

Managing behaviors during COVID-19: Medical and educational perspectives

TS Alliance Webinar
April 17, 2020



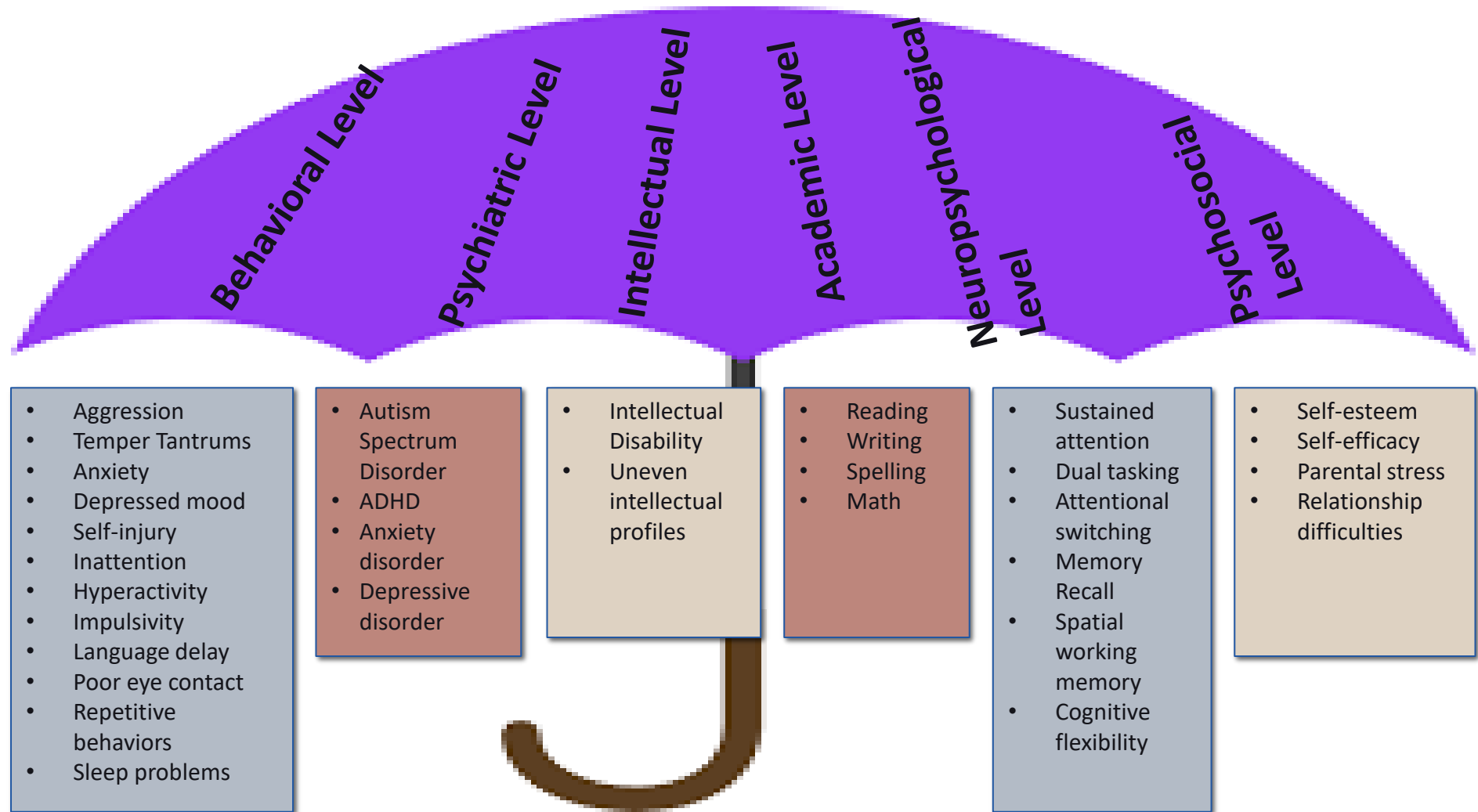
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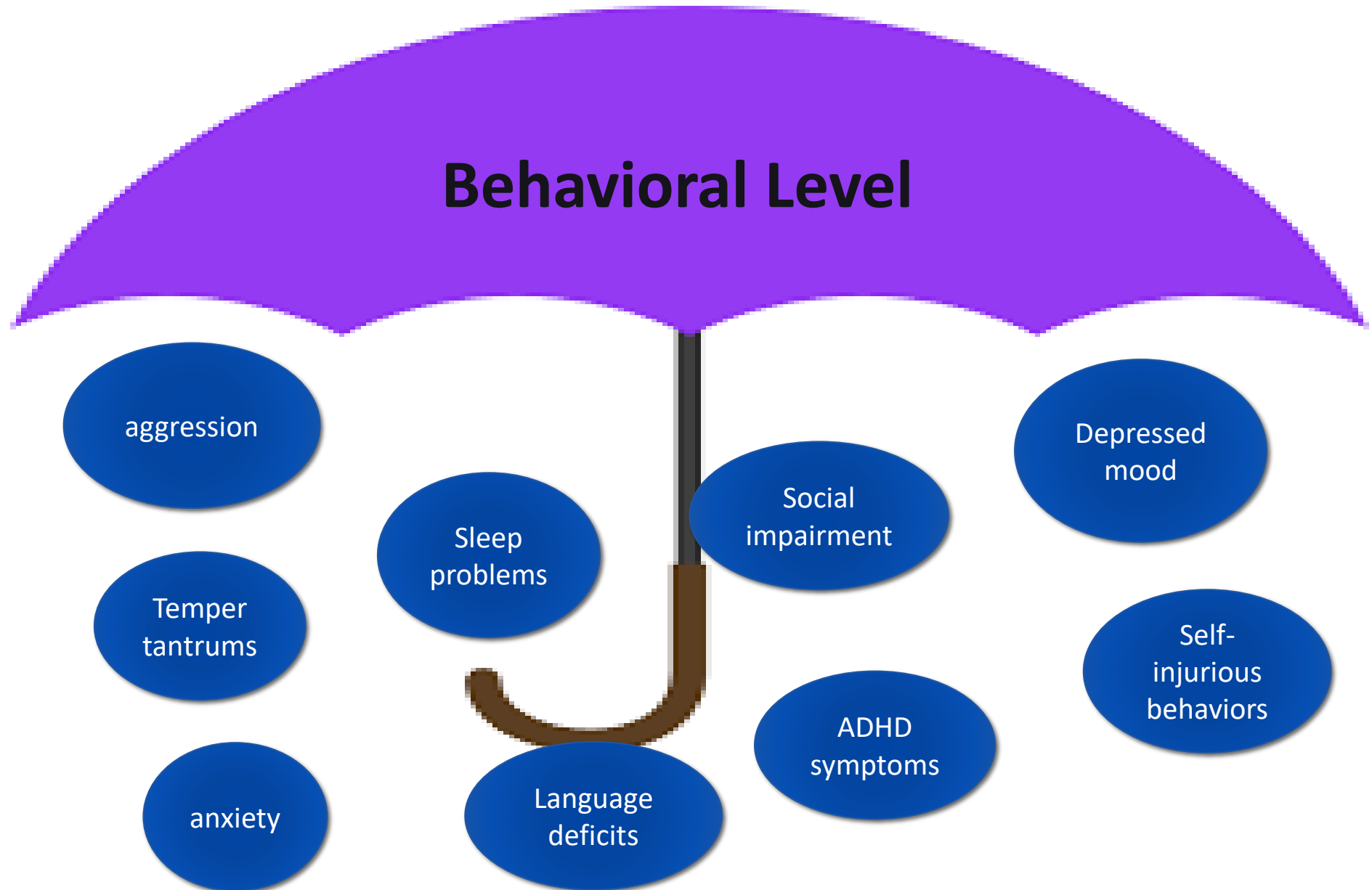
