Mass General Brigham

Autism Spectrum Disorder & Gastrointestinal Comorbidities

Mojdeh Mostafavi, MD

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About Me

EDUCATION & ACADEMIC TRAINING

Harvard T.H. Chan School of Public Health, Boston MA
Masters of Public Health - Clinical Effectiveness, *anticipated June 2026*

Massachusetts General Hospital for Children, Boston MA
Pediatric Gastroenterology and Nutrition Fellow, *anticipated June 2026*

Baystate Medical Center, Springfield MA
Combined Internal Medicine/Pediatrics Residency

Tufts University School of Medicine, Boston, MA
Doctor of Medicine, *Honos Civicus Society*

Smith College, Northampton, MA
Bachelor of Arts, Biochemistry, *cum laude, highest departmental honors*

About Me

I love someone with autism

This is my brother, Payam

Disclosures

I have no financial disclosures or conflicts of interest with the presented material

The views and opinions expressed in this webinar are my own and do not necessarily reflect those of my organization.

Disclosures

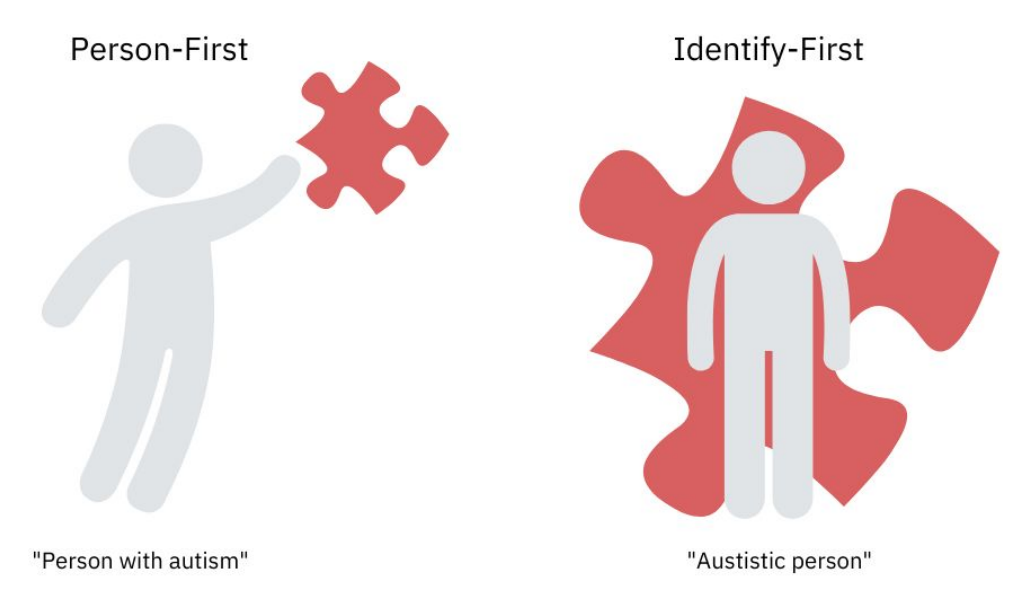
The information provided in this webinar is for educational purposes only and is not intended to replace professional medical advice, diagnosis, or treatment.

Always seek the advice of your physician or other qualified healthcare provider with any questions you may have regarding a medical condition.

Never disregard professional medical advice or delay seeking it because of something you have heard during this webinar.

Disclosures

Words matter



In this presentation, I will be using person-first language as it reflects the preference and experience of my family.

However, I understand that some individuals may prefer identity-first language.

If you are unsure about which language to use, please feel free to ask. Your understanding and respect for individual preferences are appreciated.

What is autism spectrum disorder?

