

Severe & chronic self-injurious behavior (SIB) in children and youth with Autism.

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outline

- Background on self-injurious behavior (SIB).
- SIB clinic
- Retrospective study of first 30 patients
- An algorithm for approaching irritability in Autism
- Case presentation using the algorithm
- Potential innovative treatments

Definitions

Profound Autism

The *Lancet* Commission on the future of care and clinical research in autism

Catherine Lord, Tony Charman*, Alexandra Havdahl, Paul Carbone, Evdokia Anagnostou, Brian Boyd, Themba Carr, Petrus J de Vries, Cheryl Dissanayake, Gauri Divan, Christine M Freitag, Marina M Gotelli, Connie Kasari, Martin Knapp, Peter Mundy, Alex Plank, Lawrence Scahill, Chiara Servili, Paul Shattuck, Emily Simonoff, Alison Tepper Singer, Vicky Slonims, Paul P Wang, Maria Celica Ysraelit, Rachel Jellett, Andrew Pickles, James Cusack, Patricia Howlin, Peter Szatmari, Alison Holbrook, Christina Toolan, James B McCauley*

"Profound autism" has been suggested as a term by the Lancet commission to differentiate this patient population from the spectrum

Self Injurious Behaviour in children with profound Autism: Definition & topography

- self directed, non-suicidal behaviour that results in tissue damage
- Head to object, hand to head, biting, eye gouging, teeth pulling, knee to head

Risk factors for SIB in Autism

- Degree of intellectual disability
- Genetic syndromes (e.g. SMG)
- health problems
- repetitive behaviors
- ADHD

Richards C, et al. Predictors of Self-Injurious Behavior and Self-Restraint in Autism Spectrum Disorder: Towards a Hypothesis of Impaired Behavioral Control. *J Autism Dev Disorder*, 2017

Self Injurious Behaviour in children with profound Autism:

- SIB in Autism 50%
- Severe SIB 15%
- Often associated with aggression
- SIB starts before age of 3 in 50%
- Persistence rate of nearly 80%
- Burn out in families ++
- Behavior as communication

Behavior as communication

- first description of Functional Communication Training by Ted Carr and Mark Durand in 1985

Why self injury in autism?

A behavioral model

- Rhythmic repetitive behaviors
- Pain/ sensory discomfort
- Child frustrated
- Child hits self
- Parents respond
- Dangerous behavior cannot be ignored
- Behavior becomes learned and effective
- Behavior is maintained by the environment

Frequent severe SIB



Hockey padding



OT helmet

Kevlar



Frequent &
repetitive,
SIB

- Dependence on the protective equipment
- Self- restraint
- Richards C, et al. Predictors of Self-Injurious Behavior and Self-Restraint in Autism Spectrum Disorder: Towards a Hypothesis of Impaired Behavioral Control. J Autism Dev Disorder, 2017



SIB clinic
BC Childrens'
Hospital
started 2017

Transdisciplinary

- Pediatrics
- Behavioral
- Psychiatry



MULTIDISCIPLINARY



INTERDISCIPLINARY



TRANSDISCIPLINARY

Retrospective study of first 30 patients

Research Article

Characteristics of children with autism and unspecified intellectual developmental disorder (intellectual disability) presenting with severe self-injurious behaviours

Alison Fong  , Robin Friedlander, Anamaria Richardson, Katie Allen & Qian Zhang

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 Cite this article  <https://doi.org/10.1080/20473869.2022.2113321>



Study of first 30 children

- SIB frequency
- 70% hourly (4)
- . SIB severity
- 50% severe tissue injury 3.

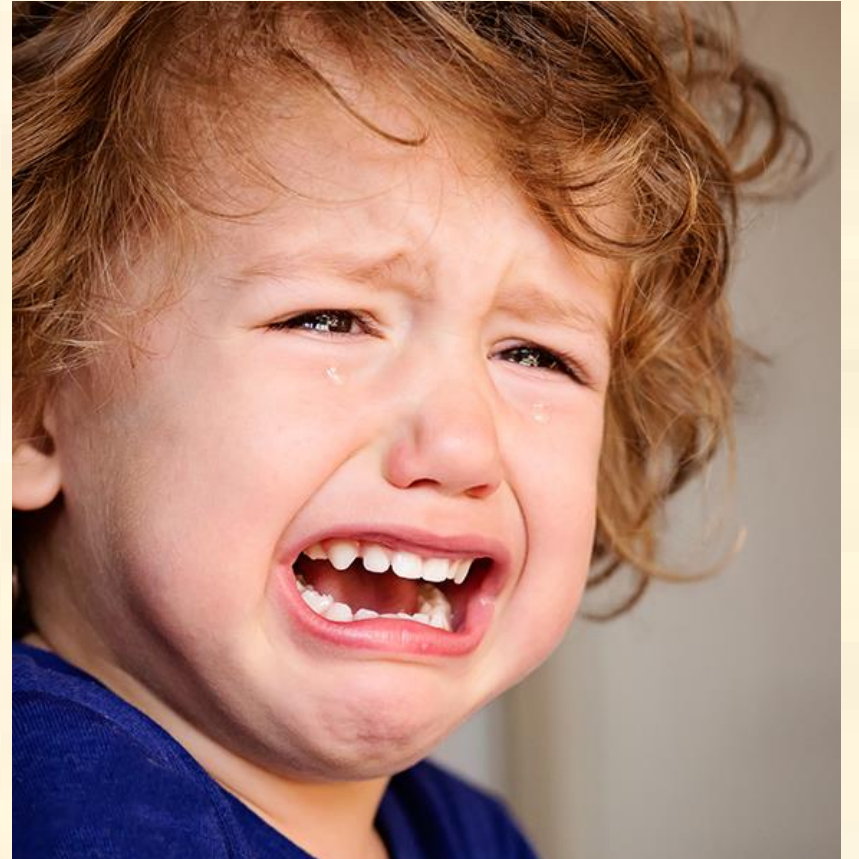
- SIB frequency and severity documented using Likert rating scales (Rojahn et al.) as part of the Behaviour Problems Inventory-Short Form (BPI-S)

Psychiatric comorbidity in first 30 patients

- ADHD 93%
- Insomnia 73%
- Tics 50%
- Anxiety 30%
- Mood disorder 20%
- Catatonia 13%
- Avoidant/ Restrictive Food Intake Disorder (ARFID) 13%
- Obsessive-Compulsive Disorder 10%

Ethan...

- Male diagnosed with Autism at age 3
- received intensive early intervention.
- age 4, admitted to Childrens hospital because of regression (6 month history of only sleeping 4 hours a night, less verbal, resorting to sounds and grunts and appeared more sensitive, anxious, sad and irritable.)
- Mental status noted he was non-verbal, very active and hitting out at his mother for no clear reason.



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Evaluating and managing irritability and aggression in children and adolescents with autism spectrum disorder: An algorithm



