

AMERICAN ACADEMY OF
CHILD & ADOLESCENT
PSYCHIATRY

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**When Behavior Tells a Story:
Trauma-Informed Care for Individuals with Intellectual Disabilities**

Presenters: Ilana Slaff-Galatan, MD, Kari Harper, MD, Jennifer McLaren, MD

Moderator: Ciara Styles, MD

August 20, 2026

Virtual Forum Logistics

- All participants are in listen-only mode
- Technical issues or AACAP-related questions → use the Chat box
- Questions for the presenters → use the Q&A box
 - Due to time limitations, we may not be able to answer all questions, but we will do our best to address as many as possible.
- Today's session will be recorded and posted to www.aacap.org/virtual_forum within the next 24 hours

Learning Objectives

At the conclusion of this session, the participant will be able to:

- Discuss the prevalence and types of trauma experienced by individuals with autism and intellectual and developmental disabilities
- Explain how trauma may manifest differently compared to neurotypical populations
- Identify barriers to diagnosis and treatment, including diagnostic overshadowing
- Learn strategies for providing trauma-informed, person-centered care

Introducing the Moderator

Ciara Styles, MD is a graduate from the Class of 2020 College of Medicine at the University of Florida. She completed her adult psychiatry residency and child & adolescent fellowship at the Medical University of South Carolina. She has served as a Diversity Leadership Fellow with the American Psychiatric Association from 2023 to 2025. She is the current Vice President of the South Carolina Psychiatric Association. She is currently employed with Weatherby Healthcare and her clinical interests include trauma-focused care, interpersonal dynamics involving families, and improving the treatment of severe mental illness.



Our Esteemed Panelists



Jennifer McLaren, MD is an Associate Professor of Psychiatry, Pediatrics and The Dartmouth Institute at the Geisel School of Medicine at Dartmouth. Dr. McLaren received her BA from University of Notre Dame in 2001 and her MD from Rutgers Robert Wood Johnson Medical School in 2005. She completed her residency in adult psychiatry at the Dartmouth-Hitchcock Medical Center in 2008 and fellowship in child psychiatry at Dartmouth-Hitchcock Medical Center in 2010. She is the Section Chief of Child and Adolescent Psychiatry and oversees the Behavioral and Neurodevelopmental Services (BANDS) at Dartmouth-Hitchcock Medical Center, a multidisciplinary group of providers who work with children, adolescents, and young adults with autism and other neurodevelopmental conditions. Dr. McLaren is the Medical Director for the Bureau of Developmental Services in NH and Chief Medical Advisor for the National Center for START Services®.

Our Esteemed Panelists

Dr. Kari Sharyce Harper, MD, is an associate professor and training director of the child and adolescent psychiatry fellowship in the Department of Psychiatry at Wright State University Boonshoft School of Medicine in Dayton, Ohio. Her professional interests include child and adolescent psychiatry, intellectual disability psychiatry, psychotherapy, and training excellent child and adolescent psychiatrists for the future. She is employed at Dayton Children's Hospital where she does outpatient psychiatry and works with the juvenile court system.



Our Esteemed Panelists



Dr. Ilana Slaff-Galatan is a sister of identical twin brothers with autism and the mother of a child with autism. She is also a board certified psychiatrist who completed an autism research fellowship at Mount Sinai Medical Center in New York. Dr. Slaff assisted with editing the chapter “Complementary and Alternative Therapies for Autism” in the Clinical Treatment Manual for Autism (2007) and has been published in the *Journal of Clinical Psychiatry*, *Current Psychiatry*, *Psychiatric Times*, and the *Psych Congress Network*. Dr. Slaff-Galatan authored the book *Don't Medicate-Educate!: One Family, Three Cases of Autism, Safe Treatment for Dangerous Behavior*. Dr. Slaff-Galatan has given CME lectures internationally on autism diagnosis and management and has also lectured to families. Dr. Slaff-Galatan has presented at numerous public hearings, including before the FDA. She has also spoken on New York's Capitol Pressroom radio show and appeared on Your News Now Capital Tonight for New York.

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Trauma Exposure in Intellectual Disability: Risk Factors, Disparities, and Epidemiology

Jennifer McLaren, MD

The Risk of Maltreatment is Elevated

31.7% of
children with
disabilities

2.08 X

2-3.32 X

Fang *et al.*, 2022; McDonnell *et al.*, 2019; Jones *et al.*, 2012, Legano *et al.*, 2021

Not All Disability Carries the Same Risk



Legano *et al.*, 2021

Trauma Exposure



Exposure Domains

- Physical abuse
- Sexual abuse
- Emotional/psychological abuse
- Bullying and peer violence
- Exploitation/other interpersonal violence
- Neglect
- Child maltreatment
- Cyberbullying

Why This Matters in IDD Studies

- Some studies combine all disabilities
- Definitions and thresholds vary
- Self-report is not always accessible
- Administrative data capture detected cases – not all exposure
- Trauma symptoms and exposure are separate constructs

Legano *et al.*, 2021; Fang *et al.*, 2022; McDonnell *et al.*, 2019; Jones *et al.*, 2012

Trauma Exposure is Often Cumulative and Ecological

Beyond a Single Index Event

Interpersonal victimization

Chronic social exclusion and bullying

Family stress, caregiver mental illness, or domestic violence

Poverty, housing instability, and limited respite or support

School mismatch, exclusionary discipline, restrictive placement, changes in routine,

Recurrent medical procedures, hospitalization, or loss of familiar caregivers

Constantino *et al.*, 2020

Child Level Factors

Dependence on Caregivers

More hands-on care creates more opportunities for both support and harm. Reduced ability to leave or seek help

Communication Differences

Difficulty describing, sequencing or narrating events can reduce disclosure and detection

Behavior

Aggression, impulsivity or oppositional behavior may increase caregiver stress or may also be a response to a trauma

Social Vulnerability

Limited understanding of boundaries, consent, or coercion; desire for peer acceptance

Legano *et al.*, 2021

Caregiver Level Factors

High parenting/caregiving stress

Low social support or isolation

Family conflict or domestic violence

Caregiver mental health or anger
reactivity

Limited respite and practical
supports

Poverty/housing or resource
instability

Legano *et al.*, 2021

System and Structural Level Factors

Fragmented
Systems of
Care

Diagnostic
Overshadowing

Staff Turnover

Legano *et al.*, 2021

Why Trauma May Remain Hidden

Barriers to Disclosure

- Communication
- Fear
- Reliance on caregiver

Common Diagnostic Errors:

- Diagnostic overshadowing
- Behavioral reductionism
- Premature psychiatric closure

Siegel *et al.*, 2019

What the Data Can and Cannot Tell Us

What is Consistent

- Youth with IDD experience a substantially greater burden of traumatic experiences
- The disparity is observed across multiple settings and forms of victimization

Fang *et al.*, 2022

Why Precise Estimates Vary

- ID is frequently groups with other disabilities
- Definitions of trauma are inconsistent
- Studies vary
- Youth with limited verbal communication and youth in highly marginalized settings are often underrepresented.

Trauma Should Not Be an Afterthought

Clinical Traps

- Behavior attributed to their ID
- Communication difference obscure disclosure
- Multiple caregivers and settings fragment history

Clinical Opportunities

- Use developmentally adapted questions
- Get information across settings
- Seek collateral information without replacing the child's voice
- Treat new behavioral change as a possible signal of trauma
- Develop a hypothesis

Legano *et al.*, 2021; McDonnell *et al.*, 2019; Wissink *et al.*, 2015

Implications for Child and Adolescent psychiatry

Trauma exposure is elevated in children and adolescents with IDD

Trauma may appear as a shift in a child's baseline functioning

Avoid diagnostic overshadowing: Trauma belongs in the differential for new or escalating psychiatric or behavioral symptoms

Ask About Trauma!