“A group of neurodevelopmental disorders that affect how people communicate, learn, behave, and socially interact” ~NIH

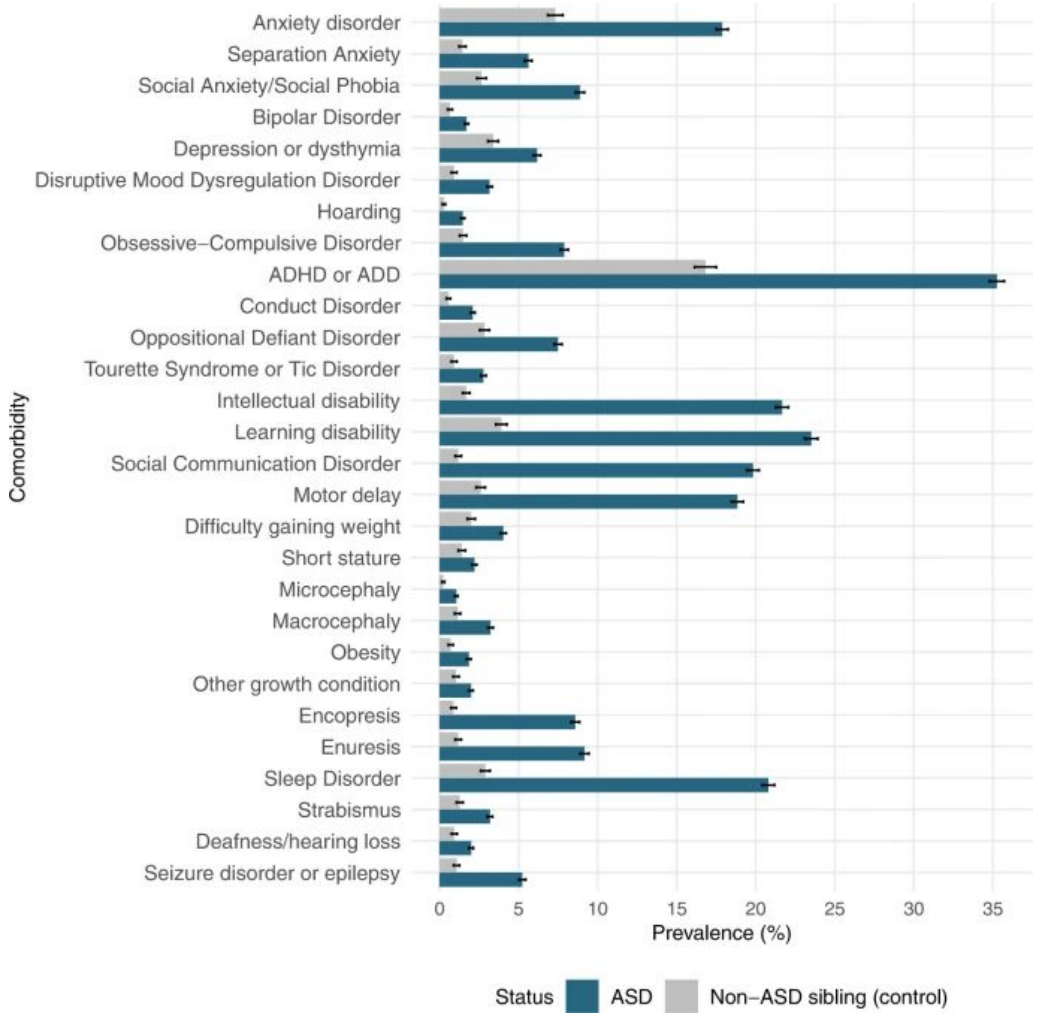
Diagnostic criteria outlined in the Diagnostic and Statistical Manual of Mental Disorders (DSM-V)

Core features:

1) Significant impairment in social interaction and communication
2) Restricted, repetitive patterns of behavior