Algorithm for assessing causes of irritability in Autism

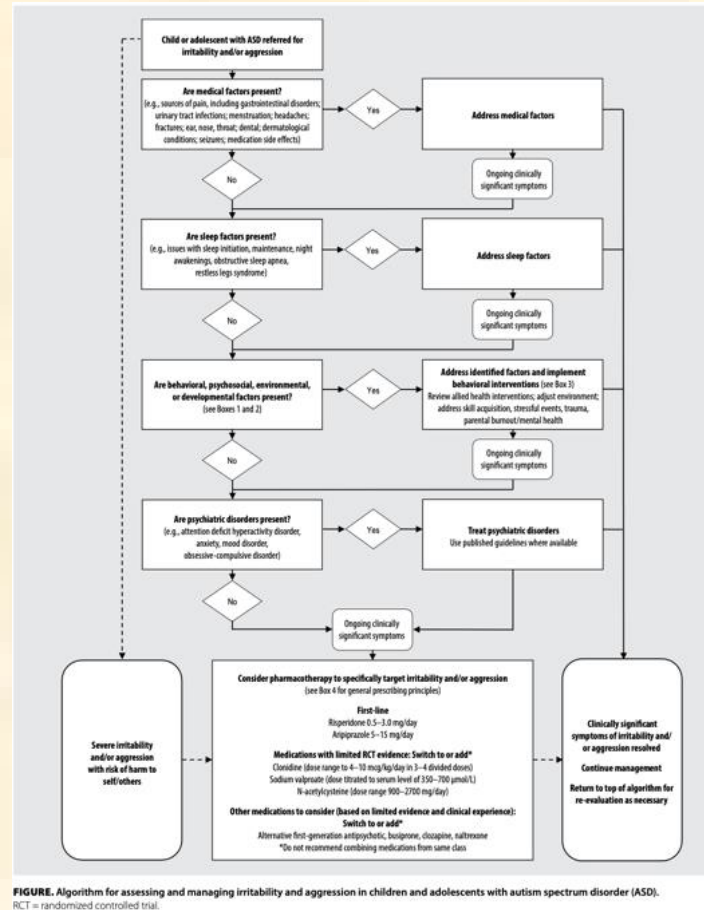
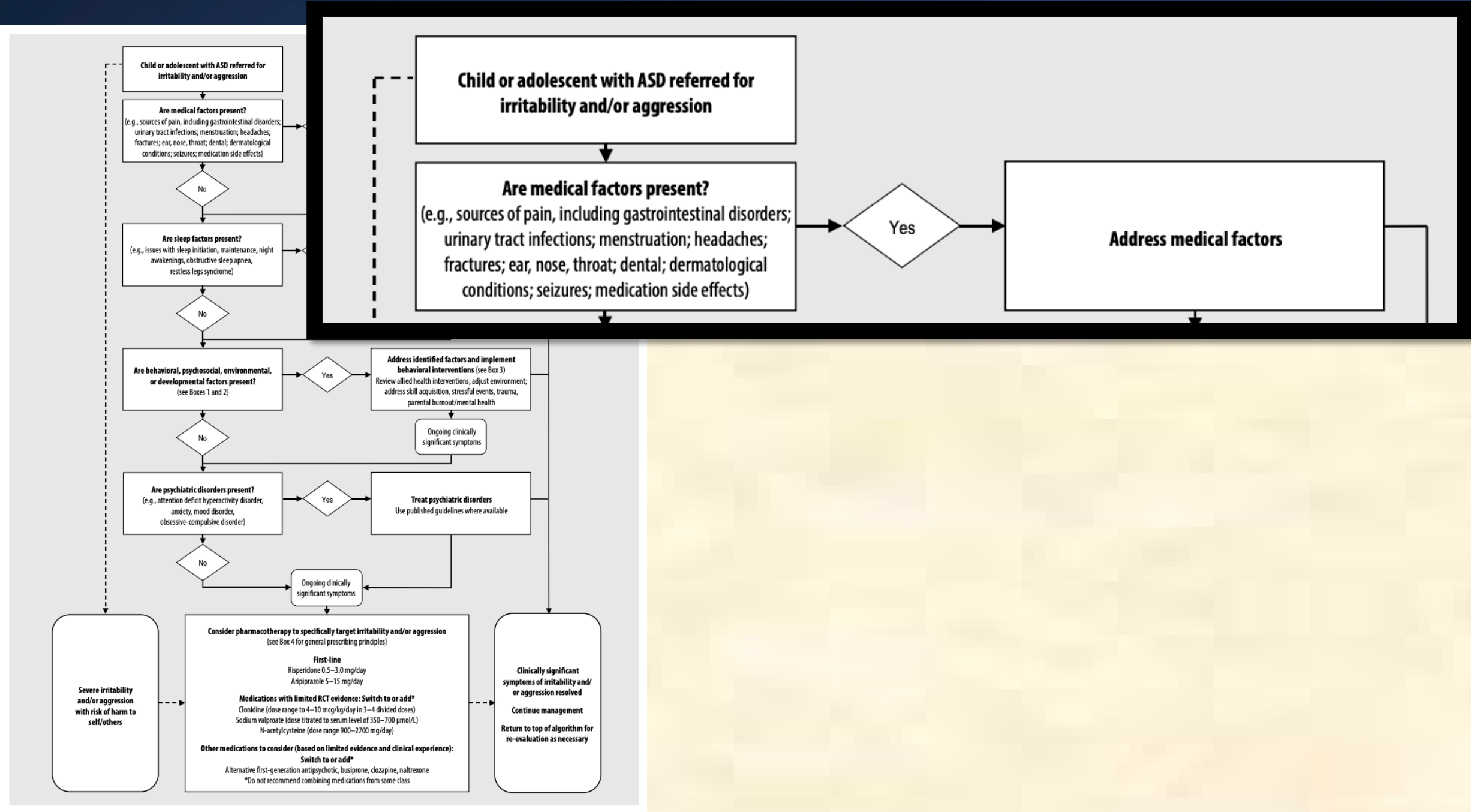


FIGURE. Algorithm for assessing and managing irritability and aggression in children and adolescents with autism spectrum disorder (ASD). RCT = randomized controlled trial.



Child or adolescent with ASD referred for irritability and/or aggression

Are medical factors present?
 (e.g., sources of pain, including gastrointestinal disorders; urinary tract infections; menstruation; headaches; fractures; ear, nose, throat; dental; dermatological conditions; seizures; medication side effects)

Yes

Address medical factors

Severe irritability and/or aggression with risk of harm to self/others

Consider pharmacotherapy to specifically target irritability and/or aggression
 (see Box 4 for general prescribing principles)

First-line
 Risperidone 0.5–3.0 mg/day
 Aripiprazole 5–15 mg/day

Medications with limited RCT evidence: Switch to or add*
 Clonidine (dose range to 4–10 mcg/kg/day in 3–4 divided doses)
 Sodium valproate (dose titrated to serum level of 350–700 µmol/L)
 N-acetylcysteine (dose range 900–2700 mg/day)

Other medications to consider (based on limited evidence and clinical experience):
 Switch to or add*
 Alternative first-generation antipsychotic, buspirone, dozapine, naltrexone

*Do not recommend combining medications from same class

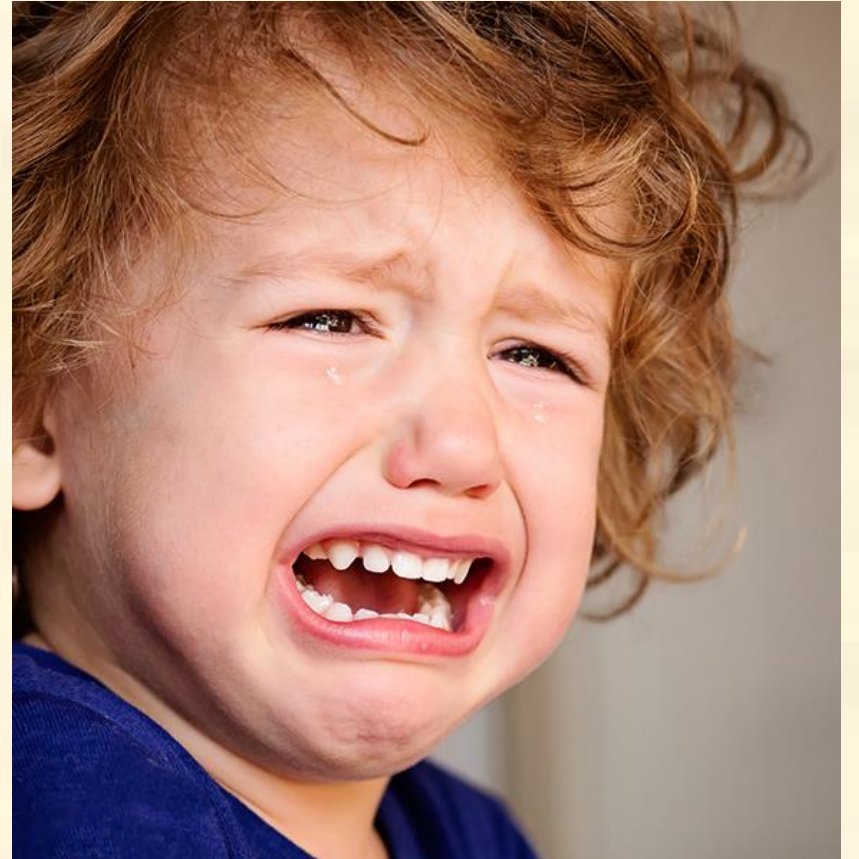
Clinically significant symptoms of irritability and/or aggression resolved

