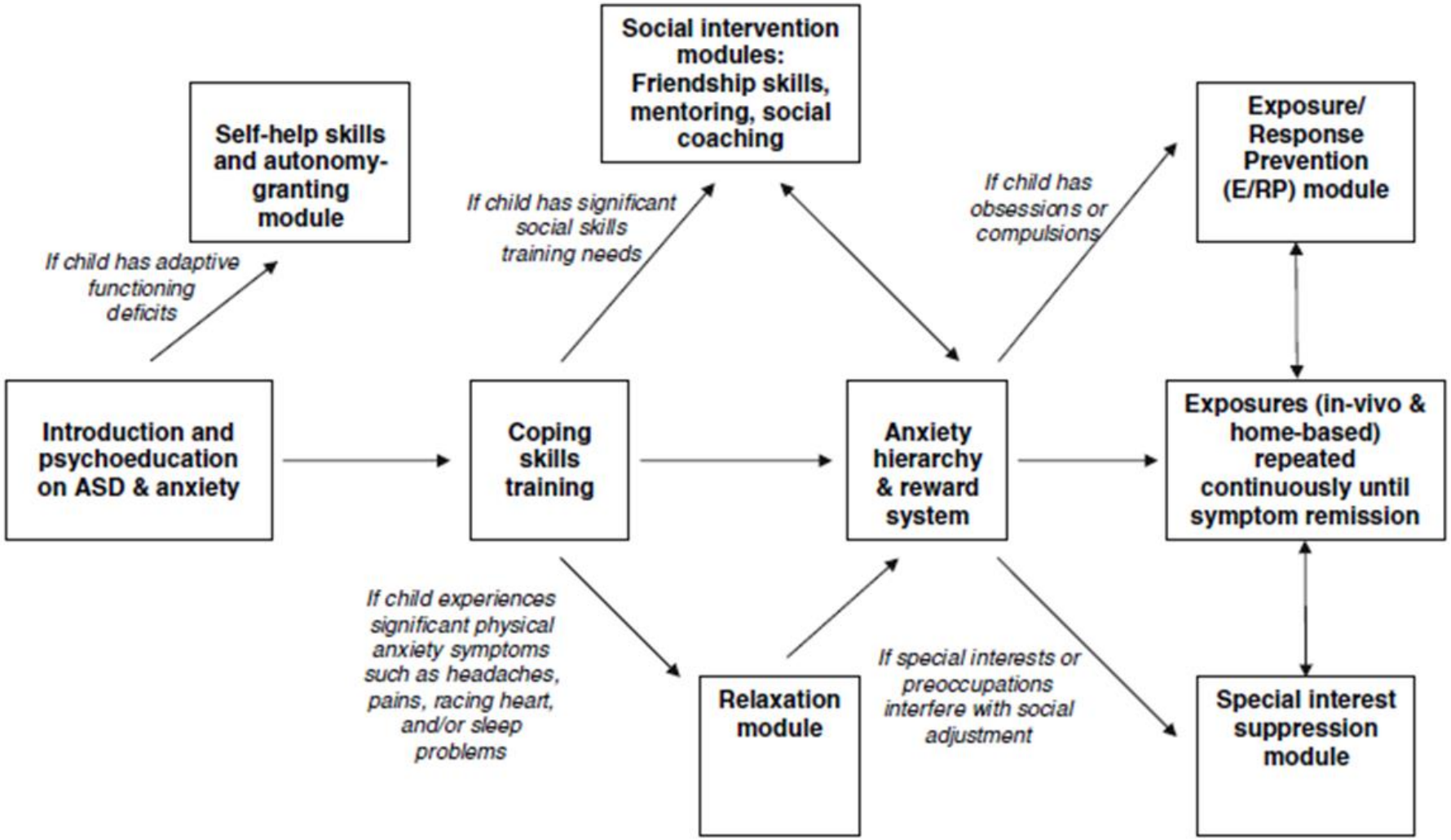
-Continued self-assessment of scope of practice and seeking consultation as needed

Cognitive-Behavioral Interventions



- Introduces individuals to the connection between thoughts, feelings, & behaviors/actions
- Emphasizes idea that unhelpful patterns are maintained due to maladaptive learned behaviors and thought traps
- Teaches clients to recognize when unhelpful thoughts surface and use strategies to alter the thought
  - -Challenging thought distortions (all-or-none, catastrophizing, never-always) by being a *thought detective*
  - -Calming somatic responses through progressive muscle relaxation, breathing exercises
  - -Identifying problem-solving strategies to interrupt avoidance patterns