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**Assessment and Treatment:
Interpreting the Story and Intervening**

Kari Harper, MD

Diagnostic Overshadowing



Definition: Trauma-related symptoms are misread as “just part of the disability” — or wrongly attributed to another psychiatric disorder — so the underlying trauma is never identified or treated

Misattributed to

Symptoms get filed under the ID itself or misdiagnosed as a psychotic or bipolar disorder instead of a trauma response.

Assessment barriers

Clinicians often lack training in IDD-specific trauma assessment and may hesitate to ask about trauma history for fear of symptom exacerbation.

Reliance on self-report

Standard PTSD assessment assumes verbal self-report; this breaks down for patients with moderate-to-severe ID or limited language.

RECOGNIZING THE PATTERN

Same Disorder, Different Vocabulary

DSM-5 PTSD symptom clusters and their common behavioral expression in patients with IDD

PTSD symptom cluster	Typical verbal presentation	Common IDD behavioral equivalent
Intrusion / re-experiencing	Flashbacks, intrusive memories	Sudden agitation or distress, behavioral re-enactment or repetitive play, some forms of self-injurious behavior, behaviors that appear psychotic
Nightmares	Recurrent distressing dreams related to trauma	Frightening dreams without recognizable content
Avoidance	Avoiding reminders, refusing to discuss	Refusal behaviors or “noncompliance”, escape/elopement, resistance to specific people, places, or care routines
Negative mood/cognition	Guilt, detachment, negative beliefs	Withdrawal, regression in skills, flattened affect, increased irritability
Hyperarousal	Hypervigilance, exaggerated startle, sleep problems	Aggression, self-injurious behavior, sleep disturbance, heightened startle

Self-injurious behavior is one of the most frequently reported presentations in children with severe/moderate ID.

CLINICAL CLUE

Think Trauma When Treatment Isn't Working



“Transformed” PTSD: Chronic, unrecognized trauma can re-emerge as treatment-refractory mood, psychotic, behavioral, or substance-use presentations — rather than classic PTSD symptoms

- Multiple medication trials with limited or partial response
- Behavioral or mood symptoms that track closely with specific people, places, or routines
- History of abuse, neglect, or out-of-home placement — even if never formally assessed

ASSESSMENT

Instruments — And Who They're Validated For

Most PTSD-specific instruments in IDD were developed and validated in adult samples only — age validity matters as much as the tool itself.

Instrument	Validated population	What it measures
DM-ID-2	All ages — a diagnostic framework, not a scored scale	Adapted <i>DSM-5</i> criteria across psychiatric disorders, including trauma
Adapted ADIS-C PTSD Section	Children & adolescents, ages 6–18, mild-to-borderline ID — the only instrument validated in this age group	The only tool that can establish an actual <i>DSM-5</i> PTSD diagnosis in youth with IDD; excellent interrater reliability, good convergent validity
DITS-ID (DITS-SID)	Adults with mild ID/BIF; a severe-ID adult version (DITS-SID) now exists	Structured diagnostic interview mapped to <i>DSM-5</i> PTSD criteria; not validated in children
LANTS	Adults with mild-to-moderate ID only	Self- and informant-report symptom severity scale; not validated in children or adolescents
IES-ID	Developed & validated in adults; some later studies include adolescents in mixed samples, not separately validated	Self/informant-report screener for the impact of a specific stressor

For adolescents specifically: The Adapted ADIS-C PTSD Section is the only tool with direct pediatric validation — LANTS, IES-ID, and DITS-ID were developed in adults and should be used cautiously, if at all, under 18

What to Ask, and How to Phrase It



Asking the patient

- Use short, concrete, direct questions — avoid abstract or hypothetical phrasing
- Pair each question with a follow-up and place events on a visual timeline
- Paraphrase, use sentence stems (“So what happened was...”), and repeat key words to check understanding

Try: “Have you ever been bullied?” → “What happened?”

“Has anyone ever hurt you, or scared you a lot?”

“Has anyone ever touched you in a way that made you feel bad?”

Use appropriate visual aids or allow patient to draw.



Asking the caregiver

- Ask about interactions with parents and other caregivers
- Ask directly about caregiver turnover and placement history — a known risk factor
- Ask about behavioral flags tied to specific people, places, or routines

Try: “How many different caregivers or placements has [patient] had?”

“Do you know if any caregiving relationships were abruptly ended or why?”

“Have you noticed self-injurious behavior or other concerning behavior around specific people or places?”

“Does [patient] avoid certain routines?”

Principles for the Encounter



Assume exposure, ask directly

Given elevated base rates, screen for trauma history routinely rather than only when a caregiver raises it



Use caregivers as informants, not the whole story

Caregiver report adds essential context but can miss internal symptoms and, at times, may reflect the source of harm



Adapt communication before ruling anything out

Simplify language, use visual supports, and allow extra processing time before concluding a symptom is absent



Treat the trauma, not just the behavior

Trauma-focused therapies (e.g., adapted EMDR, trauma-focused CBT) show benefit; behavior plans alone may miss the driver

TREATMENT EVIDENCE

What's Actually Been Tested in IDD?

Across all ages, psychotherapy has the deepest evidence base in IDD; medication evidence is limited to case reports.

PSYCHOTHERAPY — DEEPEST EVIDENCE

EMDR has case series and pilot studies spanning the age and severity range — children through adults, including case series in **adults with severe intellectual disability**, not just mild ID/BIF.

24 → 8

Participants meeting *DSM-5* PTSD criteria before vs. after an intensive EMDR-based family program for children/parents with MID-BIF — no dropout, no adverse events

Trauma-focused CBT and psychodynamic-based treatments also show promise via case reports. A 2010 review (Mevisen & de Jongh) found 9 published PTSD treatment studies in ID overall — all case-based, none randomized

MEDICATION — CASE REPORTS ONLY

That same 2010 review included medication among its 9 studies — but no randomized or controlled trial of medication for PTSD specifically in IDD, of any age, was identified. What exists:

- Isolated case reports of medication used alongside psychotherapy for PTSD symptoms (e.g., chronic sexual-assault-related nightmares) — not controlled studies
- IDD medication evidence for other indications (depression, anxiety, challenging behavior) that can inform — but not confirm — use for trauma symptoms

Implication: pharmacologic choices for PTSD in IDD are extrapolated from general-population PTSD evidence, cross-checked against IDD tolerability data for the same drugs — the next few slides walk through both

General-Population Evidence: Adults vs. Youth

Trauma-focused psychotherapy is first-line at every age — medication is adjunctive, not a replacement.

ADULTS

First-line: SSRIs / SNRIs

Sertraline & paroxetine are FDA-approved. Cochrane meta-analysis (66 RCTs, n=7,442): SSRIs reduced symptoms vs. placebo (RR 0.66); response rates ~60%, remission only ~20–30%.

Prazosin for nightmares

First-line adjunct for trauma-related nightmares/sleep disruption, especially with comorbid alcohol use disorder.

Second-line

Mirtazapine, TCAs, MAOIs; SGA augmentation (aripiprazole, risperidone, quetiapine) for partial responders.

Avoid benzodiazepines

No proven benefit for core symptoms and associated with worse overall outcomes.