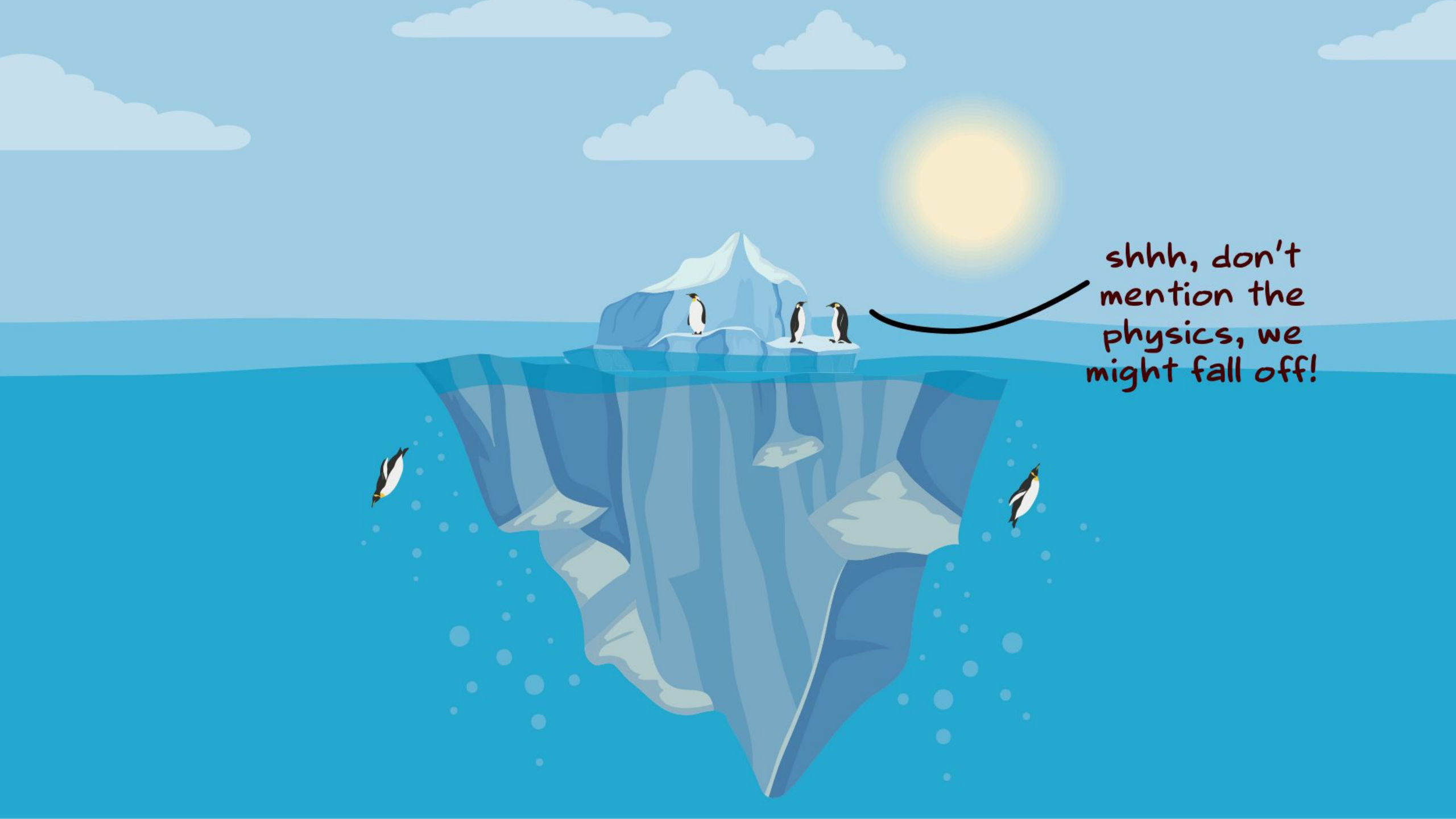
ASD comorbidities

- Genetic conditions (ex: Fragile X, tuberous sclerosis)
- Intellectual disability -> very difficult to assess, estimated ~30%
- Seizure disorders
- Other neurologic conditions
- Psychiatric disorders (e.g. ADHD, anxiety, depression, OCD)
- **Gastrointestinal disorders**
- Autoimmune conditions
- Sleep disturbances



Doshi-Velez, F., Ge, Y., & Kohane, I. (2014). Comorbidity clusters in autism spectrum disorders: an electronic health record time-series analysis. Pediatrics, 133(1), e54-e63.