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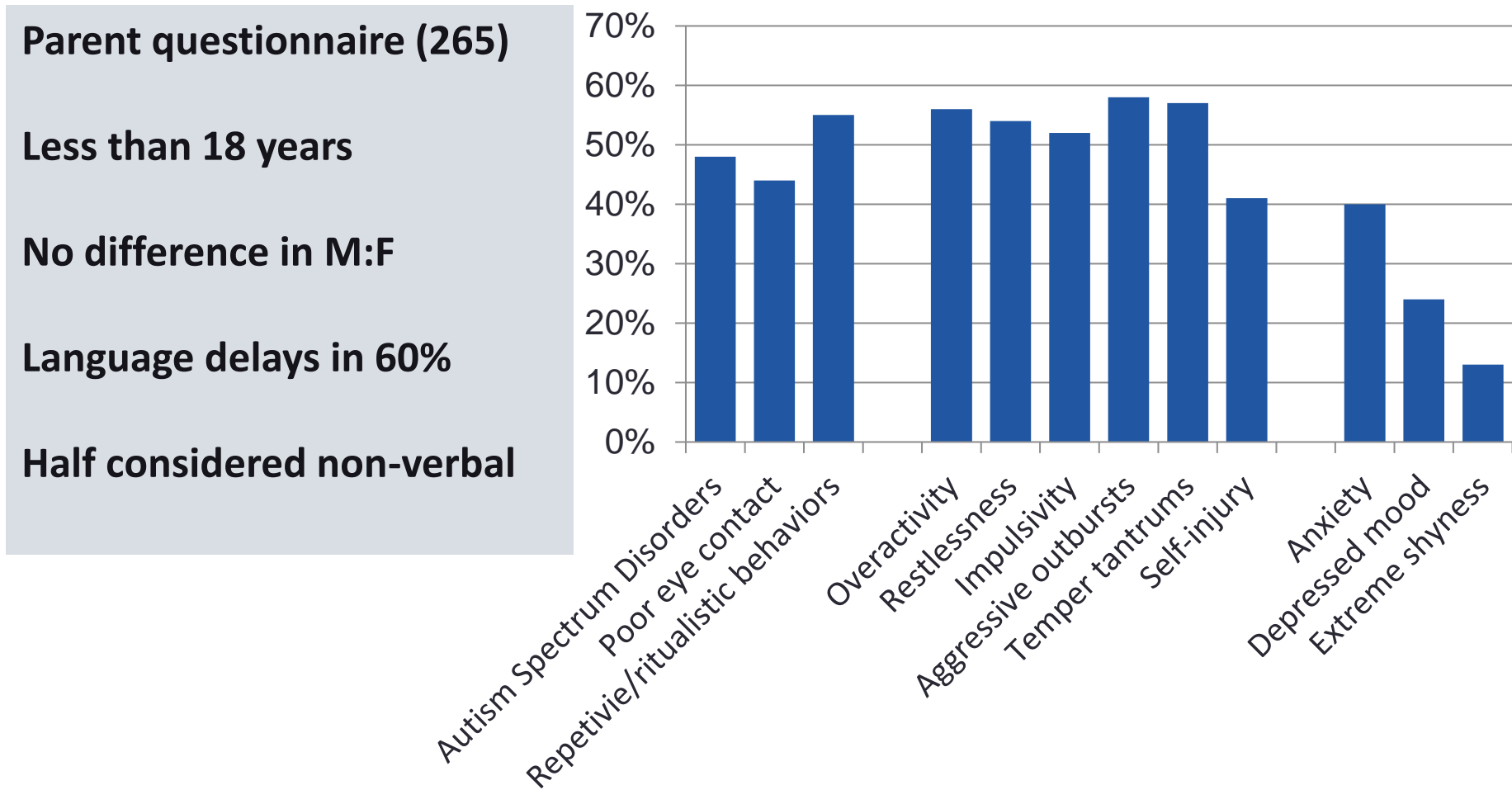
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TAND (TSC associated neuropsychiatric disorders)