CHILDREN & ADOLESCENTS

TF-CBT remains first-line

Medication is reserved for inadequate response to trauma-focused psychotherapy or severe symptoms.

Evidence base is much thinner

No SSRI is FDA-approved for pediatric PTSD; controlled trials have not supported SSRIs as first-line specifically for pediatric PTSD.

When medication is needed

SSRIs (citalopram, fluoxetine) plus antiadrenergic agents (prazosin, guanfacine, clonidine), based on clinical experience and limited trial data.

Black-box warning applies

All antidepressants carry a suicidality warning in youth — monitor closely after initiation.

Same Drugs, IDD-Specific Evidence

Evidence below is from IDD studies of depression, anxiety, and behavior — not PTSD directly — used here as the best available tolerability/efficacy proxy.

Drug class	Efficacy signal in IDD	Tolerability signal in IDD
SSRIs (fluoxetine, paroxetine, citalopram)	Citalopram: 12/20 adults with ID and depression significantly improved (open study). Fluoxetine/paroxetine: similar efficacy to each other across 147 treatment episodes.	Generally well tolerated at lower starting doses; one study found fluoxetine/paroxetine gave no benefit in 40% and worsening in 25% when used for perseverative/behavioral symptoms specifically.
SSRIs in autism (comorbid IDD)	Limited evidence of effect in autistic adults; no evidence of effect in autistic children for repetitive behavior.	Emerging evidence of harm reported in some pediatric autism studies; sertraline-for-anxiety RCT in autistic adults (STRATA) is still underway.
SGA augmentation (risperidone, aripiprazole)	Moderate RCT evidence for challenging behavior in ID/ASD (not trauma-specific); antipsychotics are already the most-prescribed class in this population.	Elevated risk of metabolic and neurological side effects; used in 5–45% of community and 15–74% of institutional IDD populations, often off-label.
Prazosin, alpha-2 agonists (guanfacine, clonidine)	No IDD-specific efficacy data identified for any indication.	No IDD-specific tolerability data identified — extrapolate general-population dosing cautiously with start-low-go-slow titration.

Minors With IDD: Evidence & Best Practice

The AACAP 2020 Practice Parameter is the strongest dedicated evidence base in this deck — though still graded a “clinical option,” not definitive evidence.

EVIDENCE BY SYMPTOM DOMAIN (RCTs, n>10)

Irritability / aggression

Risperidone — best-studied agent, multiple RCTs, effects sustained through 48-wk extensions. Risperidone/aripiprazole are also FDA-approved for autism-related irritability (ages 5–17, ~60% response vs. ~20% placebo) — an ASD indication, not an ID indication.

ADHD

Methylphenidate remains first-line; effective in ~40% with ID/IDD, smaller effect size (0.39–0.52) than typically developing children (~0.8–0.9). One positive RCT for clonidine.

Anxiety / depression

No ID-specific trials since 1999 — SSRIs (fluoxetine, sertraline) remain treatment of choice, extrapolated from typical-development evidence.

Mania / psychosis

No ID-specific trials — mood stabilizers; atypical antipsychotics preferred over first-generation agents due to EPS sensitivity.

Sleep

Melatonin — one positive RCT in adolescents with ID.

BEST-PRACTICE PRINCIPLES

No FDA-approved medication for ID/IDD itself

Unlike the ASD irritability indication, there is no FDA-approved medication for ID/IDD as such — every recommendation here is graded a “clinical option.”

Target a diagnosis, not just a behavior

Reserve behavior-targeted medication for risk of harm to self/others, severe impulsivity, or risk of losing placement or services.

Monitor systematically

The Aberrant Behavior Checklist is the most-used outcome measure; document baseline stereotypies before starting, since these are common in ID and can be mistaken for medication-induced movement.

Assent matters

Guardian consent is required, but assent should reflect the minor's actual developmental capacity to understand — assessed per-decision, not assumed globally.

Prescribing in IDD: Practical Considerations

No medication is FDA-approved specifically for PTSD in patients with IDD.



Start low, go slow

Patients with IDD are often more sensitive to side effects and may have more difficulty self-reporting them — titrate cautiously and monitor closely.



Watch for antipsychotic overuse

49–63% of people with ID/ASD are prescribed psychotropics, often off-label for “challenging behavior” without a clear psychiatric diagnosis.



Polypharmacy is common — and risky

Multiple concurrent psychotropics increase adverse events and drug interactions; deprescribing is often difficult once started.



Benzodiazepine caution

Paradoxical disinhibition is more common in IDD — ask directly: “Have you ever had a medication that gave you the opposite reaction than expected?”

KEY TAKEAWAYS

What to Carry Into Clinic

- 1 Patients with IDD face higher trauma exposure and likely-underdiagnosed PTSD.
- 2 Diagnostic overshadowing is the single biggest reason trauma gets missed — ask about it explicitly.
- 3 PTSD often shows up as behavior: self-injury, aggression, avoidance, and regression, not just verbal re-experiencing.
- 4 Adapt interview questions for patients (concrete, timeline-based) and caregivers (broadened wording, ask about placement turnover).
- 5 In IDD, psychotherapy (especially adapted EMDR) has direct supporting evidence; medication for PTSD specifically does not — treat psychotherapy as first-line.
- 6 When medication is used, borrow dosing/agent choice from general-population PTSD evidence, then cross-check tolerability against IDD-specific data on that drug.
- 7 In minors with IDD, the AACAP 2020 Practice Parameter gives the strongest dedicated evidence — risperidone for irritability/aggression, methylphenidate for ADHD — but still no FDA-approved medication for ID/IDD itself.
- 8 Across IDD: start low and go slow, watch for antipsychotic overuse and polypharmacy, and use IDD-adapted tools (DM-ID-2, Adapted ADIS-C).

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The logo for the American Academy of Child & Adolescent Psychiatry is centered at the top of the slide. It features the organization's name in a white, serif font against a dark blue background with a geometric, low-poly pattern. The text is arranged in three lines: "AMERICAN ACADEMY OF", "CHILD & ADOLESCENT", and "PSYCHIATRY".

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Presentations, Managing Aggression, and Supporting Families

Ilana Slaff-Galatan, MD

Overview

- Intellectual Disability, Autism, Trauma and Diagnosis
- Behavioral Educational Interventions
- Parent Training or Support or Special Needs Tutoring
- Family and Caregiver Trauma
- Supporting Siblings of Individuals with Intellectual Disabilities
- Special Education Law

Trauma

- “More than ninety percent (90%) of people (both male and female) with developmental disabilities will experience sexual abuse at some point in their lives. Forty-nine percent (49%) will experience ten or more abuse incidents.”

Posttraumatic Stress Disorder and ID

- Intellectual disability is a predisposing factor to PTSD.
- They may have a more behavioral presentation and a decline in functioning.
- Events others might not find traumatic may be traumatic to someone with a developmental disability, such as moving or a bus accident.

Posttraumatic Stress Disorder and ID

- Forcing a residential placement transfer may be detrimental, such as school district residential to adult residential or moving to an in-state placement from an out of state placement.
- Ask the individual if they are verbal how they felt about the traumatic event and search for behavioral changes such as temper outbursts, sudden mood changes, aggression or self-injury. Stereotyped behavior, refusal to participate in activities and reduced self-care might also increase.
- Look for avoidance symptoms, such as program or trip refusal, presenting as non-compliance. My brother who resides at a MA facility has expressed fears of going back to NY after a five-month hospitalization including surgery for SIB in NY and when going to NY was suggested to him, he would start discussing cemeteries.