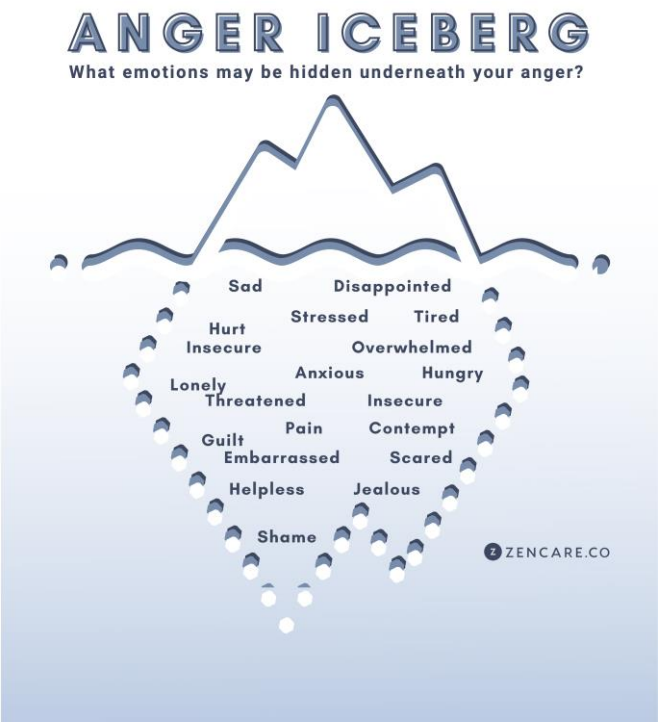
Cognitive-Behavioral Treatment- Where to Start?



Sze, K. M. & Wood, J. J. (2007).

Emotional Awareness & Identification

- For many children with ASD, we must start at recognizing and identifying emotions
  - Visual tools are very helpful
- Tendency to only notice emotions at extremes, so we can teach the "middle" emotions in a behavioral way
  - Ex: Scheduled check-ins with accuracy feedback



Cognitive-behavioral strategies in practice

- Caregiver reports verbal outbursts and negative self-statements related to “unexpected challenges” (e.g., being asked to order food from a new menu) in an autistic teen patient with low support needs & co-morbid anxiety disorder
  - Discuss antecedents- identify situational variables that may have primed response (e.g., feeling pressure due to time constraint, uncertainty about available options, parental modeling of negative self-talk)
  - Discuss thought that occurred automatically when the demand was presented (“Oh no! This *should* be easy. Why can’t I figure this out?”)
  - Provide education on thought traps and self-talk- “should” statements, “critic’s voice”
  - Practice coping self-talk as a replacement behavior using role play and coaching
    - What would you say to a friend who was struggling with something new?
  - Review other situations that lead to *should* statements and imagine responses and develop practice plan (involve support from others as needed)…as well as parent feedback!
- If pattern is unclear- take data! (thought-feeling-action log)

Mindfulness-based interventions

- Hold promise in improving psychological wellbeing of all involved in care services- people with disabilities & both formal and informal caregivers
- Teaching individuals to focus on the present moment/experience through intentional behavioral practices
  - Breathing practice, visualizations (tons of free resources online to choose individually)
- Adolescents and young adults with ASD (+/- IDD) can learn to regulate their emotions well enough to significantly reduce verbal and physical aggression.
- When parents engage in a mindfulness training program, the change in their psychological wellbeing results in measurable behavioral improvement for their children.

Singh, N. *Mindfulness-based Interventions for People with Autism and their Caregivers*