Prevalence of TAND-related behaviors/difficulties



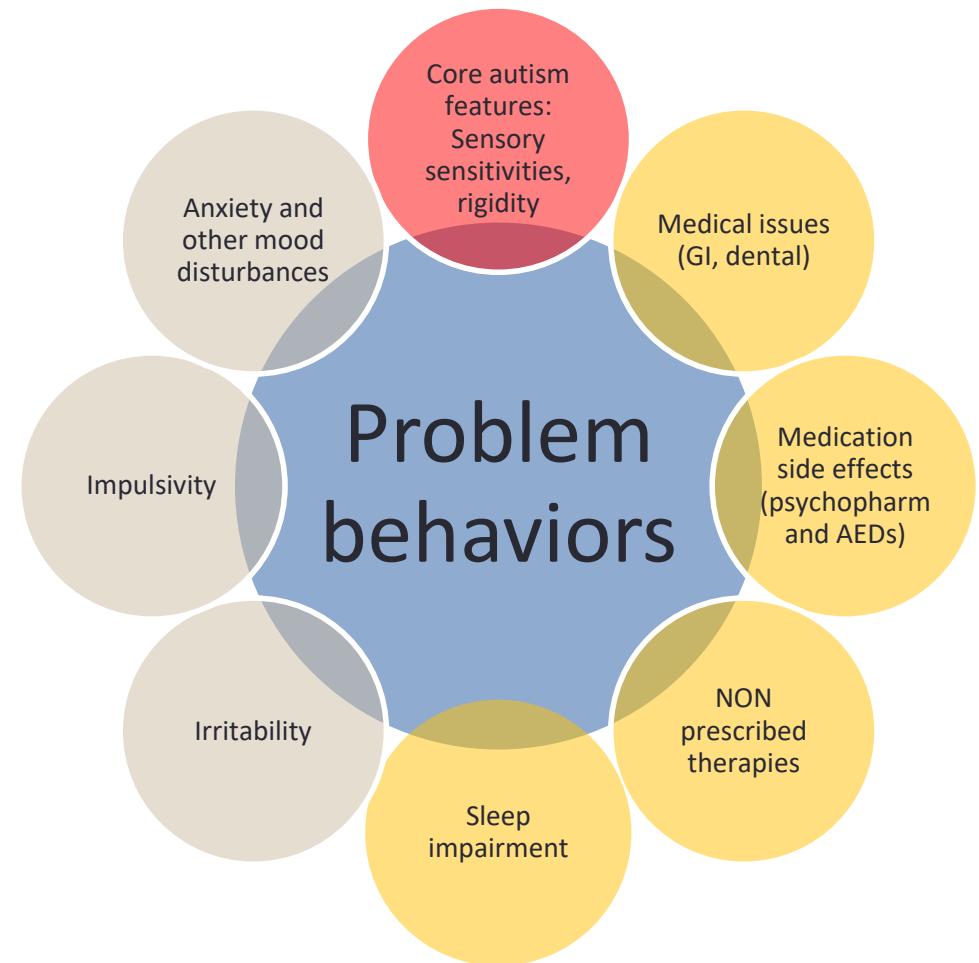
Why are behaviors more challenging now?