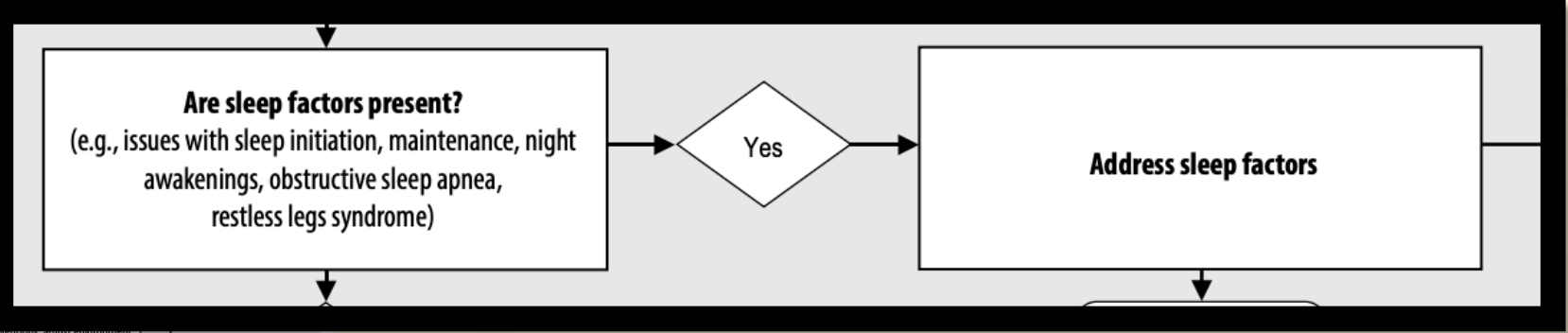
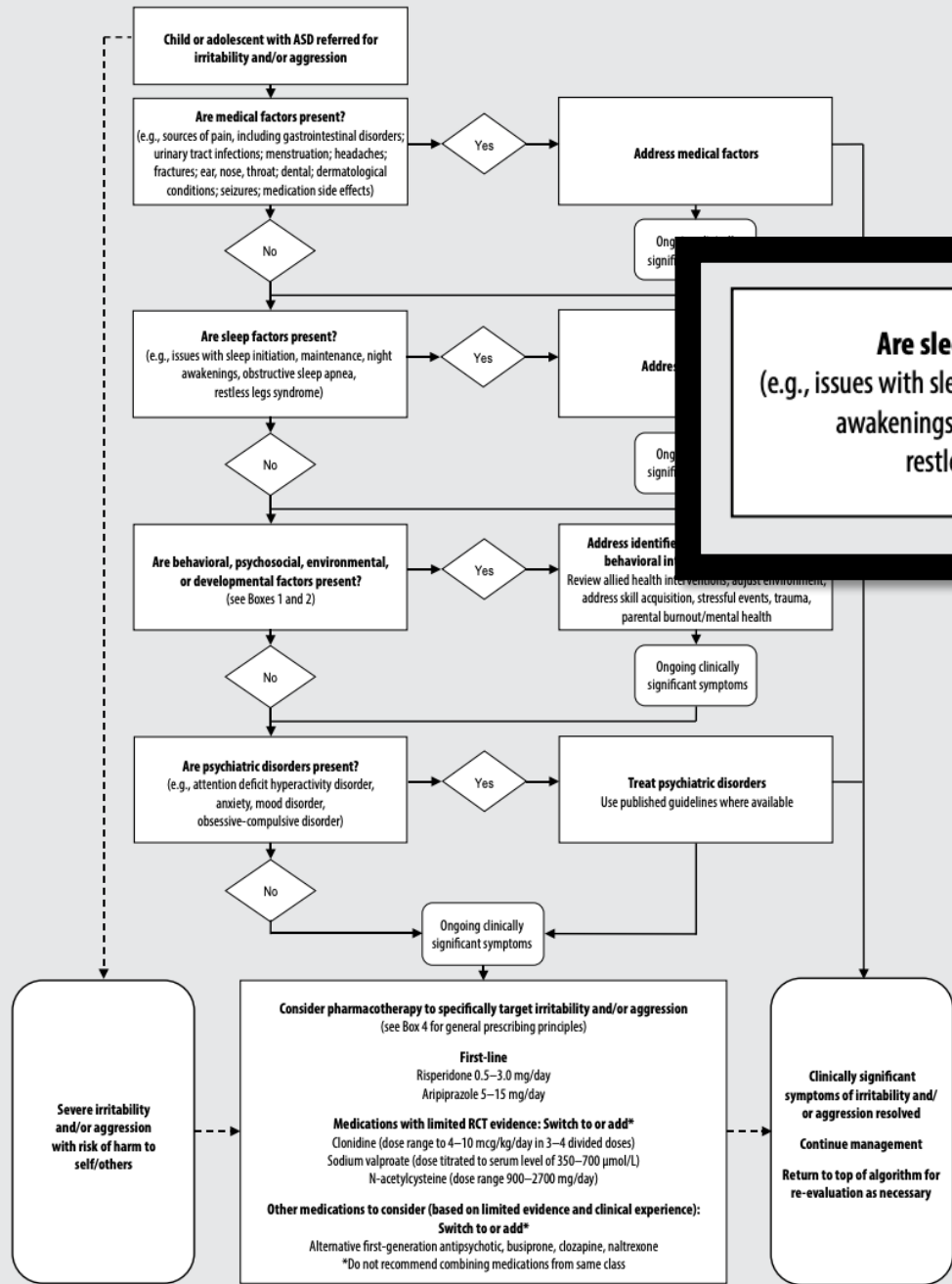
Continue management

Return to top of algorithm for re-evaluation as necessary

Ethan...

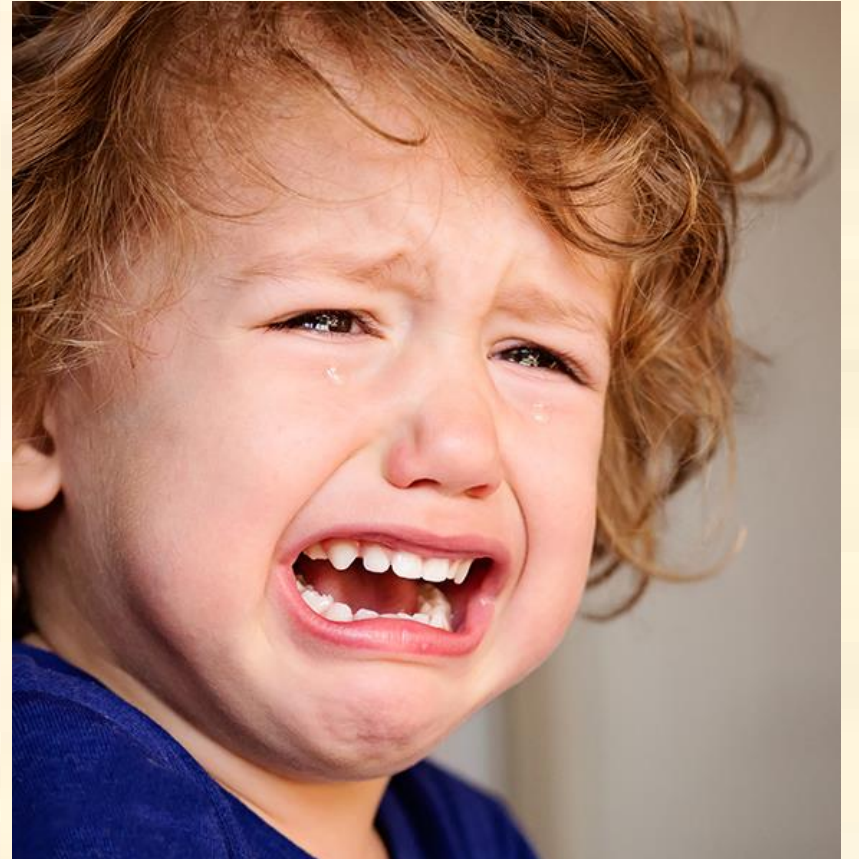
- Extensive medical workup was non-contributory.
- Cause of regression unclear.





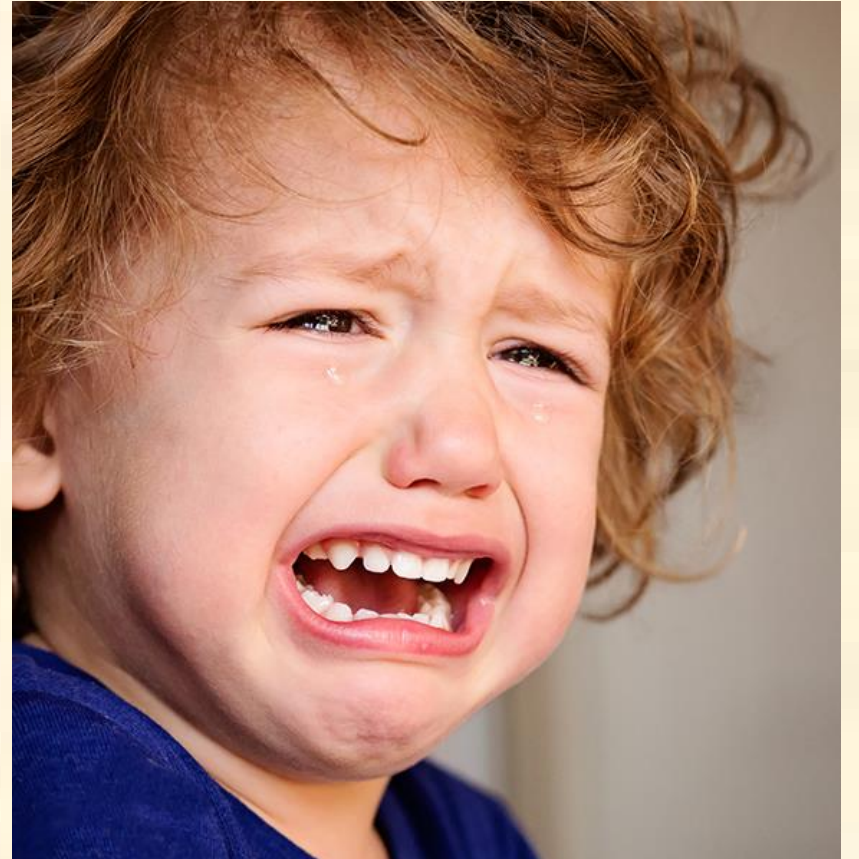
Ethan...

- Only sleeping 4 hours a night.
- He was treated with clonidine 0.2mg for sleep and risperidone 0.25mg PRN.



Ethan...

- SIB (head banging) emerged 3 months later (aged 4 years).
- He would hit his head with fist about 15 times a day, 3 to 4 hits each time when frustrated. He would also dive bomb the floor and hit the front of his head on the floor.