Posttraumatic Stress Disorder and ID (cont'd)

- Some adults with severe ID, trauma specific reenactments may be displayed as seen in children.
- The lower the developmental level, there is a greater likelihood of behavioral symptoms rather than expressive language.
- Trauma specific reenactments can be mistaken for psychotic symptoms and may be distressing and even threatening to others present.
- Flashbacks may be expressed as current experiences.
- Distressing dreams might appear that do not resemble the traumatic event.

Intellectual Disability and Autism

- At least 10% of individuals with ID have an autism spectrum disorder with some ID conditions having a higher comorbidity.
- There is “mounting evidence for stress and trauma as a risk factor for comorbidity and the worsening of core ASD symptoms.”

Autism Symptoms, Trauma, and Diagnosis

- An increase in problem behaviors can reflect anxiety and depression.
- "Anxiety comorbidity is associated with greater ASD symptom severity and concomitant impairments in psychosocial functioning. For example, patients with ASDs and comorbid anxiety are at increased risk for displaying externalizing behavior problems."

Autism Symptoms, Trauma, and Diagnosis

- "In a patient with ASD, depression frequently presents as an increase of existent ASD symptoms. What is important to note is not the symptoms themselves, but their heightened intensity."
- "[M]any cases of other psychiatric disorders, such as depression, may in fact themselves be posttraumatic conditions."

Medication and Psychosocial Interventions

“For many children and adolescents with ADHD and disruptive disorders, it is likely that aggression and disruptive behaviors are the clinical targets of antipsychotic treatment. Clinical practice guidelines addressing the management of aggression or disruptive disorders in children and adolescents recommend the use of psychosocial interventions before use of antipsychotics, including children with autism.”

Applied Behavior Analysis (ABA)

- What is ABA?
 - Began in the 1950s-early 1960s
 - Identifying environmental variables that influence behavior and making manipulations to those variables to move behavior in the desired direction
 - Identifies and treats **socially significant behaviors**
 - Applied behavior analysts use principles developed in behaviorism to develop techniques and treatment approaches for analyzing and changing behavior, and ultimately to improve lives
 - ABA has been empirically shown to be effective across a wide variety of areas
- Who is ABA implemented with?
 - Most recognition and largest body of research with individuals with Autism
 - However, research supports ABA with parent training, substance abuse treatment, dementia management, brain injury rehabilitation, occupational safety intervention, psychosis, intellectual disabilities among others

Applied Behavior Analysis and Intellectual Disabilities

- An RCT of twenty-nine families of children with intellectual and developmental disabilities with 16 families receiving online applied behavior analysis and 13 families in the wait list control group were studied.
- Online ABA training decreased problem behaviors and parental stress and improved caregivers' self-efficacy.

Certification in Behavior Analysis

- BCBA-D
 - Doctoral designation for board certified behavior analysts with doctoral training in behavior analysis
- BCBA
 - Graduate level certification in behavior analysis
- BCaBA
 - Undergraduate level certification in behavior analysis
- RBT
 - A paraprofessional who practices under the close, ongoing supervision of a BCaBA, BCBA, or BCBA-D

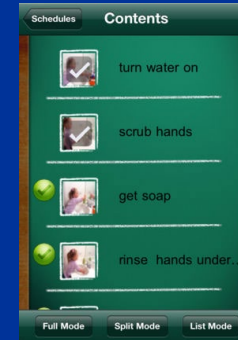
Visual Supports

- **Timers**
 - Helpful to set clear expectations of how much time the individual has with a preferred activity and when a transition will occur
 - Digital timer
 - Visual timer
- **Visual countdowns**
 - Helpful to show how much of something the individual needs to do or how many more times they can engage with a preferred activity before transitioning

Visual Supports

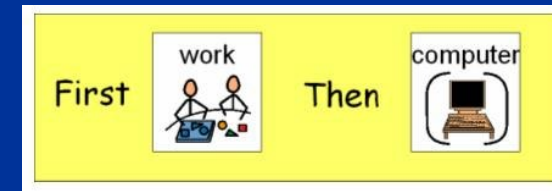
- **Visual Schedules**

- Helpful to promote independence; increase awareness of what activity is coming next and when the last activity has been finished; can help increase flexibility



- **First/then board**

- Simple visual schedule used typically to show the student what preferred activity they will get after completing the less preferred activity (premack principle)



- **Social Stories**

- They are short descriptions of a particular situation, event or activity, which include specific information about what to expect in that situation and why.