- Schedule is completely altered
- Sleep is poor (or at least less consistent)
- Behavioral and educational supports are lacking or at least not being performed in person
- Medication refills can be challenging
- Reduced telehealth visits and/or access to providers



Overall approach to challenging behaviors

- (1) TAKE A GOOD HISTORY: Ask about behaviors both at home and school, if possible gather data from teachers/aides, week-long diary, medication history
- (2) Consider language and cognitive ability
- (3) Try to determine underlying cause → many factors can converge onto the same aberrant behaviors
- (4) Treat underlying cause through behavioral and, if needed, pharmacological approaches (rather than using medications as a Bandaid on symptoms)
- (5) Often polypharmacy and med side effects are the primary problem! However sometimes medications are needed!!



What are common and modifiable targets for medications?

Irritability

ADHD

Mood disturbances

Insomnia



Irritability

Two medications approved by FDA for children ages 5-16 with ASD for *irritability*

Risperidone: Partial D2 and 5HT2 receptor antagonist

Aripiprazole: Partial D2 and 5HT1A receptor agonist

Irritability comprised of 15 items from the Aberrant Behavior Checklist—not a cohesive construct

- Self-injury (3)
- Aggression (1)
- Mood (3)
- Tantrums (4)
- Loud, dysregulated behavior (4)

| Drug | Starting dose | Effective Dose | Dosing | Side-effect Consideration | Monitoring Considerations |
|---------------------|----------------------|-----------------------|---------------|---|---|
| Risperidone | 0.25-0.5 | 0.5-3 | QDAY-TID | Weight gain, EPS/TD Hyperprolactinemia Sedation | Weight, BMI, Fasting glucose and lipid profile AIMS, Prolactin |
| Olanzapine | 2.5-5 | 5-40 | QDAY-TID | Weight gain, EPS/TD Hyperprolactinemia ¹ Sedation | Weight, BMI, Fasting glucose and lipid profile, AIMS |
| Quetiapine | 25-50 | 75-800 | QDAY-TID | Weight gain, EPS/TD Hyperprolactinemia ¹ Sedation | Weight, BMI, Fasting glucose & lipid profile, AIMS |
| Ziprasidone | 20-40 | 20-160 | QDAY-TID | Weight neutral?, EPS, QT prolongation Hyperprolactinemia Behavioral activation | Weight, BMI, Fasting glucose and lipid profile AIMS, ECG |
| Aripiprazole | 2.5-5 | 5-15 | QDAY-BID | Not quite weight neutral EPS/TD | Weight, BMI, Fasting glucose & lipids, AIMS |

JAMA Psychiatry | Original Investigation

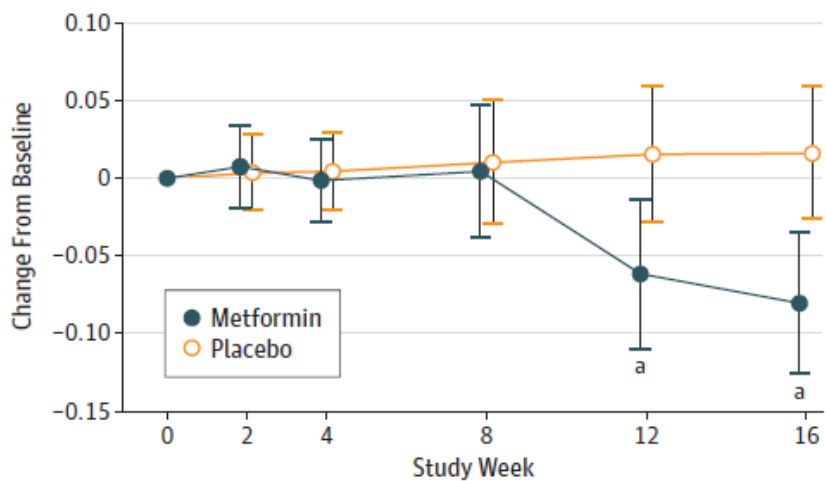
Metformin for Treatment of Overweight Induced by Atypical Antipsychotic Medication in Young People With Autism Spectrum Disorder

A Randomized Clinical Trial

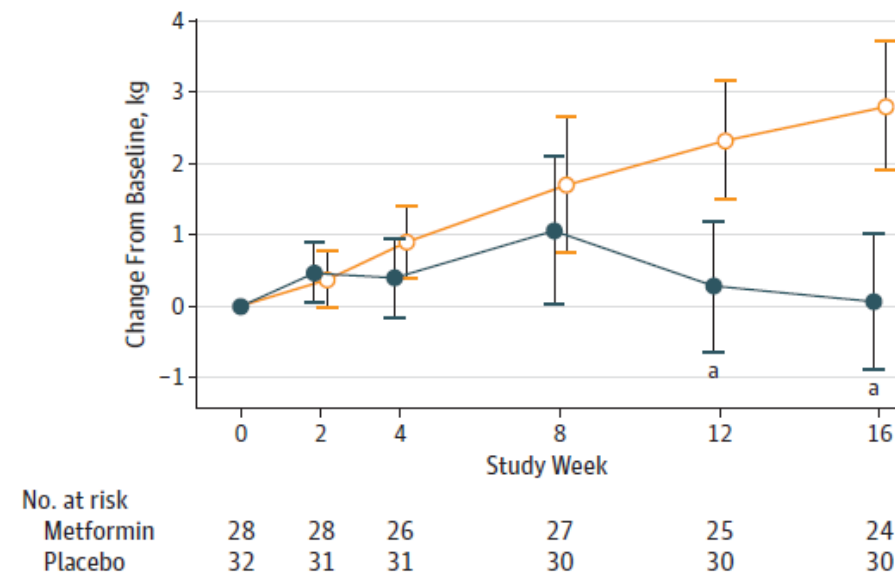
Evdokia Anagnostou, MD; Michael G. Aman, PhD; Benjamin L. Handen, PhD; Kevin B. Sanders, MD; Amy Shui, MA; Jill A. Hollway, PhD; Jessica Brian, PhD; L. Eugene Arnold, MD; Lucia Capano, MD; Jessica A. Hellings, MD; Eric Butter, PhD; Deepali Mankad, MD; Rameshwari Tumuluru, MD; Jessica Kettel, MD; Cassandra R. Newsom, PsyD; Stasia Hadjiyannakis, MD; Naomi Peleg, MSc; Dina Odrobina, BMSc; Sarah McAuliffe-Bellin, MEd; Pearl Zakroysky, MPH; Sarah Marler, MA; Alexis Wagner, BS; Taylor Wong, BS; Eric A. Macklin, PhD; Jeremy Veenstra-VanderWeele, MD