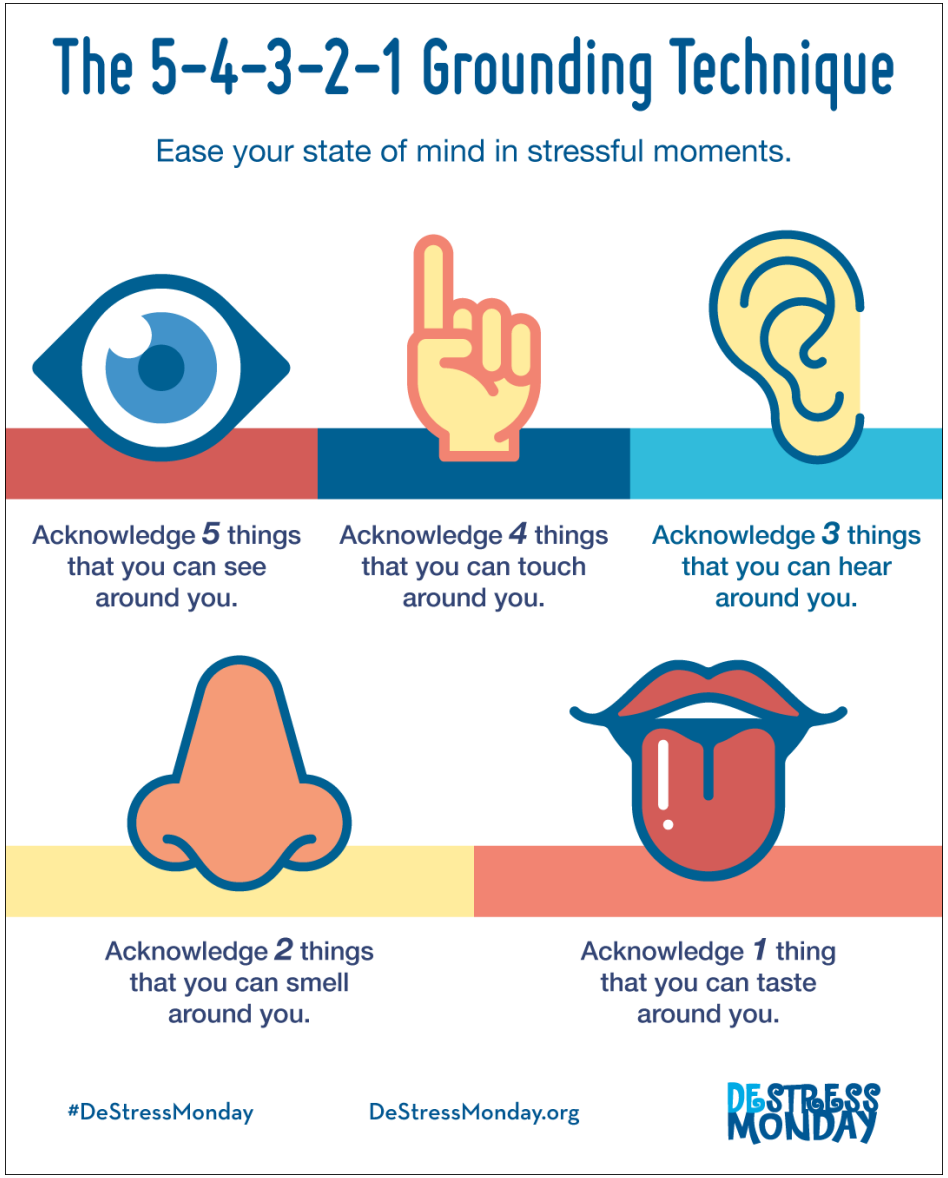
Sample intervention:

Soles of the Feet Meditation (N. Singh)

Mindfulness-Based Interventions

- Grounding Techniques
  - 5-4-3-2-1 Sensory Grounding

Greater Good in Action
SCIENCE-BASED PRACTICES FOR A MEANINGFUL LIFE



Mindfulness-based interventions in practice

- Autistic teen with psychiatric concerns having meltdown in car during virtual visit--- coaching caregiver through 5-4-3-2-1 sensory grounding in real time ("Right now, I can see the radio, the steering wheel, trees…")
- Guided visual practice- "Leaves on a stream" to teach mindful practice of noticing thoughts without judgment and incorporating breathing (can start with very short duration practice and build as individual tolerance builds)
- *Sitting Still Like a Frog* (mindfulness practices for kids)
  - Body Scan/ "Weather check"

*Important to emphasize the need for consistent practice (e.g., committing to daily exercise, and practicing under calm conditions so that the skill is easier to use under stressed conditions)

Acceptance and Commitment Treatments

- Under the umbrella of Cognitive-Behavioral interventions, but rather than challenging thoughts, we accept the thought as a response to a situation and decide how we want to react
- Goal of increasing *psychological flexibility* and living aligned with personal values
- Changing the function of the private event, not trying to change the private event itself
  - Notice the thought and acknowledge it
  - Use distancing or defusion strategies to reduce distress
    - "I'm having the thought that…."
    - "There's that thought again…"
  - "Passengers on the bus" or "uninvited party guest" metaphors (videos on YouTube)
  - Autism Live Podcast- April 4, 2022 episode