Khachadourian, V., Mahjani, B., Sandin, S., Kolevzon, A., Buxbaum, J. D., Reichenberg, A., & Janecka, M. (2023). Comorbidities in autism spectrum disorder and their etiologies. Translational Psychiatry, 13(1), 71.


shhh, don't mention the physics, we might fall off!

ASD & GI symptoms

Approximately 40-70% of children with ASD have a positive hx of GI symptoms, significantly higher lifetime prevalence when compared to both children with other developmental disabilities and children without ASD/IDD. (McElhanon et al., 2014; Huang et al., 2024)

- Significant heterogeneity amongst individuals with ASD
- Significant variability in definition and assessment of GI symptoms

Children with ASD have been found to have a higher prevalence of GI symptoms when compared to their non-ASD siblings (42% vs 12%). (Wang et al., 2011)

McElhanon, B. O., McCracken, C., Karpen, S., & Sharp, W. G. (2014). Gastrointestinal symptoms in autism spectrum disorder: a meta-analysis. *Pediatrics*, *133*(5), 872-883.

Hung, L. Y., & Margolis, K. G. (2024). Autism spectrum disorders and the gastrointestinal tract: insights into mechanisms and clinical relevance. Nature Reviews Gastroenterology & Hepatology, 21(3), 142-163.

Wang, L. W., Tancredi, D. J., & Thomas, D. W. (2011). The prevalence of gastrointestinal problems in children across the United States with autism spectrum disorders from families with multiple affected members. Journal of Developmental & Behavioral Pediatrics, 32(5), 351-360.

ASD & GI symptoms

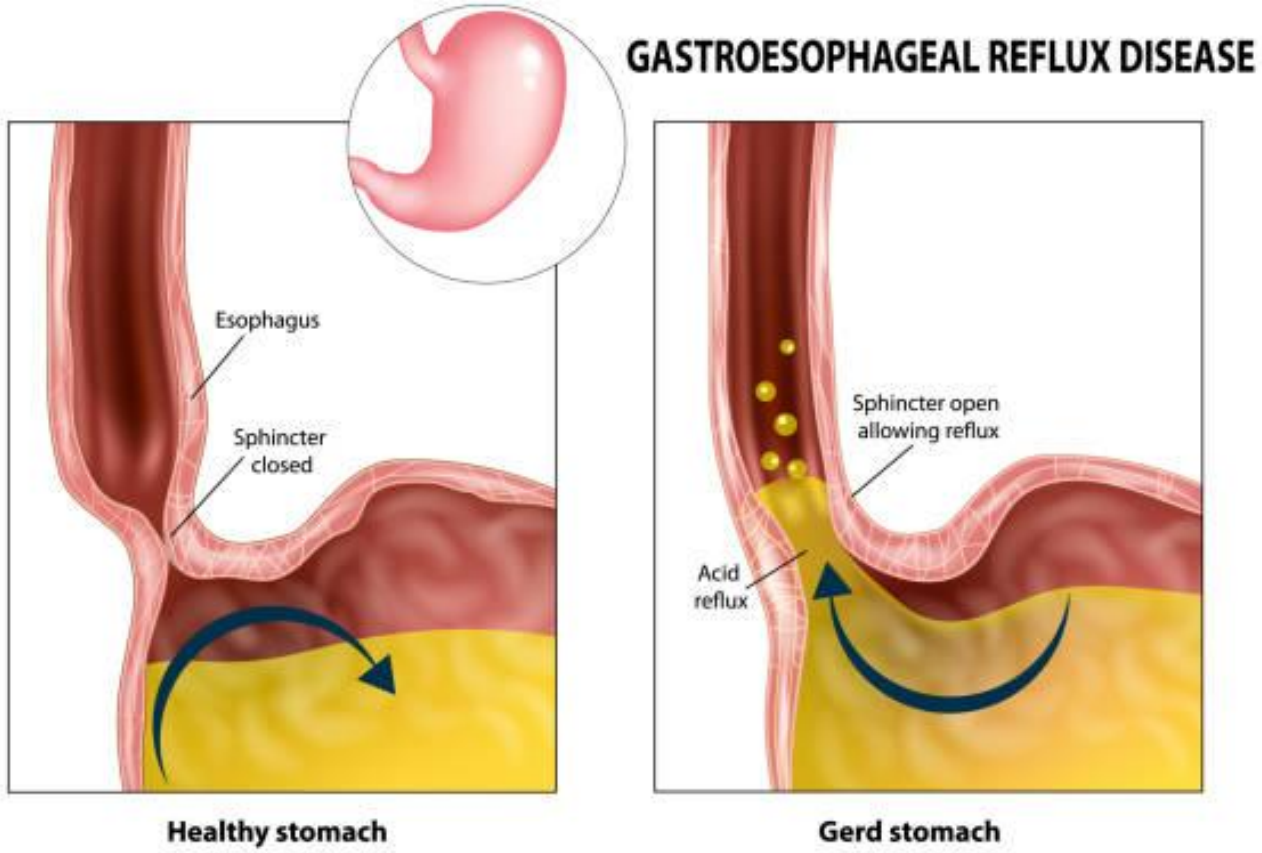
Children with ASD and history of language regression were found to have an increased frequency of abnormal stooling patterns when compared to children with ASD without history of language regression (40% vs. 12%). (Valicenti-McDermott et al., 2008)