Figure 2. Metformin Effect on Body Mass Index (BMI) z Score and Weight Change

A BMI z score



B Raw weight



Treating ADHD

- Stimulants (methylphenidate, amphetamines)
 - Target core symptoms
 - May exacerbate comorbid diagnoses (anxiety, irritability, sleep difficulties)
 - Common side effects → decreased appetite, irritability, headaches, insomnia
- Non-stimulants (Guanfacine, clonidine, atomoxetine)
 - Alpha-2-agonists used off-label in preschool ages; also help with sleep
 - Common side effects → drowsiness, paradoxical worsening of behaviors
 - May also help with anxiety

Treating mood disturbances

- Anxiety (SSRIs, SNRIs, Buspirone)
- Depression (SSRIs, SSNRIs, Bupropion)
- Side effects of these medications: GI (nausea), dizziness, sleep issues, agitation / irritability, also can have drug interactions

Treating Insomnia

Melatonin: (RCT) 5-15 mg, given 30 minutes before bedtime, improves total sleep time by 30 minutes and significantly decreases sleep latency – XR also works well for nighttime awakenings!

Clonidine: 0.05-0.1 mg, improved sleep latency, decreased number of nighttime awakenings

Gabapentin: 5 mg/kg, one study showed improved sleep, but higher doses can cause agitation

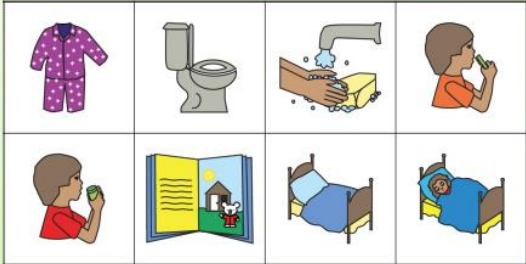
Benzodiazepines: shorten sleep latency and increase total sleep time, but cause daytime sleepiness and risk of withdrawal

Iron supplementation: 6 mg/kg x 8 weeks, Improves restless sleep



Wright, 2011; Garstand, 2006; Wirojanan, 2009; Paavonen, 2003, Biannotti, 2006; Malow, 2011; Andersen, 2008

Treating sleep: behavioral sleep modifications

| | |
|---|--|
| <p>Sample Bedtime Checklist</p> <ul style="list-style-type: none"> <input type="checkbox"/> Put on pajamas <input type="checkbox"/> Use the bathroom <input type="checkbox"/> Wash hands <input type="checkbox"/> Brush teeth <input type="checkbox"/> Get a drink <input type="checkbox"/> Read a book <input type="checkbox"/> Get in bed <input type="checkbox"/> Go to sleep | <p>Sample Visual Bedtime Routine</p>  |
|---|--|

Sample Story to Support the Bedtime Pass

People need sleep. Sleep helps people feel rested and have more energy. Sleep helps people stay calm during the day. Sleep helps people do better in school too!

My parents want to help me get a good night's sleep. They want me to be rested, calm, and do well in school. They know that some nights I have trouble going to sleep.

My parents have made a bedtime pass to help me. The bedtime pass is like a ticket. The bedtime pass can be traded for a drink or to get out of bed. If I ask for a drink of water or get out of bed, I have to give them the bedtime pass. When I am able to stay in bed all night, I get to keep the bedtime pass. This is a good thing! In the morning I can trade the bedtime pass for a treat.

A good night's sleep will help me be rested, calm, and do well in school. My parents like it when I get a good night's sleep.



- Routine done in same order each night, ideally in the bedroom
- Determine which events are calming vs. stimulating
- Time should be the same each night and wake up time same each morning
- Try to avoid co-sleeping

Treating sleep: OTHER KEY TIPS

- ✓ Avoid light exposure at night (ie iPads and other screens)
- ✓ Promote exercise during the day
- ✓ Avoid caffeine at least 5 hours before bedtime
- ✓ Avoid eating right before bedtime

What else can caregivers do for their kids?