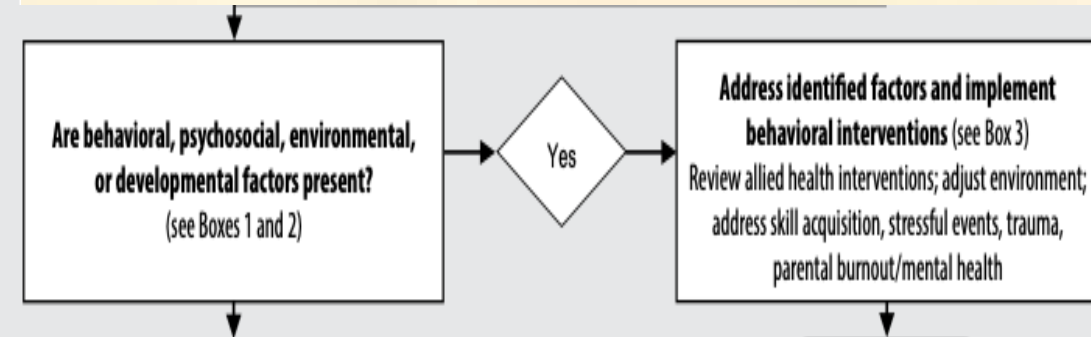
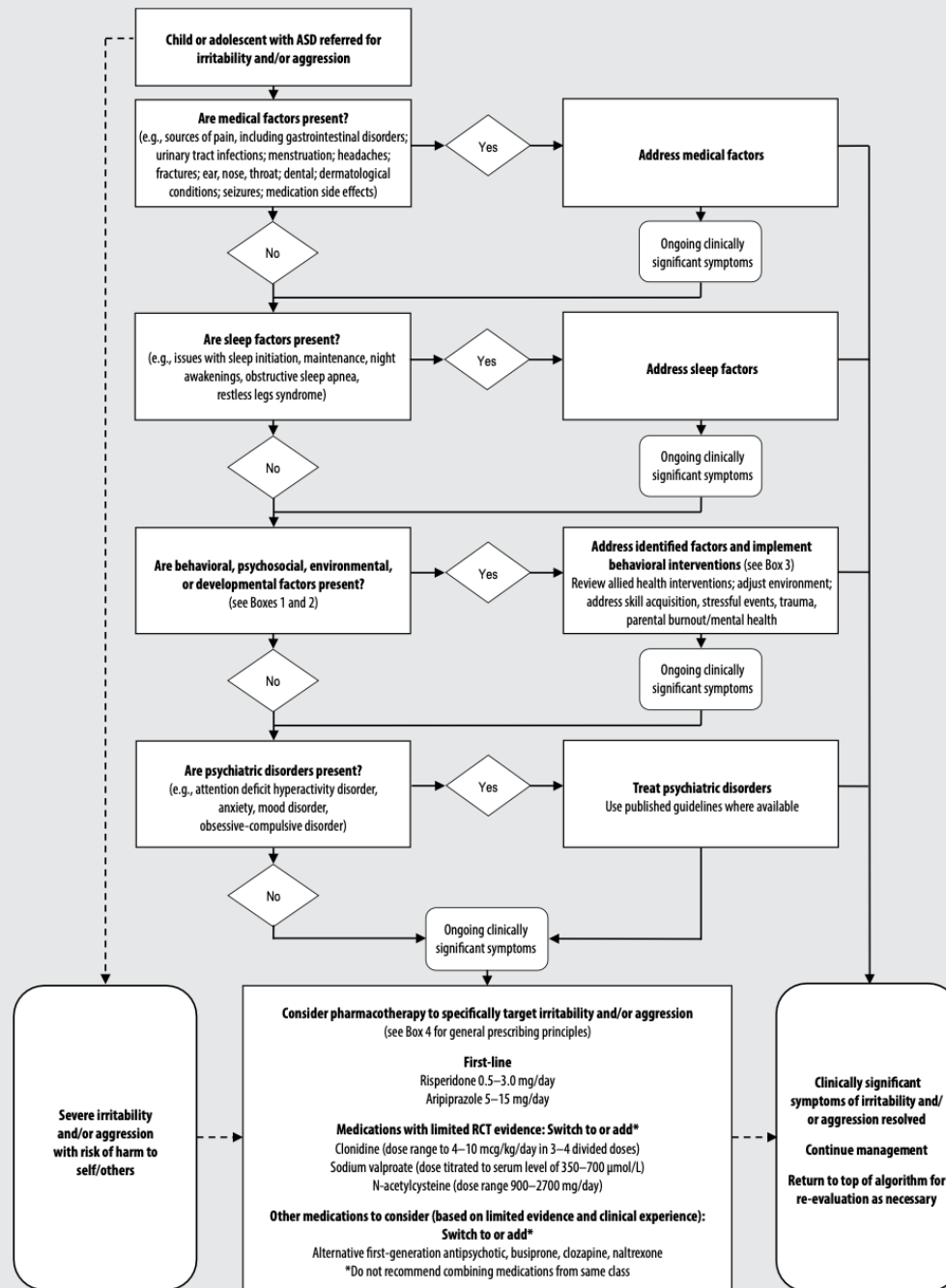
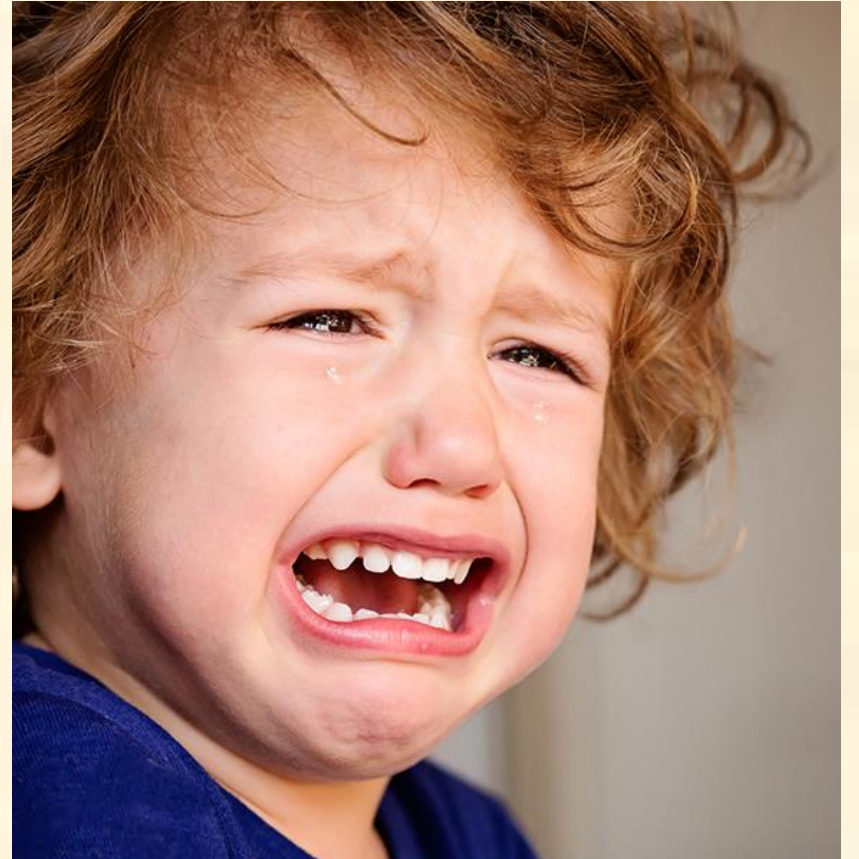