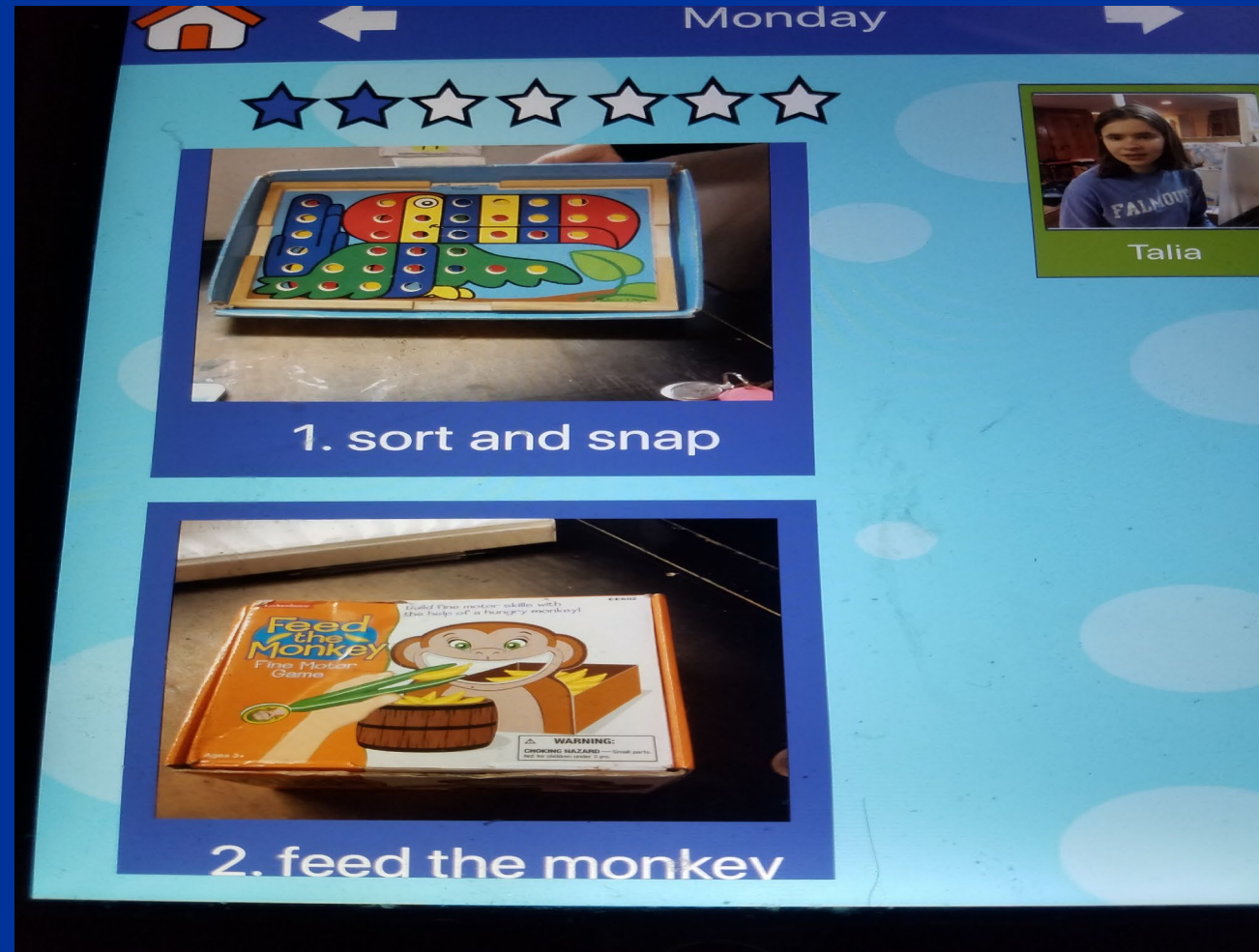
Using Visuals

- Individuals with ASD can have impairments in processing and interpreting auditory information
- In one study, males with “autistic-like social features” had enhanced visual perceptual skills
- In a randomized study with 68 participants, cognitive behavior therapy, adapted for autism with a dense visual component, significantly improved “measures of emotion regulation (ie, emotionality, emotion regulation abilities with social skills) and aspects of psychopathology (i.e., a composite measure of internalizing and externalizing symptoms, adaptive behaviors) compared to those in the waitlist control condition.”

Adherence to Medical Procedures (Venipuncture)

- Instructions for the parents, with an outline explaining how to practice with their child
- Instructions for the child, in more simplistic language and format
- An individualized social story
- An individualized positive reinforcer
- A picture schedule including the reward for appropriate behavior and adherence
- No reward for negative behaviors
- A packet of venipuncture materials to practice with except for the needle
- The outcome rate for the 152 participants who did complete the program was 143 out of 152 (94.1%)

Part of My Daughter's Visual Schedule



My Daughter's Communication Device: Proloquo2Go



Brushing My Daughter's Hair Before Functional Communication Training



Brushing Hair with Functional Communication Training

My Brother's Functional Communication Tokens

Because much of Matthew's most problematic behavior is escape motivated, based upon his current Functional Behavior Assessment (FBA), several positive behaviors and program components have been designed to help him express his needs and desires in a more effective and socially appropriate way and to obtain breaks from activities in a more appropriate fashion.

Functional Communication Tokens – Matthew is being trained to use Functional Communication Tokens. Monday through Friday, he will receive 1 token every hour and can use it to escape from demands or access a specific reinforcer at anytime. This will allow access whatever state of affairs (e.g., break, social attention, tangible item) at anytime simply by handing the staff members one of the tokens given to him each day. Having his workshop staff teach Matthew how to utilize the Functional Communication Tokens should decrease the inappropriate behaviors that he currently exhibits to escape from tasks and activities and access breaks, helping to reduce the frequency and utility of his inappropriate behavior.

Over the past year Matthew has used his Functional Communication Tokens (FCTs) at a mean rate of 54.5 times per week, an increase over the previous year's (2/15/13-2/15-14) mean of 36 times per week.

Functional Communication Training

- Based on a literature analysis of 91 articles, consisting of 204 participants, (195 with intellectual disability and 81 with autism)
“Functional communication training (FCT) is one of the most common and effective interventions for severe behavior problems.”

REWARD PROCEDURES

DRO contracts: Contracts in which if Matthew can go for certain periods of time without showing certain inappropriate behaviors, he earns certain special rewards.

- | | |
|------------------------------|---|
| 1. LTD Contract | No (Aggress1)(HDB 1)(HDB 2)(EdSoc1)(IVB1) and no more than 1 IVB from breakfast to 1PM earns a 15 minute break. From 1PM-7PM earns a 15 minute break. If beating daily aim, he will earn a preferred activity. |
| 2. MTD Contract | No (Aggress1)(HDB 1)(HDB 2)(EdSoc1)(IVB1) and less than 2 IVB per day for 3 days, earns additional 15 minutes on the internet. He will call his mother during the evening hours when he arrives to his residence. |
| 3. Overnight Contract | No (Aggress1)(HDB 1)(HDB 2)(EdSoc1) during ON hours, earns free time until transport (upon completion of his morning routine). |
| 4. Special Contract 1 | No (EdSoc1)(IVB1) for every 3 hours, earns his maps and books for 10 minutes. |
| 5. Special Contract 2 | No (EdSoc1)(IVB1) from wake-up until arrival at school earns the opportunity to have a preferred staff cut his nails. |
| 6. Special Contract 3 | No (Aggress1)(HDB 1)(HDB 2)(EdSoc1) and no more than 2 IVB per day for 2 weeks earns a preferred activity on YBR for 30 minutes and a snack of his choice. |
| 7. Field Day K | No (Aggress1)(HDB 1)(HDB 2) from Monday 1pm to Monday 1:30pm (7 days) earns going to field day. |

Preferred Rewards

Misc. Reward Notes

Types of reward items that Matthew particularly responds to:

1. Superman movies
2. Maps/books on trains, bridges and subways.
3. Rocking chair
4. Museums
5. Pasta
6. Socializing with preferred staff. (or staff assisting him clip nails). He loves to talk about bridges, subways, maps, tv guides, wheel of fortune, movies, his Jewish heritage (ie. songs), his family, etc.
7. Browsing the internet.
8. Watching TV and DVD's.

Key for Matthew's Behavior Intervention Plan

- **DRO:** Differential reinforcement of other behavior. Using intervals established and based on the frequency of occurrence of problem behaviors, a specific interval is set up (may be as brief as 10 seconds or as long as a full day)
- **AGGRESS:** Aggression (bite, kick, push, grab, head-butt)
- **EdSoc:** Educational/Social: refuse to perform a learned task correctly
- **IVB:** Nag, not minding own business
- **HDB:** Hit self, bite self, head bang, pick/rub/scratch skin to bleeding
- **ON:** Overnight
- **OOB:** Rub fingers together, blow on fingers, grind teeth
- **Destroy:** Property destruction

Talia's Variable DRO with Response Cost to Reduce Aggression and Self-Injury

Parent Training and Applied Behavior Analysis

- Children can have improved behavioral outcomes with lower doses of medication
- Parent training was found to be superior to parent education that did not include behavior management

Mindfulness, Parent Training, and ABA

- 432 families were studied using mindfulness to facilitate behavior parent training compared to parent training without mindfulness
- The components consisted of “listening with full attention,” “nonjudgmental acceptance of the self and child,” “emotional awareness of the self and child,” “self regulation in parenting,” and “compassion for self and child”
- Improvements occurred in both groups in “multiple dimensions of parenting, including interpersonal mindfulness in parenting, parent-youth relationship quality, youth behavior management, and parent well-being,”
- The mindfulness intervention boosted and better sustained some of the effect and was especially helpful to fathers compared to standard parent training

Providing ABA, Parent Counseling and Training, Can
Help Safely Manage These Behaviors and Therefore
Decrease Abuse

Parental Trauma and Intellectual Disability

- “Parents who have recently learned of their children’s intellectual disability often experience psychological and emotional trauma due to uncertainty and lack of knowledge and understanding of intellectual disabilities.”
- “Parents of children with intellectual or developmental disabilities show high levels of stress, anxiety, and depression in meta-analyses and population-based studies.”

Caregiver Trauma

Siblings and Intellectual Disabilities

- A study of 99 individuals with intellectual and developmental disabilities completed questionnaires examining involvement, personal resources (self-efficacy and sense of coherence), loneliness, and adjustment.
- “Results indicated that siblings who are more involved and perceive their efficacy and coherence as higher and loneliness as lower, experience higher levels of mental wellbeing and lower levels of mental distress. Personal resources also meaningfully predicted siblings' adjustment, and mediated the relations between involvement and wellbeing.”
- We need intervention programs to support “efficacy and coherence as resilience factors that promote adjustment.”