See Tarbox, Szabo & Aclan, 2022; Association for Contextual Behavioral Science

ACT in practice--- Tarbox, Szabo,& Aclan (2020)

Target Audience	Phrasing	Concepts/Functions
With everyone-- Patient/Client/Parent/ Coworker	*"I notice I'm having the thought that I'm not being very helpful to you right now, and it's getting in the way of me actually listening and figuring this out with you. Would it be OK if we pause for a second and start over?"*	Defusion • Our mentalistic society has trained us all to believe that the mind causes behavior, and therefore that we should take our thoughts very seriously…Defusion procedures are about teaching people to notice their thoughts for what they really are: just more stimuli in their environment
With child/adolescent learner	*"Look, I hate losing too. If you can win, awesome, then win. But when I can't win, one thing that helps me is to repeat my thought back to myself but in the voice of Yoda from Star Wars. If I'm losing a game, and it's driving me nuts, I might just say "Lose this game, I can't!" [while talking in a silly accent that resembles the Yoda character]. Are you willing to give it a shot? Try it—just say something like Yoda."*	• Defusion exercise (gives flexibility and space between thought and action) • Adds humor to maladaptive thought Not about silly voices, per se… What matters is that, functionally, the practitioner helps the learner engage in more flexible and varied behavior in the presence of whatever rules are evoking avoidant behavior…Defusion is about teaching learners to "not take their own minds so seriously."

Motivational Interviewing Strategies

- Helpful when we as the provider, our clients, or our teams, feel *stuck*
- Involves concretely defining goals for change, as well as pros and cons of change, potential barriers to change, etc. with input actively gathered from the other person
  - What changes do you want to make?
  - What is the most important reason to make this change?
  - What do you think could get in the way of making changes?
    - How hard will it be for you to make it to sessions consistently?
    - How much will you be willing to practice at home?
    - What are you willing to do if things get in the way?

E.g., Nock & Kazdin, 2005

Social Skills Training

- Social connectedness is one of the best protective factors for mental health, and one of the most common areas of challenge for children & adolescents with autism
- Evidence-based interventions to improve social skills for a variety of ASD/IDD and mental health conditions
    - Teach, Model, Practice/Role-Play, feedback
    - PEERS® (text by Elizabeth Laugeson)
        - UCLA PEERS® Clinic has developed free, accessible resources, including video models of a wide range of social skills, to be combined with didactic and practice
- Importance of incorporating meaningful, structured social experiences as part of school programming

Guiding Practices Across Approaches

Power of Validation

- Letting others know that we can understand their perspective
- Validation is not the same as agreement or approval. We can validate the person's feelings, but not the (problematic) behavior.
- Validation helps de-escalate conflict and reduces intensity of emotional behavior
- Achieved through a combination of nonverbal and verbal affirmations
  - Leaning forward
  - Nodding head
  - Open body posture, oriented towards client
  - "I hear you saying that…"
  - "You are letting me know that…."
  - "It makes sense that you…."
- Ex: Responding to Eric's emotional experiences following episode at school

Trauma-Informed Care

Important lens that applies across modalities and approaches

"Trauma-informed care shifts the focus from *"What's wrong with you?"* to *"What happened to you?"*

Emphasizes the importance of having a "complete picture of a client's life situation — past and present — in order to provide effective healthcare services with a healing orientation."

"Use of trauma-informed practices can potentially improve patient engagement, treatment adherence, and health outcomes, as well as provider and staff wellness."

*my patient's experience with his RBT

- Dr. Bruce Perry: *What Happened to You*

Regulate. Relate. Reason. "In order to communicate rationally and successfully with anyone, you have to make sure they are *regulated*, make sure they feel a relationship with you, and only then try to reason with them." (151)

Further Considerations

- Person-Centered Care
  - Viewing person with ASD from lens of strengths and potential, rather than deficits
  - Acknowledgement of increasing knowledge gained from autistic self-advocates
  - “Does your face light up?” “Do you see their light?”
- Self-determination
  - Fundamental human right to exert control over personal decisions without unnecessary interference from others
    - For people with developmental disabilities, having opportunities to make choices and be a self-advocate is a strong predictor of self-determination---which is linked to higher quality of life, more likelihood of participation in community, and to be earning higher pay in future employment
    - This can be achieved through educating individuals on self-advocacy skills, including problem solving, decision making, and goal setting

“All people have the right to eat too many doughnuts and take a nap…

But along with rights come responsibilities. Teaching clients how to exercise their freedoms responsibly should be an integral part of the habilitation process. While learning, clients should be encouraged to make as many choices as their abilities allow, as long as these choices are not detrimental to the client or to others.”