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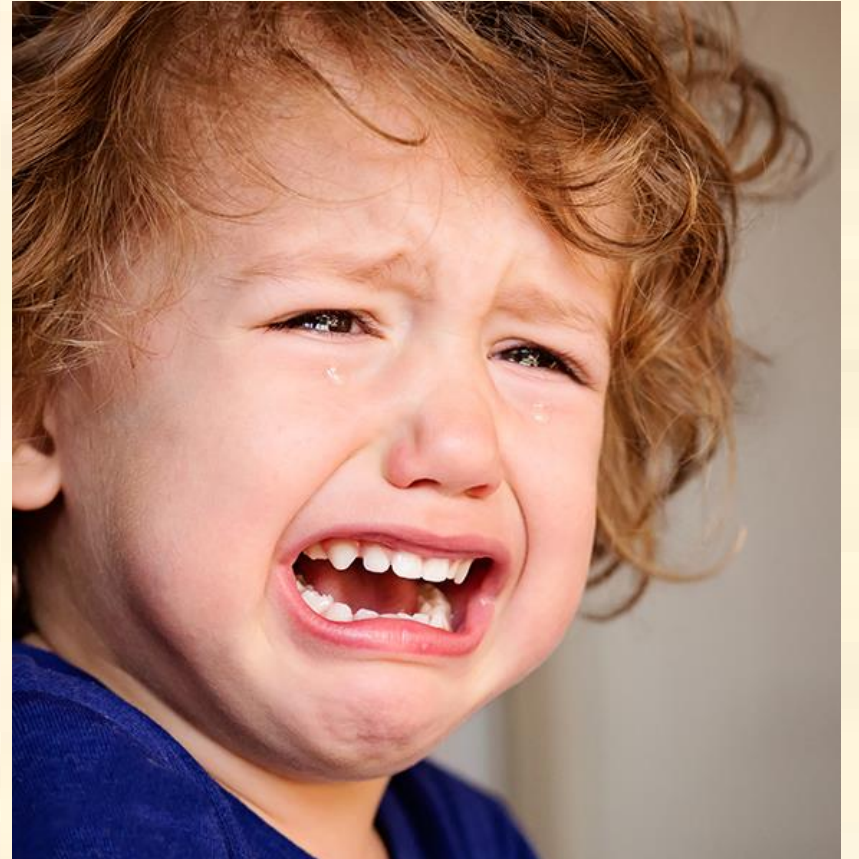
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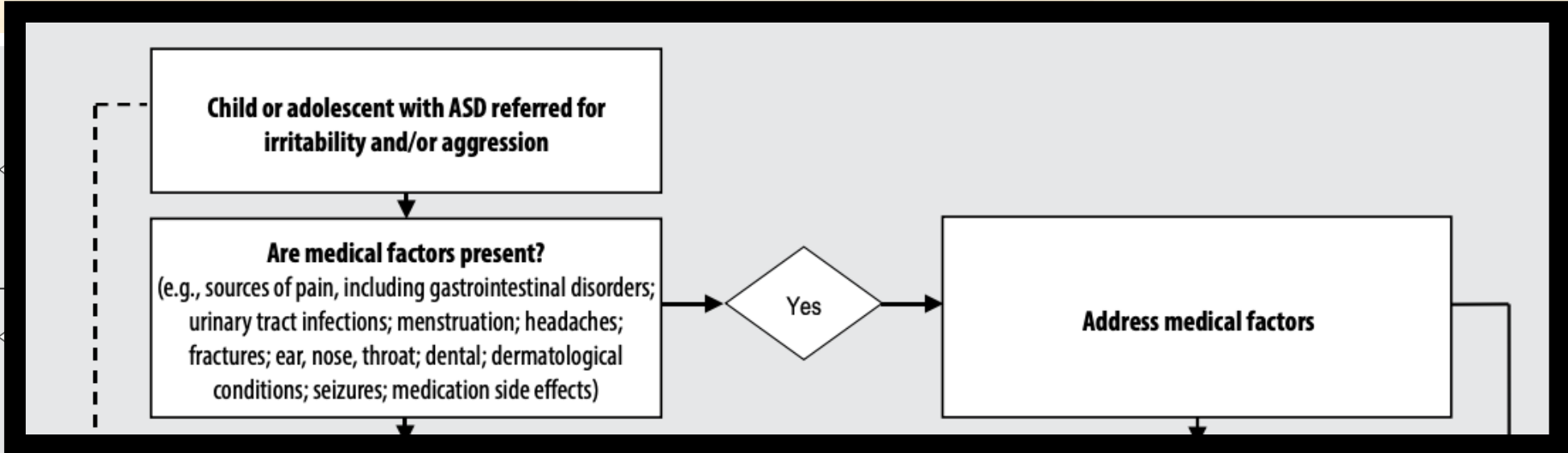
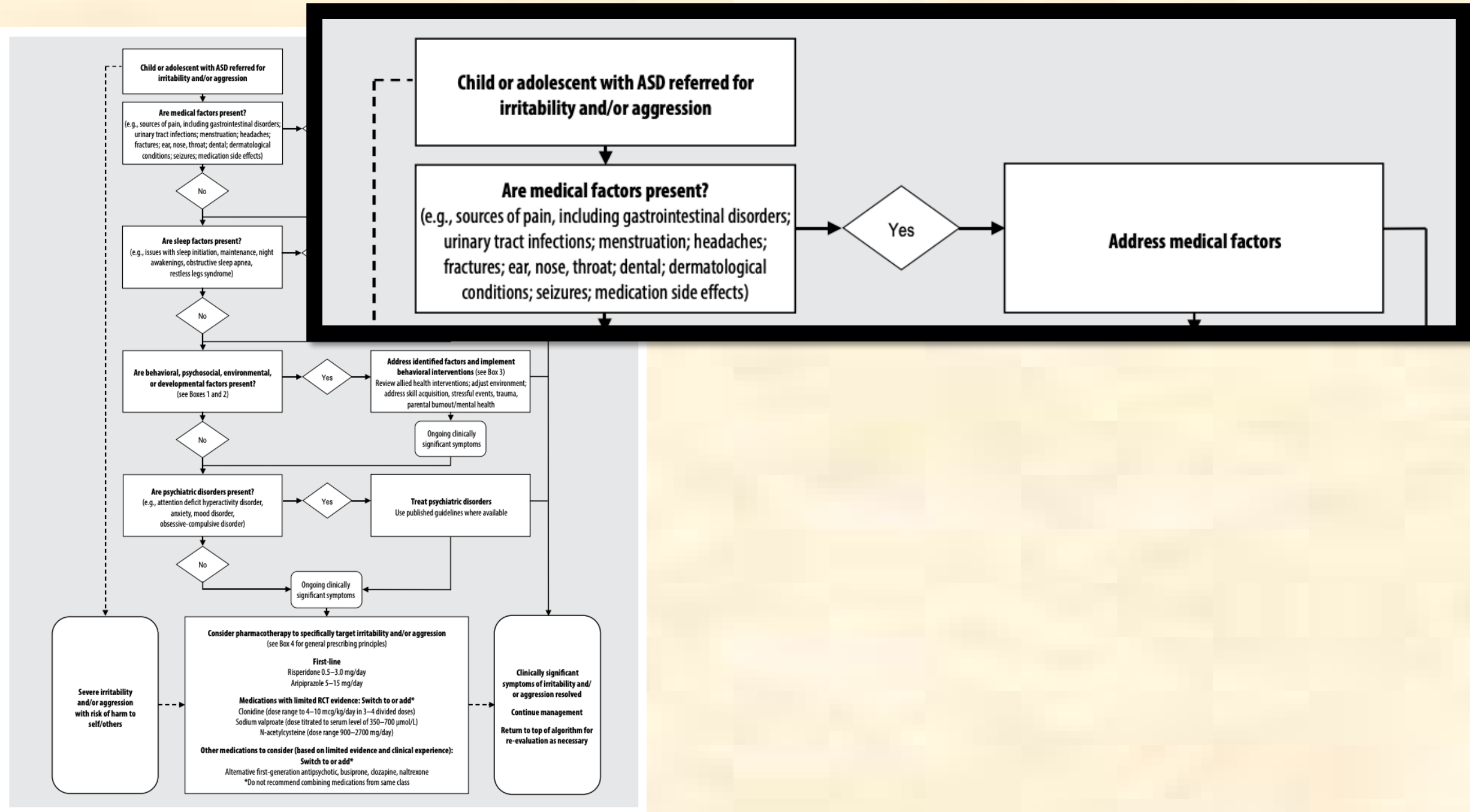
- Combination of internal & external reinforcement
- Community behavioral consultant lacked expertise in severe SIB



Ethan...

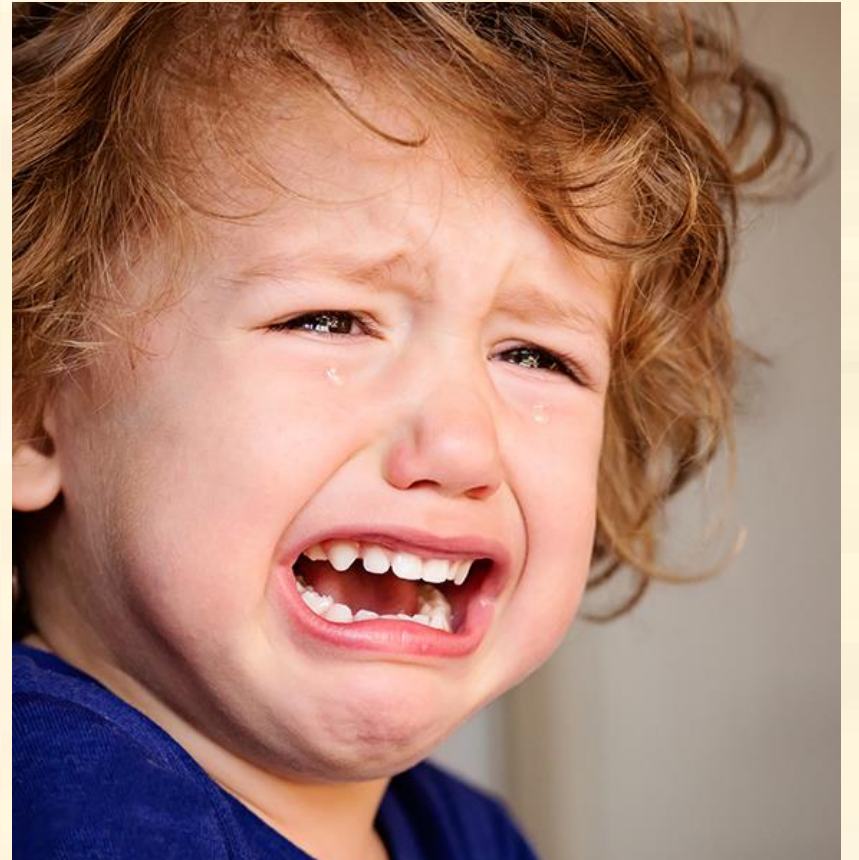
- He started holding his head and would cry for hours at a time.





Ethan...

- Headaches suspected.
- Trial of ibuprofen 200 mg Q6h for one week.
- Improvement, but not sustained.
- Referred to Neurology.