- Take care of yourself first and foremost!!
 - Alone time each day (even if it's 3 minutes!)
 - Relaxation / meditation practices
 - Good nutrition
 - Limiting alcohol and other substances
 - Sleep hygiene
 - Finding fun activities to do with your kids
 - Staying connected with others!! (physical isolation does NOT equate to social isolation)



What else can caregivers do for their kids?

- Develop a weekday schedule
 - especially first 2 and last 2 hours of the day
- Sleep hygiene should be a priority
- Communicate with your providers (email, phone, telehealth)
- We can treat this acute period with medications if needed!
- But avoid medication adjustments, supplements or any new treatments without talking with your provider



Research continues!

The logo for the Baby BIBS study features the text 'Baby BIBS' in a dark blue font. A brown teddy bear wearing a blue and white striped bib is positioned between the words. Below the text is a stylized DNA double helix with blue and yellow segments. Underneath the DNA is the text 'Baby Brain Imaging & Behavior Study' in a smaller, black font.

Baby BIBS
Baby Brain Imaging & Behavior Study

The logo for the JETS study features the word 'JETS' in large, light blue, block letters inside a white cloud. Below the cloud is a brown propeller airplane with a pilot wearing a red helmet and goggles. Underneath the airplane is the text 'JASPER Early Intervention for Tuberous Sclerosis' in a black, sans-serif font.

JETS
JASPER
Early Intervention
for Tuberous Sclerosis

Research modifications



→ Remote screening and enrollment

- **Screen** families through phone and email
- **Consent** over the phone

→ Remote visits

- **Online questionnaires** completed through email link, entered directly into database
- **Phone check-in** with study coordinator to collect data (e.g. parent concerns and treatment intervention history)
- **Phone interview** with clinician to measure adaptive behavior
- 10-minute **play video** uploaded to online server; research staff will code for play skills
- Continued **remote intervention**

We will complete direct assessments/repeat some remote measures when in-person visits resume

Behavioral Therapy

ABA (applied behavior analysis):

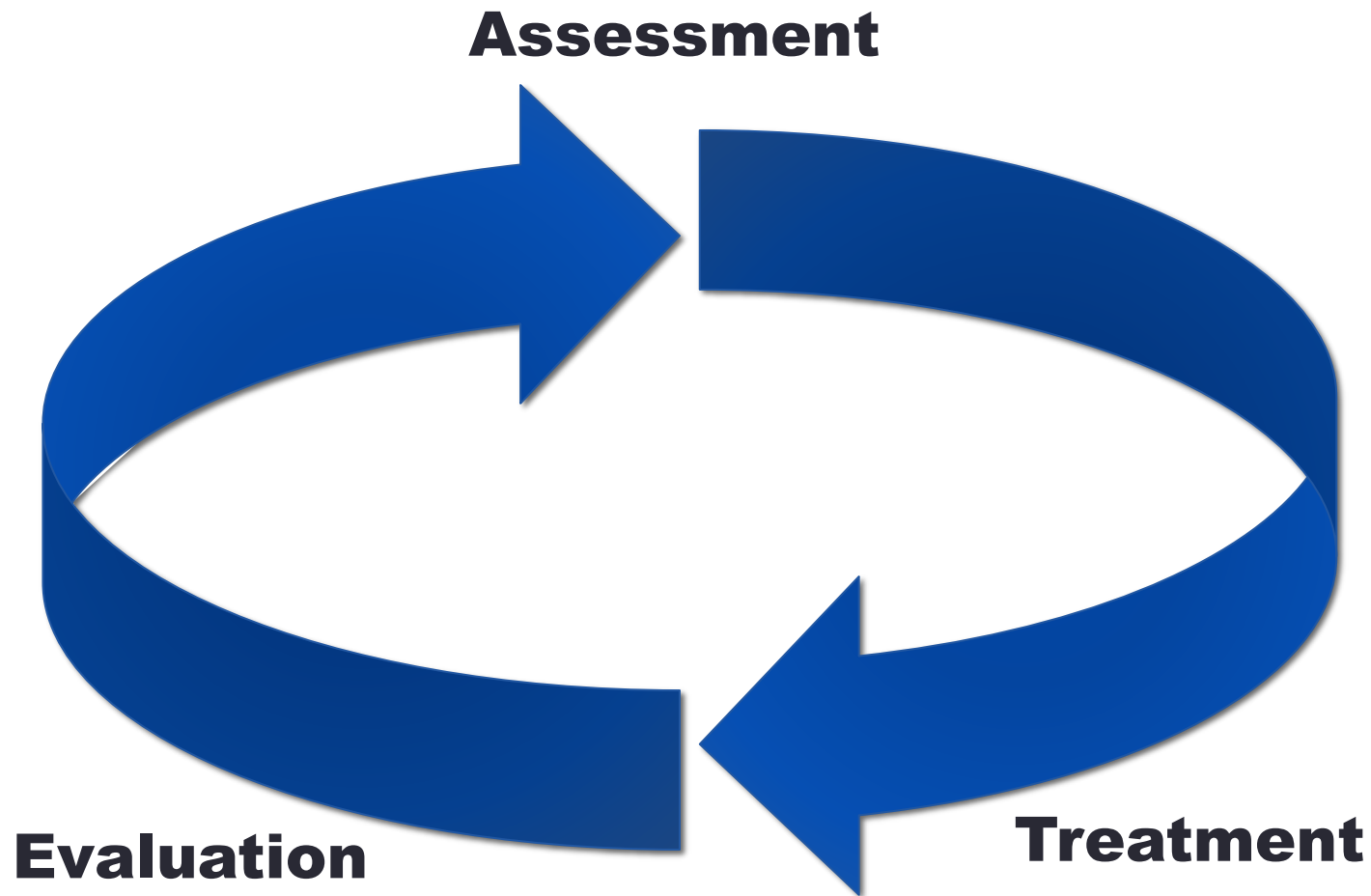
- Umbrella term for most types of treatments used in ASD
- Shape and reinforce new behaviors and reduce undesirable ones
- Focused on improving all domains of functioning, including activities of daily living, reading, academic skills, social communication skills