Applied Behavior Analysis and the Law

- According to federal law, a functional behavior assessment and a behavior intervention plan should be considered for any student (up to age 21) that has a behavior that interferes with learning
- Students have the right to an education and to make meaningful progress. Students are entitled to an appropriate placement which may include intensive applied behavior analysis
- In the recommendations, **use the words “needs” and “requires”**
- Terminology to **avoid**: “consider”; “best”; “would benefit from”; “gold standard”

Aversives

- In an analysis of 109 articles on positive behavior supports, the frequency of problem behavior was suppressed by 90% in only about one-half of participants using positive approaches alone
- Aversives are procedures that are arranged as consequences for undesired behaviors with the purpose of decreasing the future frequency of those behaviors
- Disulfiram is an FDA-approved medication for alcohol dependence and it is used as an aversive

Aversives (cont'd)

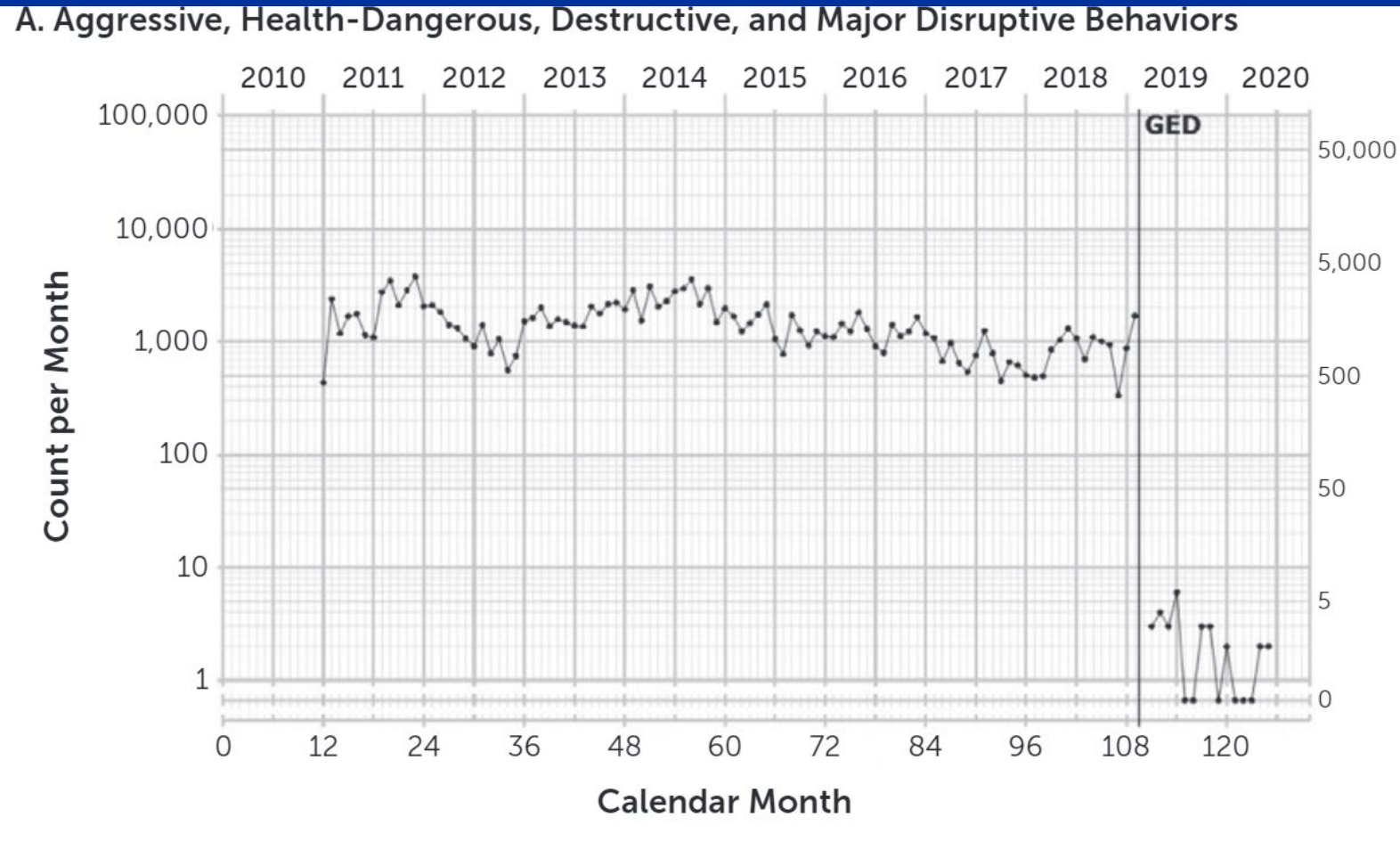
- Aversives are effective when combined with dense positive reinforcement and aversives without dense positive reinforcement can increase agitation.
- The majority of studies on aversion therapy have used skin shock treatment. “Punishment may be critical to treatment success when the variables maintaining problem behavior cannot be identified or controlled.”
- There are 148 peer reviewed articles and a PhD dissertation on skin shock treatment.

Blenkush N, et al. *Int J Psychol Behav Anal* 2020;6(167):1-10. Lerman DC, et al. *J Appl Behav Anal*. 2002;35(4):431-464. Bibliography on Skin-Shock., accessed 7/30/2026, <https://judgerc.org/wp-content/uploads/2024/01/bibliography.pdf> ; Blenkush N, *Int J Psychol Behav Anal*. 2017; 3(121). Jan ter Mors, et al. *BMJ Case Reports* 2012;bcr0220125932; Salerno J, “Efficacy, Risks, and Ethics of Aversive or Positive Therapy in Identical Twins,” *Walden University and Doctoral Studies*, 2019.

Aversives (cont'd)

- Studies have also shown that using aversives stops the need for physical restraints
- Physical restraints can be deadly
- One subject had a diagnosis was autism and moderate intellectual disability with chronic self-injury resulting in concussions, callouses, and lacerations and aggression that resulted in 340 staff injuries and 5,354 restraint episodes over 98 months.
- GED was added as a consequence for her aggressive, health dangerous, destructive, and major disruptive behaviors which occurred at a mean monthly rate of 1,476.09 behaviors a month over 98 months.
- “In the 16 months after the GED intervention was introduced, the mean monthly frequency decreased to 1.87 per month.”