Most common GI symptom complaints: constipation, abdominal pain, feeding difficulties, vomiting, encopresis, and weight loss/failure to thrive (Mostafavi et al., 2024)

Valicenti-McDermott, M. D., McVicar, K., Cohen, H. J., Wershil, B. K., & Shinnar, S. (2008). Gastrointestinal symptoms in children with an autism spectrum disorder and language regression. Pediatric Neurology, 39(6), 392-398.

Mostafavi, M., & Sayej, W. (2024). Characterization of Initial Gastrointestinal Evaluation of Children with Autism Spectrum Disorder: A Descriptive Study. Journal of Autism and Developmental Disorders, 1-6.

Gastroesophageal Reflux Disease (GERD)



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ASD & GERD

A recent retrospective cohort study including over 2.4 million subjects with GERD (4430 with ASD) (Kamionkowski et al., 2022)

Patients with GERD and ASD had a much higher risk for developing:

- Erosive esophagitis as compared to those without ASD (OR 13.53, 95%CI 12.22–14.99, $p < 0.001$)
- Esophageal ulcer as compared to those without ASD (OR 1.64, 95%CI 1.27–2.12, $p < 0.001$)

Patients with GERD and ASD had a lower risk for developing:

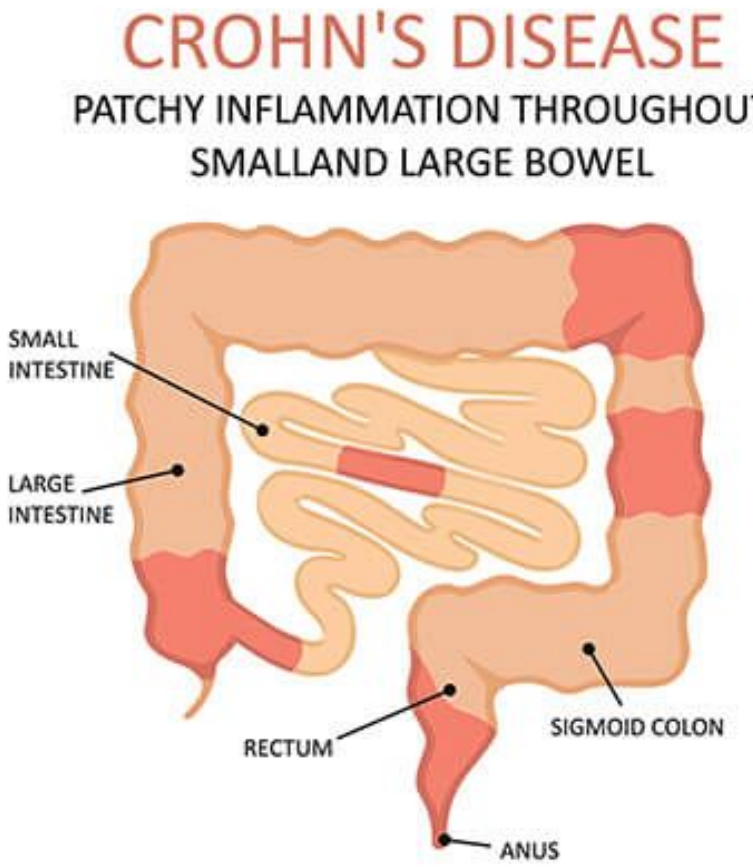
- Barrett's esophagus as compared to those without ASD (OR 0.57, 95%CI 0.45–0.71, $p < 0.001$)