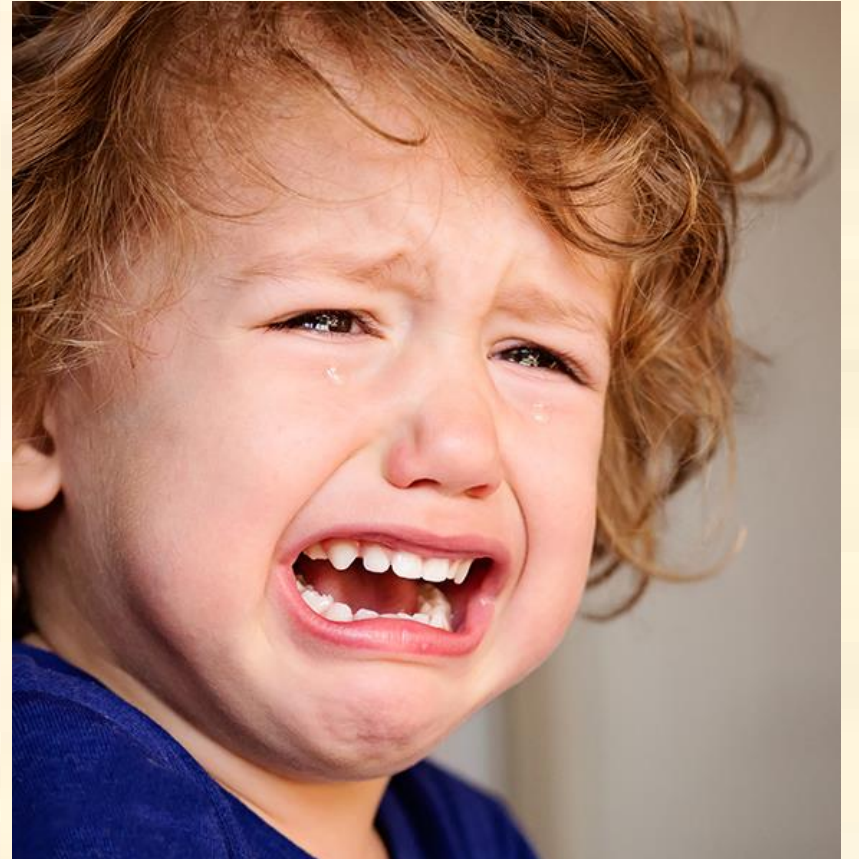
Ethan

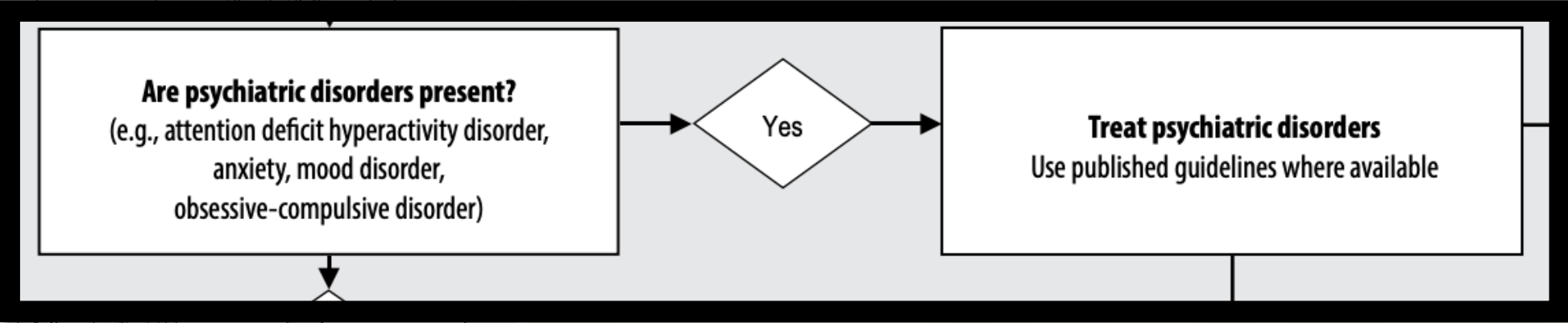
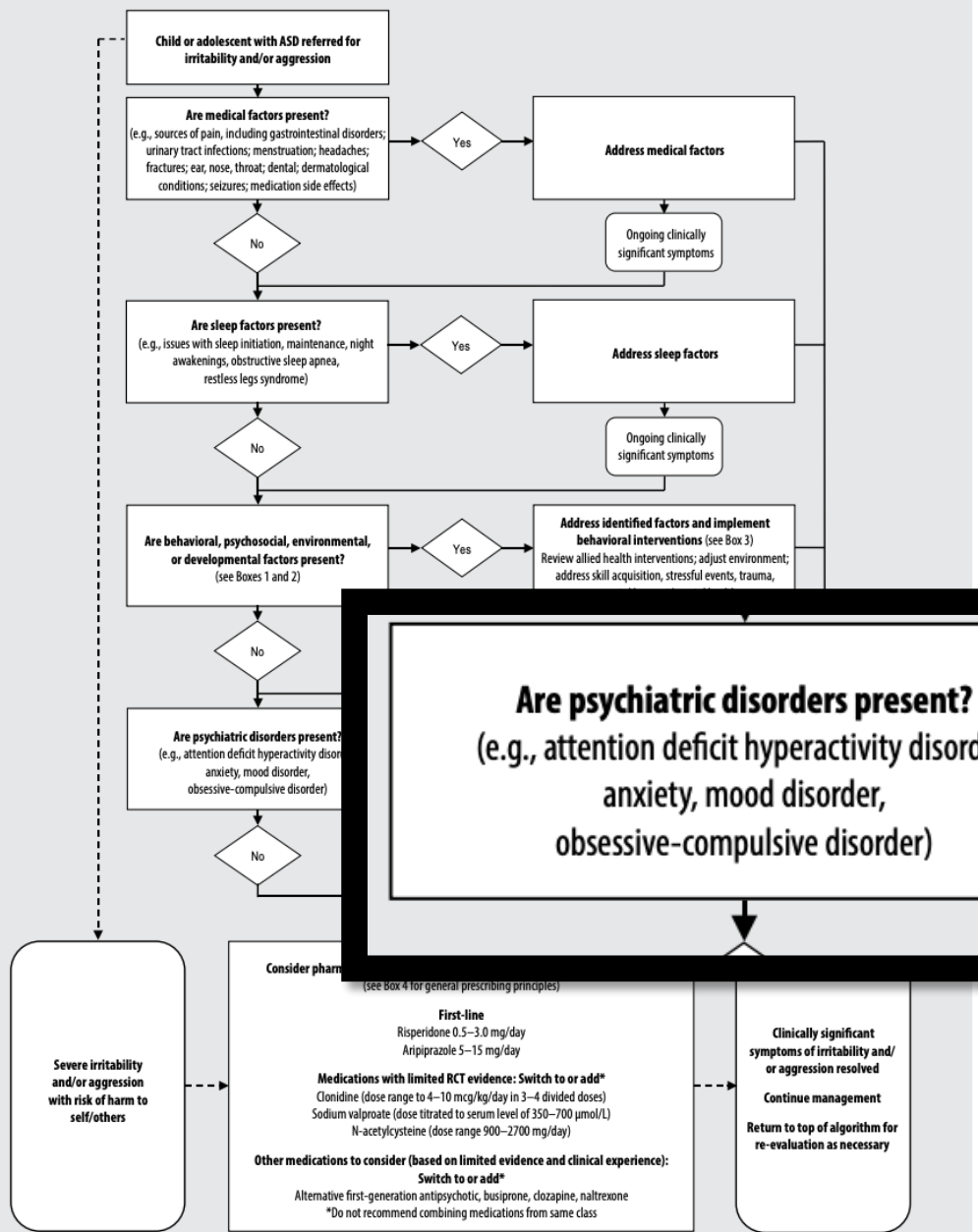


Started on gabapentin – to address headaches as well as ongoing difficulties with sleep
Initially markedly improved.
required escalating doses of gabapentin until it was no longer effective
and he was back to his 'pain' spells – crying 7-8H per day, engaging in SIB, looking for a quiet room

Ethan...

- Over the course of the following year, cycles of increased SIB associated with poor appetite, low energy, worsening sleep and decreased attention.
- He was no longer interested in coloring or watching TV.
- He would walk around hitting himself or crying.





Are psychiatric factors present?