Aversives (cont'd)

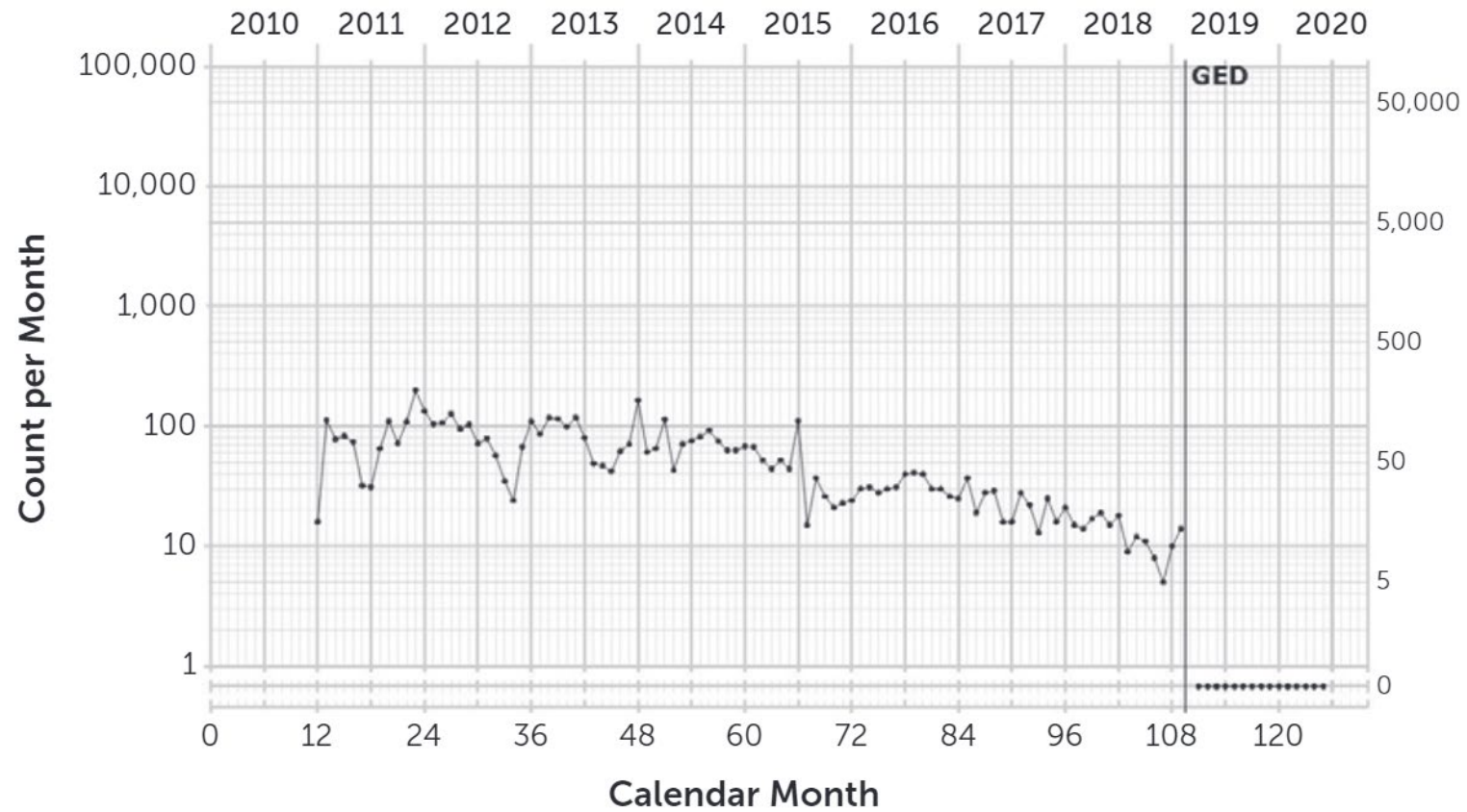


Aversives (cont'd)

- Figure 1B shows the monthly frequency of emergency physical restraints before and after the introduction of the GED intervention.
- Although some deceleration in restraint frequency was observed prior to introduction of the GED, this intervention immediately and completely eliminated the need for emergency restraint.

Aversives (cont'd)

B. Emergency Restraint



Aversives (cont'd)

- 173 individual cases between 2001 and 2019 with follow up to 15 years, 80% one or less shocks per month
- “Overall, a 97% reduction in the frequency of severe aggressive and health dangerous (e.g., self-injurious) behaviors was observed in the first full month of treatment”
- Diagnoses included intellectual disability, ASD, ADHD, oppositional defiant disorder and other disorders
- Treatment was combined with differential reinforcement for positive behaviors

My Brother Before and After Aversives

Health Dangerous Behaviors

- Baseline: 400–500× month
- Positive Only Treatment: 60–70× month
- Supplementary Aversives: most months less than 10, never more than 40, many months 0

Physical Aggression

- Baseline: 900–1000× month
- Positive Only Treatment: 400–500× month
- Supplementary Aversives: 0–40× month, most months 0

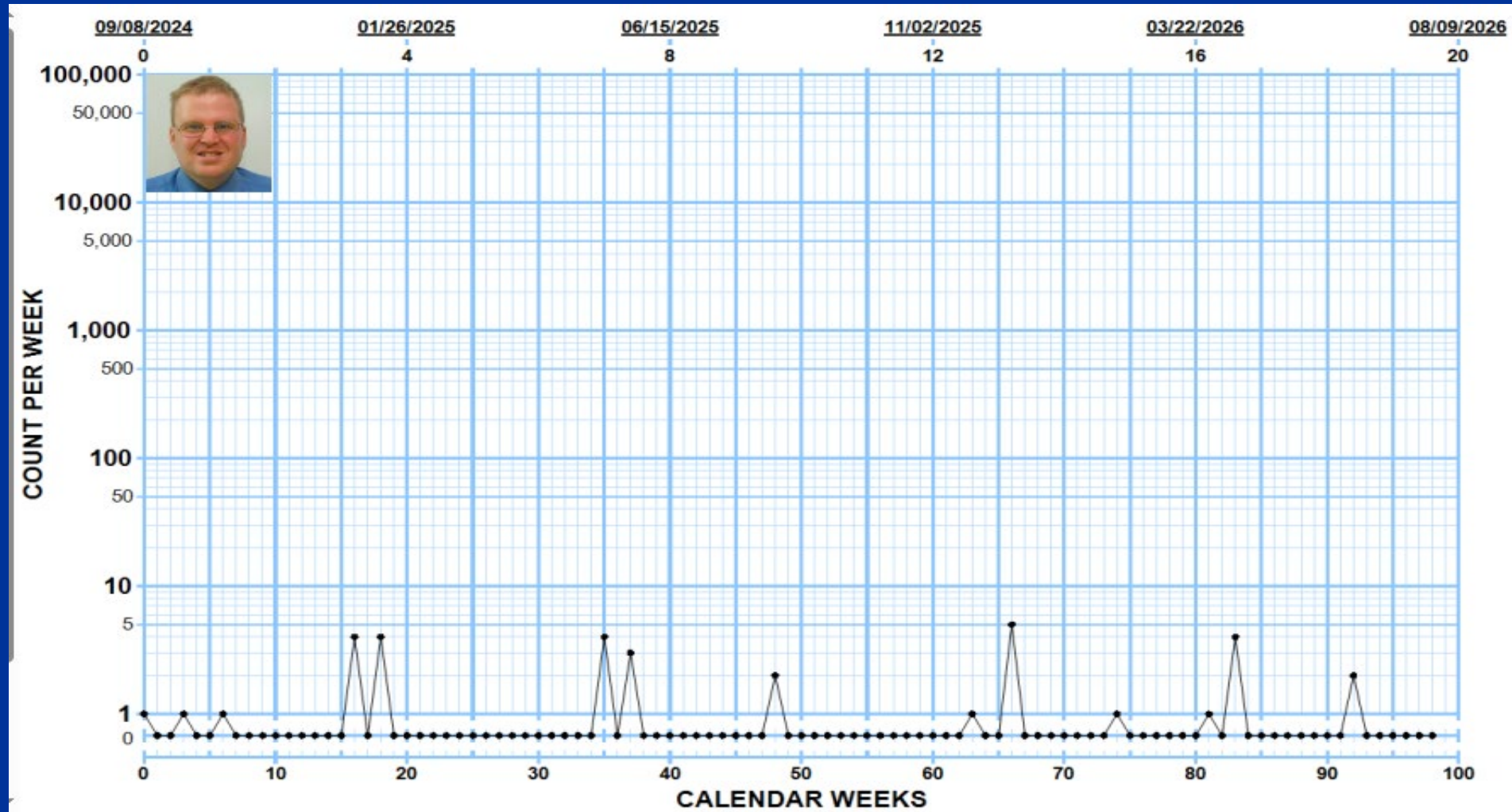
Property Destruction

- Baseline 80–90: × month
- Positive Only Treatment: 50–60× month
- Supplementary Aversives: 0–2× month