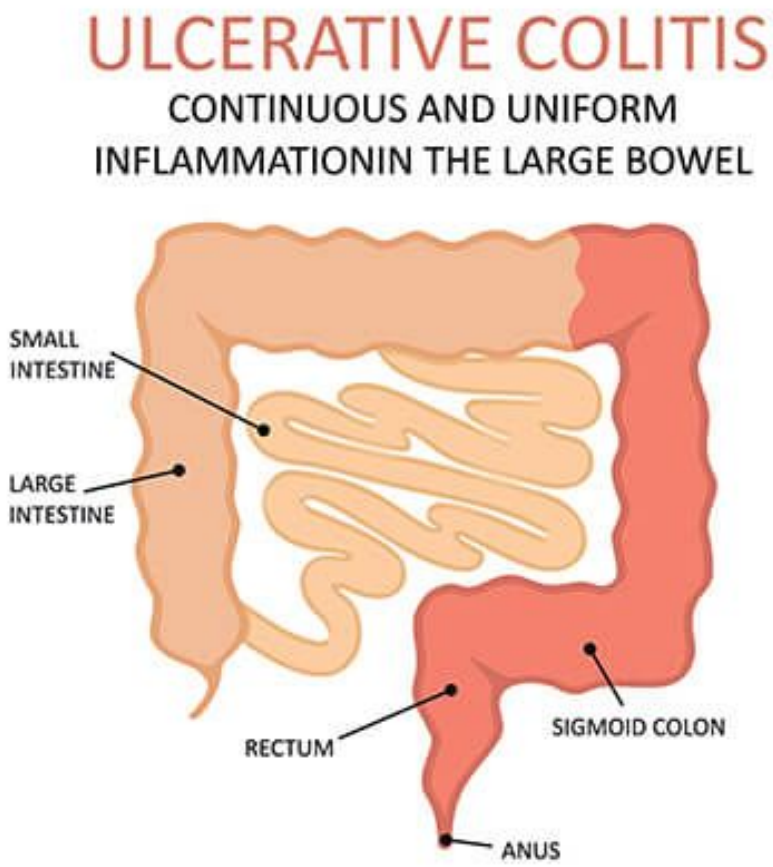
BRAVO wireless pH is well tolerated and feasible in evaluating GERD in ASD (Rodriguez et al., 2022)

Kamionkowski, S., Shibli, F., Ganocy, S., & Fass, R. (2022). The relationship between gastroesophageal reflux disease and autism spectrum disorder in adult patients in the United States. Neurogastroenterology & Motility, 34(7), e14295.

Rodriguez, L., Morley-Fletcher, A., Winter, H., & Timothy, B. (2022). Evaluation of gastroesophageal reflux disease in children on the Autism spectrum: a study evaluating the tolerance and utility of the BRAVO wireless pH monitoring. Journal of Pediatric Gastroenterology and Nutrition, 75(4), 450-454.