- Self-injurious behavior (SIB) is sometimes presented as if it were a unitary behavioral entity.
- Nothing could be further from the truth.
- SIB is no more than the occasion for a neuropsychiatric differential diagnosis
- (Tom Gualtieri Psychopharm Bull, 1989)

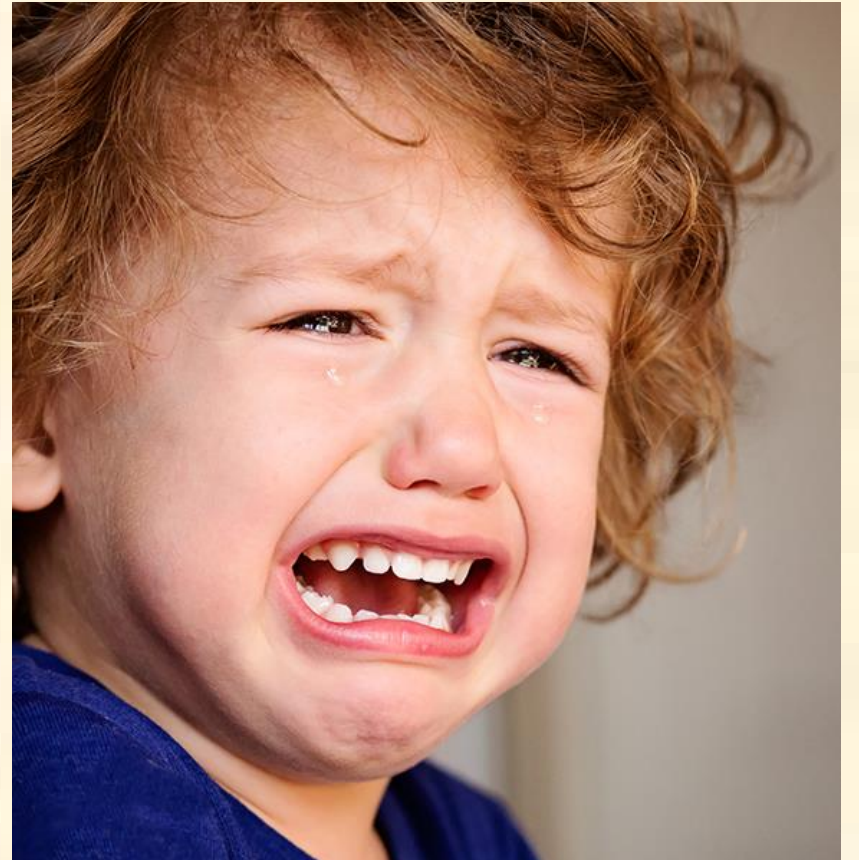
Important
concepts

Diagnostic
overshadowing

Baseline
exaggeration

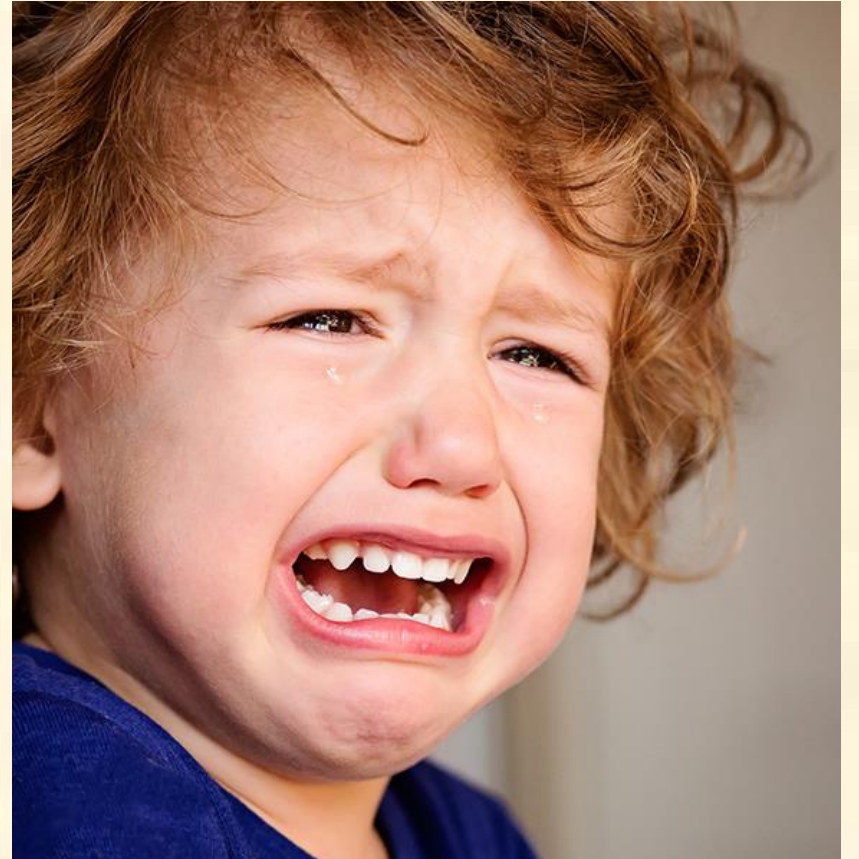
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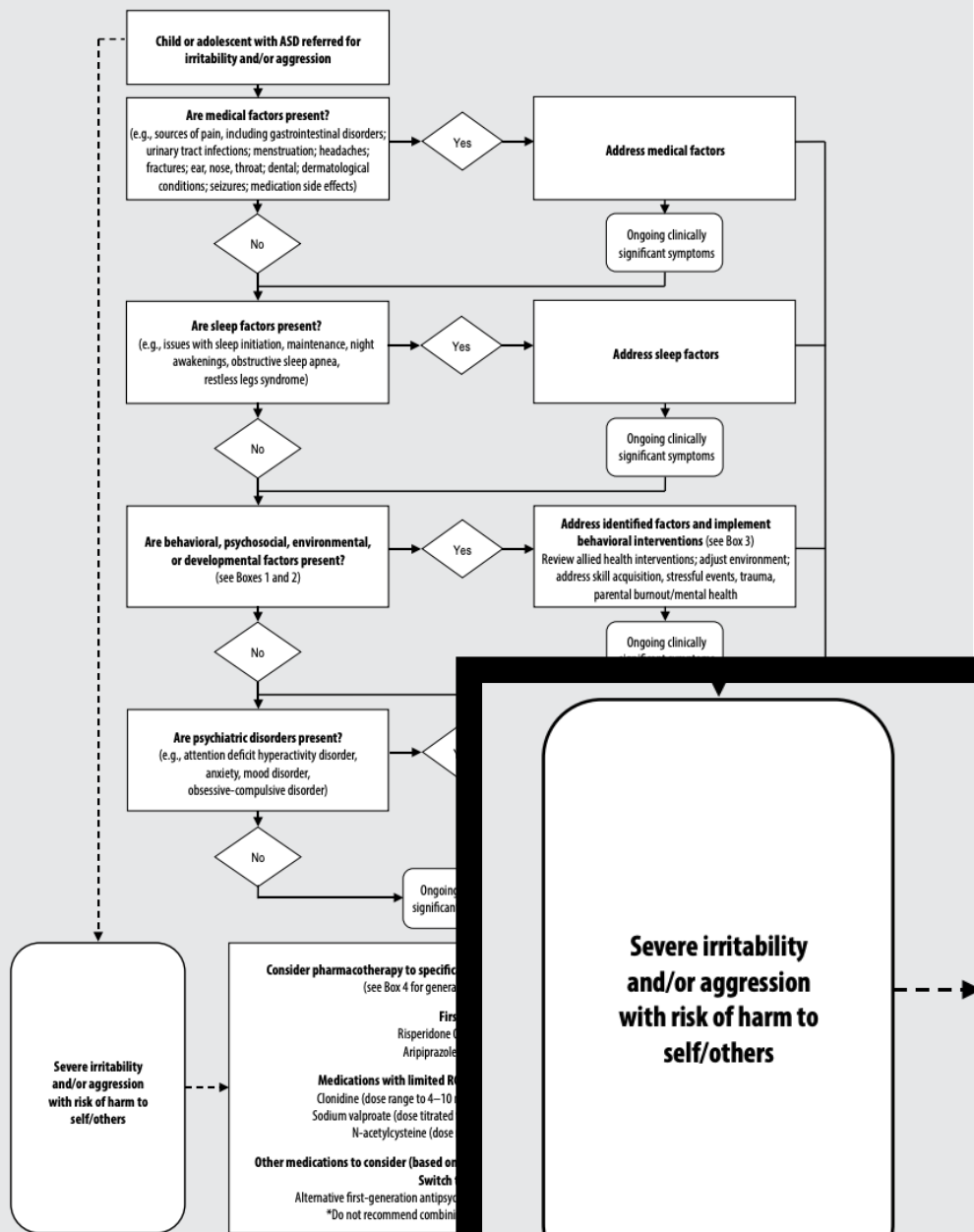
- A strong family history of mood disorder noted.
- symptoms consistent with major depressive disorder.
- treated with Fluoxetine 10mg daily.
- Mood, sleep and energy improved significantly.
- He started dancing again.
- Head banging to hard surfaces stopped completely, although he would still hit his head twice a week if frustrated.



Ethan...

- 6 months later...
- Hits head on anything when angry.
- Outbursts last 1 - 2 hours.
- damage to drywall and windscreen of car caused by head banging
- At school needs 2:1 because of outbursts
- Triggers at school are his ipad being removed/ any demand.
- School call mom to pick him up early.
- Mom unable to work because of the child's high support needs.
- Rx. Risperidone 0.25mg
- .





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Other medications to consider (based on limited evidence and clinical experience):

Switch to or add*

Alternative first-generation antipsychotic, buspirone, clozapine, naltrexone

*Do not recommend combining medications from same class

Severe irritability and/or aggression with risk of harm to self/others

Clinically significant symptoms of irritability and/or aggression resolved

Continue management

Return to top of algorithm for re-evaluation as necessary

Pharmacological
intervention for
irritability, aggression,
and self-injury in autism .

- Atypical antipsychotics
(Risperidone & Aripiprazole)
- improve irritability in autism

ABC irritability scale

15 items

1. Injures self

1. Aggressive to others

1. Screams inappropriately

1. Temper tantrums

1. Irritable

1. Yells inappropriately

1. Depressed

1. Needs demands met quickly

1. Cries over minor things

1. Mood liability

1. Cries/screams inappropriately

1. Stomps feet/banging on objects

1. Deliberately hurts self

1. Does physical violence to self

1. Throws temper tantrums

Pharmacological intervention for irritability, aggression, and self-injury in autism .