Bannerman, Sheldon, Sherman, & Harchik (1990)

Self-Care

Burnout is REAL

Importance of intentional actions to promote emotional regulation & resilience for YOU!

“A dysregulated adult cannot regulate a dysregulated child. An exhausted, frustrated, dysregulated adult can’t regulate anybody.”

(Dr. Bruce Perry, p. 284)

Ethical Imperatives when Expanding Scope

- *Practicing within Scope of Competence:* We all are committed to practicing only within the areas we have been trained and licensed, but may expand within that area after accessing appropriate study, training, supervised experience, consultation, and/or co-treatment from professionals competent in the new area. *Otherwise, refer or transition services to an appropriate professional.
  - Example: Parent with depression in parent training for child with ASD (Tarbox et al., 2022)
- Seek ongoing training, supervision, and consultation as needed
- Selected sources for training on interventions with mental health applications:
  - Association for Contextual Behavioral Science
  - Association for Behavior Analysis International
  - *Trauma-Informed Behavioral Interventions: What Works and What Doesn't*, Karyn Harvey, PhD.
- Great free tools online to find local therapists with various specialties if a need falls beyond your scope: PsychologyToday.com (Find a Therapist tool), FindAPsychologist.org**

Decisions around scope and referring out

Situation	ABA Practitioner	Psychotherapy Practitioner
A BCBA is engaging an adolescent with autism in social skills training, and the adolescent reports that he feels like a loser because he has no friends.	Consider referring the adolescent to a clinical psychologist for assessment for potential depression if the reports continue. In the context of social skills training, adapt ACT components to help the adolescent learn new and variable rules about himself in the context of social relations.	If the adolescent's negative affect rises to the level of depression, treat the adolescent for depression with psychotherapy.

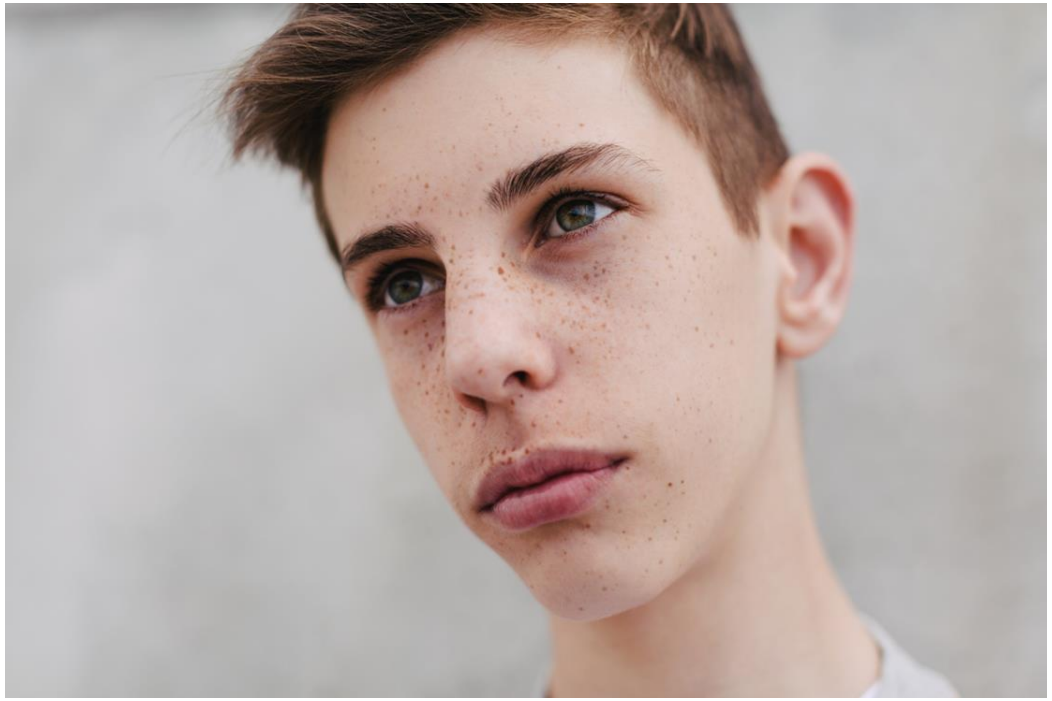
Tarbox, Szabo,& Aclan (2020)

Back to why it matters…

Eric’s case

- What should/could have support looked like at school?
- What questions weren’t being asked?