- **DTT (Discrete trial training)**: Target specific behaviors or domains with constant reinforcement
- **PRT (pivotal response training)**: Identifies pivotal skills that affect broad range of behavioral responses
- **JASPER (Joint attention symbolic play engagement regulation)**: Play based, child directed learning focusing on joint engagement

DIR/Floortime (Developmental, individual difference, relationship based): Builds relationships and abilities by following natural emotions and interests of the child

Basic Assumptions of Behavioral Therapy

- Behavior is communication
- Behavior is a function of the interactions between the person and the environment
- Intervention must address variables maintaining the behavior
- Outcomes must be evaluated functionally



The ABC's of Behavior

- Antecedent
 - The event that occurs immediately prior to the behavior
- Behavior
 - The SPECIFIC behavior that you are interested in understanding
- Consequence
 - The event that occurs immediately following the behavior

Troubleshooting at Home

- What are the challenging behaviors that you're experiencing?
 - What is the most important thing to address right now?
- What function does that behavior serve?
 - What happens right before the behavior (antecedent)?
 - What does the behavior accomplish (consequence)?
- How else can the child get that need met (replacement behavior)?
 - Do they need to learn new skills?
 - Do they need a reminder system (antecedent) or a reward system (consequence)?

Talking to your providers

- Identify your priorities
- Ask for specific help
- Identify things that are not working, or things that are working well
- Experiment!
 - But stick with a strategy long enough to see its effects

Basic Strategies

- Establish routines
- Structure activities
- Use visual supports
- Set up a reward system
- If you set a limit, follow through
- Praise your child for their best effort



Reward Systems

- Reach out to your providers to help you set one up
- Identify “target behaviors”
- Decide on rewards
 - What will the rewards be?
 - Immediately following the behavior or delayed (token economy)
- If you use delayed rewards:
 - How often will your child earn points?
 - How many points are needed for the “big” reward?
- Natural opportunities for rewards?

Setting Expectations

- Set reasonable expectations for what you and your child are capable of during this time
- Identify certain times of day or activities when you will work on certain skills, and don't worry about them at other times!
- Quality of quantity – it's better to have short periods of high quality learning/interaction than long periods of low quality
- Find activities that you can enjoy together

Resources

- Child Mind Institute:
<https://childmind.org/coping-during-covid-19-resources-for-parents/>
- National Association of School Psychologists:
<https://www.nasponline.org/resources-and-publications/resources-and-podcasts/covid-19-resource-center>
- UNC Frank Porter Graham Child Development Institute:
<https://afirm.fpg.unc.edu/sites/afirm.fpg.unc.edu/files/covid-resources/Supporting%20Individuals%20with%20Autism%20through%20Uncertain%20Times%20Full%20Packet.pdf>
- UCSB online PRT training (ages 12-48 months, ASD diagnosis):
<https://education.ucsb.edu/autism/research/participate-research-studies>

Remote resources

Resources for Families



The COVID-19 virus and resulting social distancing, school closures and general panic are taking a unique toll on autism families.

We have compiled this list of resources and will update it frequently.