Cochrane Database of Systematic Reviews
2023, Issue 10.

Iffland M, Livingstone N, Jorgensen M, Hazell
P, Gillies D.

- Atypical antipsychotics may reduce self-injury
 - 1 study, 30 participants
 - low-certainty evidence
 - possibly indicating a large effect.
-
- McDougle, 1998

Innovative treatments

**YOU ARE NOW ENTERING A
POOR QUALITY
EVIDENCE ZONE**

Naltrexone.

- Experience of pain may be different
- endogenous opioid system may be involved.
- Naltrexone blocks opioid receptors.
- Evidence for efficacy is limited.
- Of great interest in 1980' and 90's.
- Negative findings in DBPC of naltrexone 50-150 mg/day in adults with ID/Autism & SIB (Willemsen-Swinkels, 1995)
- reserve for refractory cases

NAC (N acetyl cysteine)

- antioxidant; inhibits glutamate release.
- May reduce sensory discomfort similar to that experienced in excoriation disorder (for which there is evidence)
- case report of a 4 year old boy with reduced face scratching (NAC 1800mg/day). Marler et al,JAACAP,2014)
- DBPC study of 2700mg/day in children with autism aged 3-12 years); significant improvement on the ABC irritability subscale

Clonidine

- Binds to the alpha 2 adrenoreceptors reducing overarousal.
- Only 2 case reports
- Frequently used in clinical practice (Sabus et al, pharmacotherapy, 2019)

gabapentin

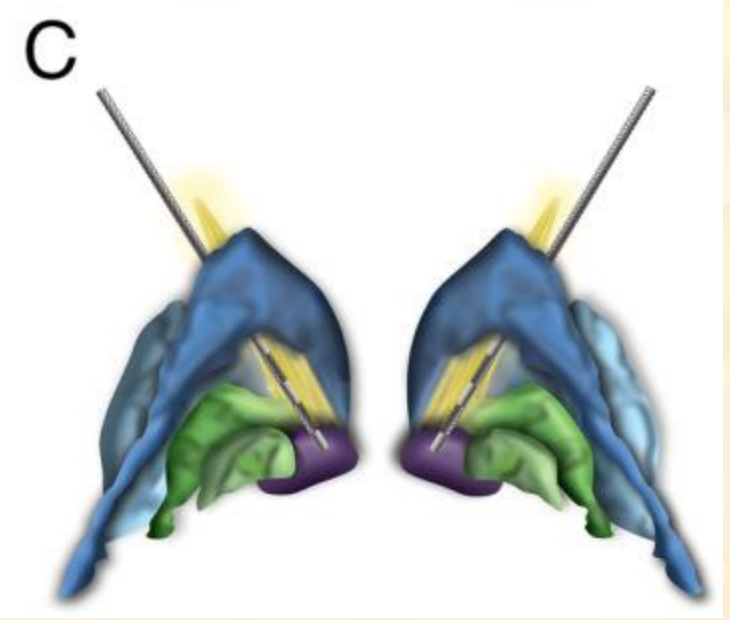
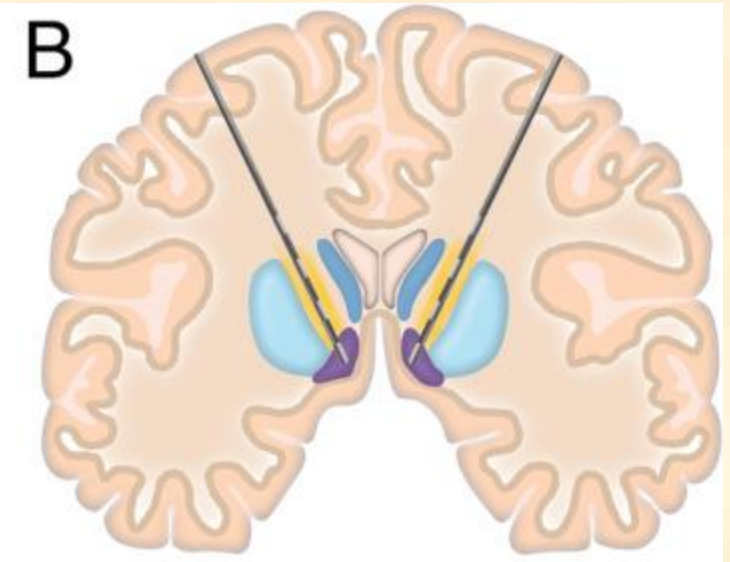
- 2 case reports
- 3-year-old male patient with Lesch-Nyhan syndrome. He would bite inside of cheek and lower lip day and night; treated with gabapentin 800mg/day with cessation of SIB within 3 weeks (McManaman, Ped Neurology, 1999)
- 22 year old male with Autism & severe ID; Treated with gabapentin 900mg/day with significant improvement in SIB (Marini, European psychiatry, 2023).

Fluphenazine

- D1 dopamine hypersensitivity model of self-injurious behavior
- mixed D1/D2 dopamine antagonist fluphenazine improves SIB in open study (Gualtieri, psychopharm bull, 1989).

Deep brain stimulation DBS

- “ he slaps his cheekbone and jaw severely and is constantly seeking restraints (can't help himself from hitting and he is in much distress). He also puts his fists down his throat, engages in uncontrollable lip biting and eye-poking so much so that the white of his eye was completely blood red”.
- Child refractory to pharmacology and behavioral treatment
- Successful use of DBS of nucleus accumbens in Dystonia and SIB.
- Currently a study at Sick kids in Toronto of DBS for SIB in Autism (Ibrahim. G).

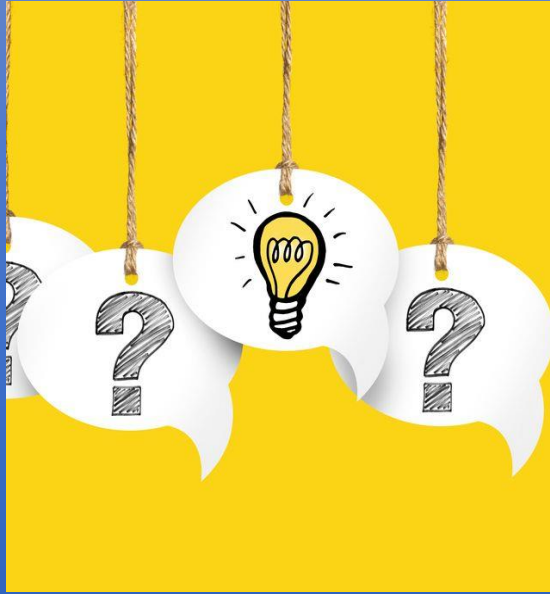


Every answer one finds
leads to ten more
questions. The more we
learn the less we know.

Robert M Pirsig

PICTUREQUOTES.COM

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- SIB is heterogeneous
- SIB effects the whole family
- Psychiatric comorbidity frequent & treatable.
- There is no one treatment for SIB
- SIB is a major health problem flying under the radar screens

What we've learned

the 3 main drivers of SIB in Autism

- Health related pain/distress
- Psychiatric disorders
- Behavioral (learned behavior, sensory and communication)

Algorithm for assessing causes of irritability in Autism

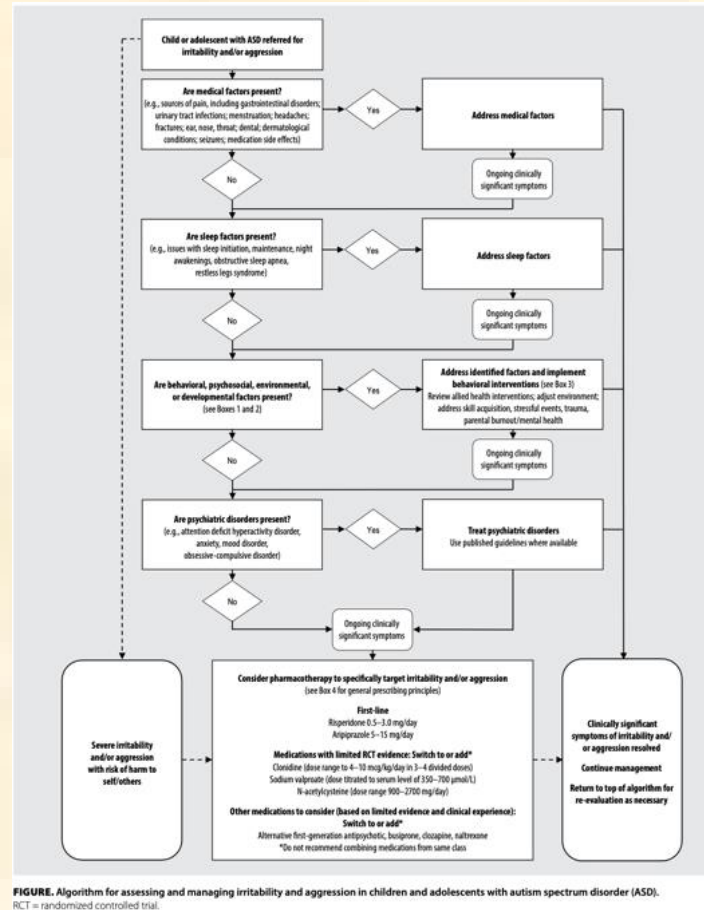


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RCT = randomized controlled trial.