Risks if approach doesn’t change



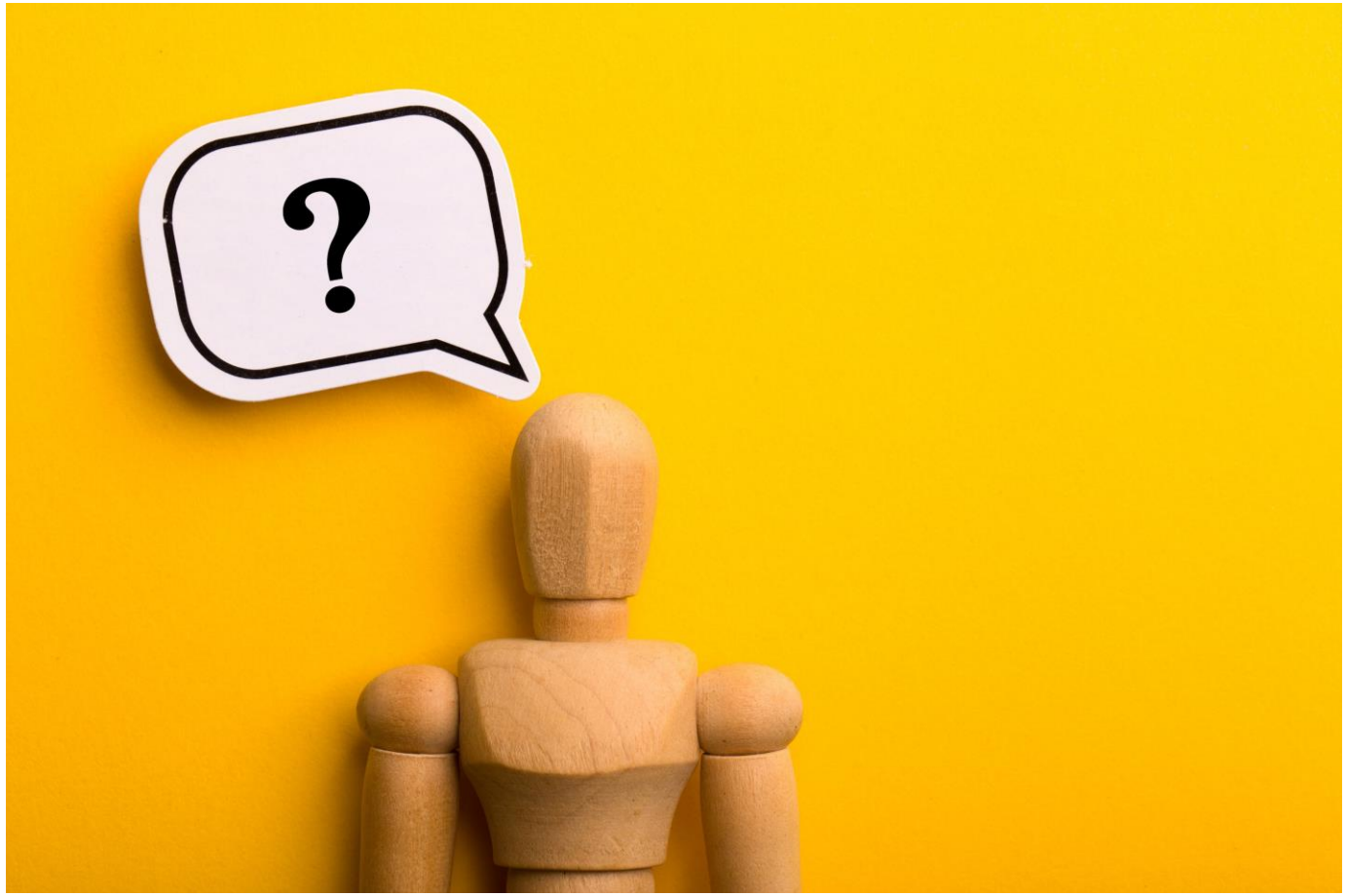
King’s case

Critical crossroads-
school-to-prison pipeline

Reactionary approach, rather than preventative

Changing the story of what disruptive behavior means

Q&A



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