Teaching Tools

Behavior Management

Policies and Legal Information

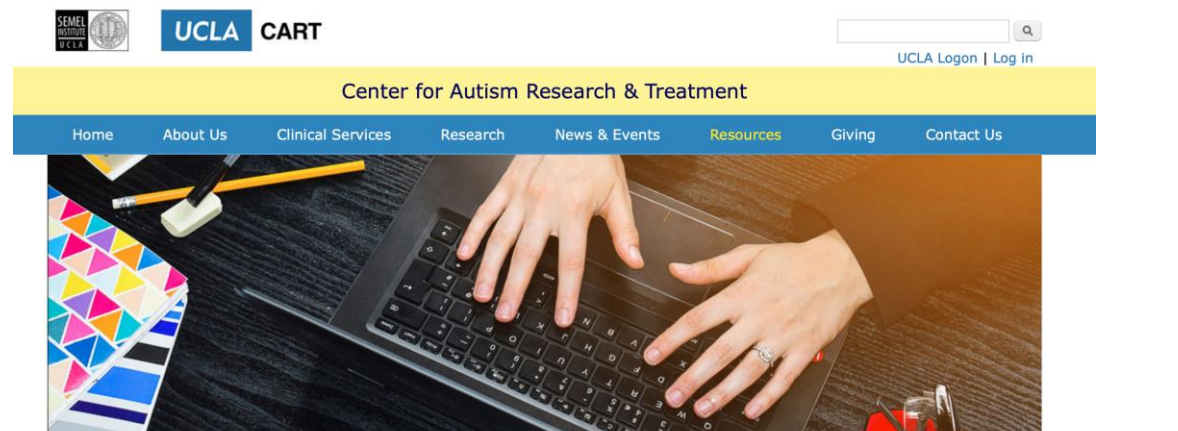
Mental and Physical Health

Partner Toolkits

En Espanol

Do you have a resource you would like to share?
Email us at contactus@autismsciencefoundation.org

www.autismsciencefoundation.org



Resources

[COVID-19 information](#)

2018 Symposium

2017 Symposium

COVID-19 information

UCLA CART understands the ongoing concerns surrounding COVID-19, and the added challenges it brings to the autism community. We have compiled up-to-date resources, approved by leading clinicians and designed to help you feel informed and empowered. We will continue to update this list.

<https://www.semel.ucla.edu/autism/covid-19-information>

Family Routines Intervention for children with social communication difficulties

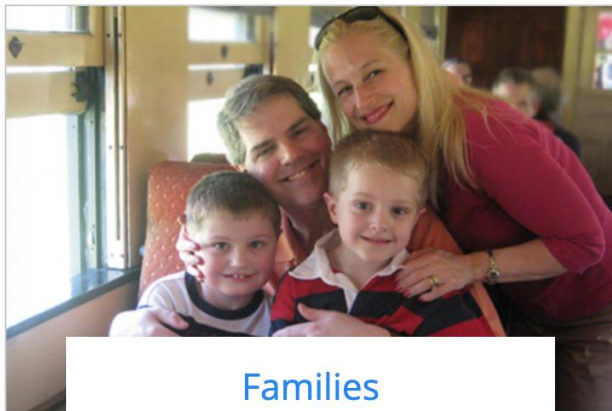
We are **actively enrolling** young children and their mothers to participate in a **free social communication intervention** with the Developmental Studies Laboratory at **Purdue University!**

In this **parent-mediated intervention**, families are provided with supportive strategies to foster their child's social development during **everyday family routines** (e.g., feeding, diaper changes, indoor play). Each treatment session/week focuses on one routine and how to facilitate social communication development.

Eligibility: Any child developing at risk between 6 months and 6 years (examples include born preterm, sibling of a child with autism or another developmental concern, child born with a genetic syndrome like Trisomy 21 or Dup15Q, or any child that is showing signs of a social or communication delay). **No formal diagnosis is required.**

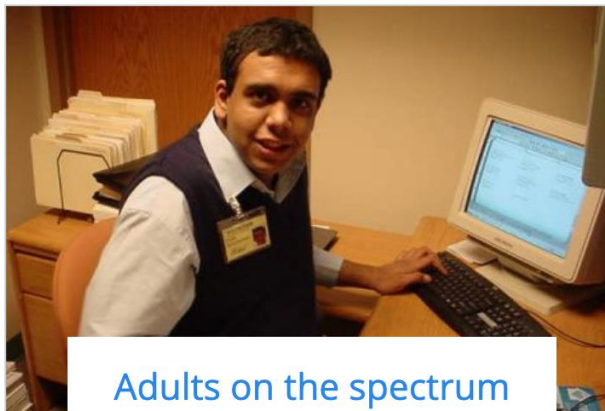
ajlab@purdue.edu 765-494-6610

Explore more



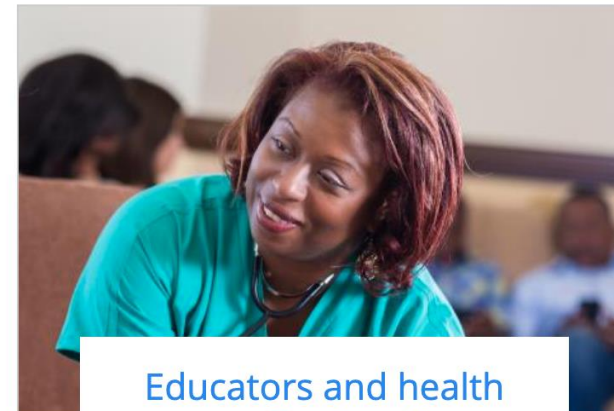
Families

COVID-19 information for families



Adults on the spectrum

COVID-19 information for adults on the spectrum



Educators and health professionals

COVID-19 information for educators and health professionals

<https://www.autismspeaks.org/covid-19-information-and-resources>

https://www.youtube.com/watch?v=NczoO6YWMZM&feature=emb_logo&fbclid=IwAR08fy4P8ZhaCq19-meEKbnTdXjv0D0wDkwzQPWd5kG2kG2myJU9g-hziYE



https://uclahs.az1.qualtrics.com/jfe/form/SV_3dXLwMJYag0ukND

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