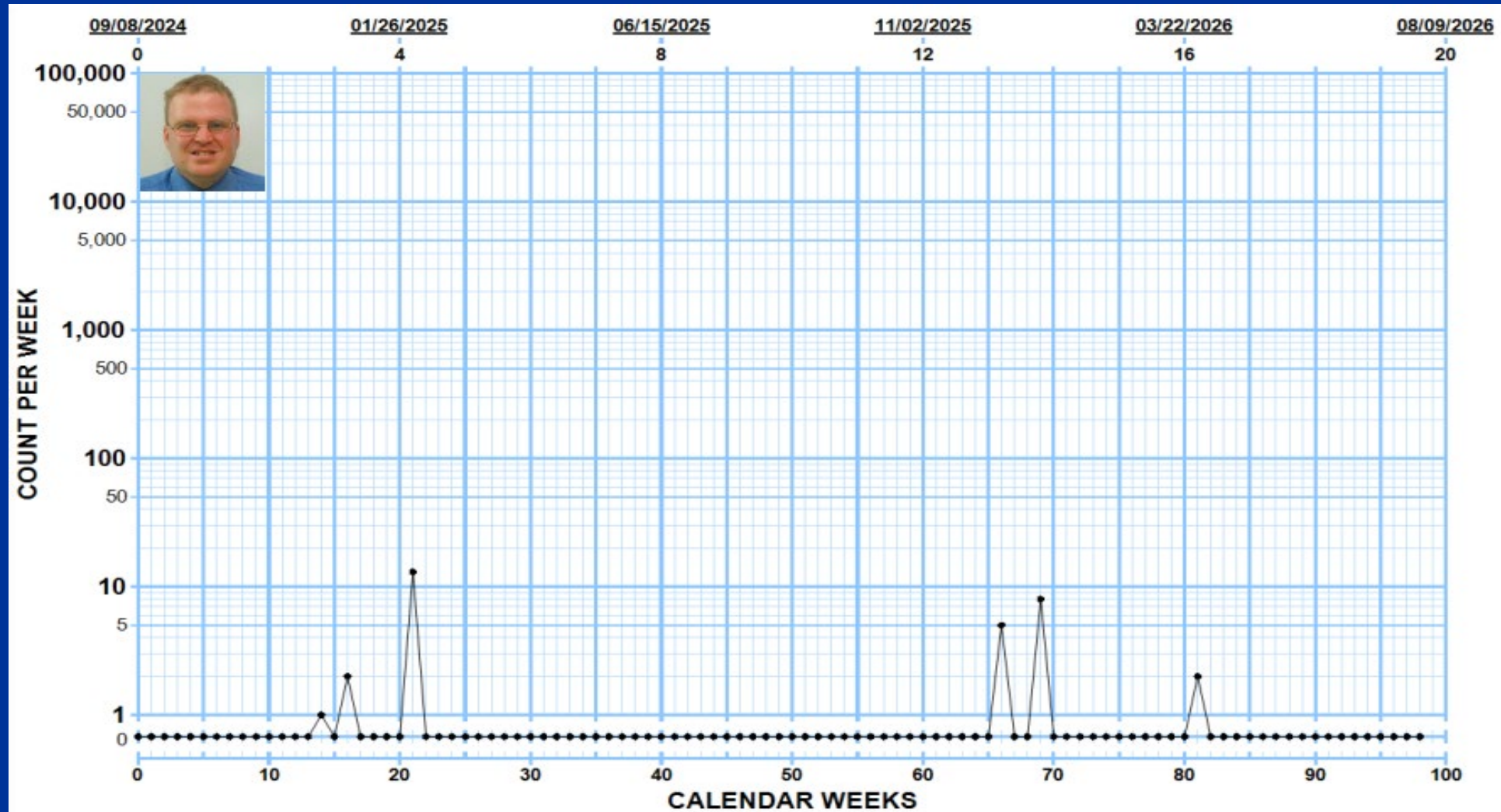
Now has paid job at school, goes on trips, no medications in over 37 years, last skin shock

9/5/2012

Matthew's Recent Self-Injurious Behavior



Matthew's Recent Aggression



Fading Aversives

- 7 published research studies describe individuals with dangerous behaviors who maintained their treatment gains after the shock devices were partially or completely faded

Yadollahikholes G, et al, *BMJ* 2021; 14(5): CP 2021;14:e241204. Blenkush N, et al. *Int J Psychol Behav Anal* 2020;6(167):6-7. Foxx RM, et al. *Am J Ment Retard.* 1989;94(1):27-36. Linscheid TR, et al. *Child and Adolescent Mental Health Care.* 1993;3(2):67-76. Williams DE, et al. *Res Dev Disabil.* 1994;15(6):487-501. Salvy SJ, et al. *Behavioral Interventions.* 2004;19(2):59-72. Israel ML, et al. *Journal of Behavior Analysis of Offender and Victim Treatment and Prevention.* 2008;1(4):119-166.

My Brother's Head Banging



Matthew After Treatment



Matthew in the Community

My Brother Who Had No Applied Behavior Analysis

Stuart's Medication List as of August 2015

Catapres 0.1 mg at bedtime
Lamictal 150 mg twice daily
Thorazine 150 mg twice daily
Seroquel 300 mg twice daily
Desyrel 50 mg at bedtime
Effexor XR 150 mg at bedtime
Amitiza (lubiprostone) 24 mcg twice daily
Miralax powder 17 g twice daily
Vitamin C 500 mg once daily
Kristalose powder (lactulose) 17 g twice daily
Mineral oil 2 tablespoons 3 times a day
Senna 34.4 mg at bedtime
Colace (docusate sodium) 400 mg at bedtime
Philips Colon Health Probiotic 1 tablet daily
Omeprazole 20 mg daily
Bisacodyl 10 mg twice daily
Vitamin D3 1,000 IU once daily
Multivitamin 2 tablets at bedtime
Advair Diskus (fluticasone propionate/ salmeterol xinafoate) 100/50 mcg twice daily
Singulair (montelukast) 10 mg at bedtime
Benadryl (diphenhydramine) 25 mg as needed for allergy
Bentyl (dicyclomine) 20 mg one tablet twice daily as needed for gastrointestinal upset
Simethicone 80 mg 3 times daily as needed for gastrointestinal upset
Claritin (loratadine) 10 mg as needed daily for allergy
Patanol ophthalmic (olopatadine) 0.1% solution eye drops twice daily as needed for allergy

Mom Before Glioblastoma January 2025



Mom After Glioblastoma Diagnosis June 2025



Conclusions

- Medications are sometimes necessary for comorbid conditions, but should never be used as a replacement for an effective behavior plan
- Medications need to benefit the individual, not the placement
- Recommend applied behavior analysis supervised by a BCBA at home and/or school or a BCBA consultation if needed
- Advocate for parent training
- Support all caregivers including parents and support siblings.
- Nobody is hopeless and everyone can learn!

Q&A Session

I.