Inflammatory Bowel Disease





https://www.thesurgeons.sg/services/inflammatory-bowel-disease/

ASD & Inflammatory Bowel Disease

Recent systematic review & meta-analysis included six studies consisting of over 11 million participants

Primary outcome = association between ASD and later development of IBD

ASD was significantly associated with subsequent incident IBD

- Any IBD, OR = 1.66, 95%CI 1.25–2.21, $p < 0.001$
- Ulcerative colitis, OR = 1.91, 95%CI = 1.41–2.6, $p < 0.001$
- Crohn's disease, OR = 1.47, 95%CI = 1.15–1.88, $p = 0.002$

Kim, J. Y., Choi, M. J., Ha, S., Hwang, J., Koyanagi, A., Dragioti, E., ... & Solmi, M. (2022). Association between autism spectrum disorder and inflammatory bowel disease: A systematic review and meta-analysis. Autism Research, 15(2), 340-352.

ASD & Inflammatory Bowel Disease

ASD and IBD were also associated regardless of temporal sequence of diagnosis

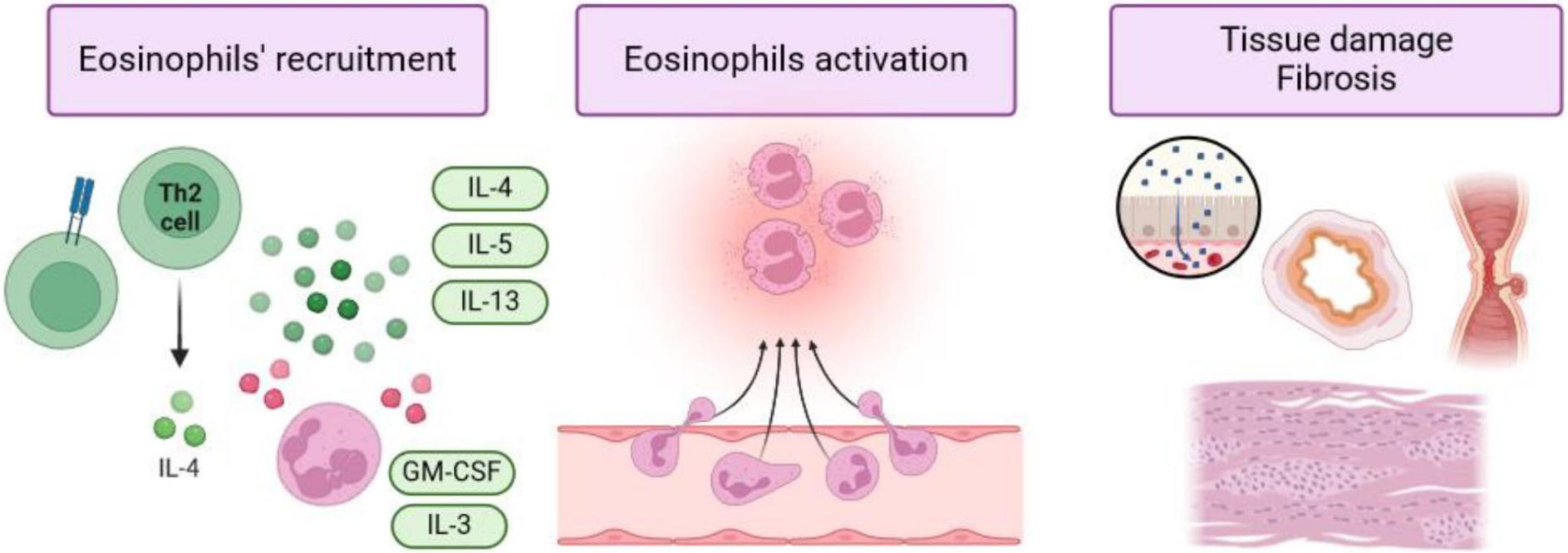
- Any IBD, OR = 1.57, 95%CI 1.28-1.93, $p < 0.001$
- Ulcerative colitis, OR = 1.7, 95%CI = 1.36–2.12, $p < 0.001$
- Crohn's disease, OR = 1.37, 95%CI = 1.12–1.69, $p = 0.003$

Children with ASD may have more severe phenotypes of IBD as indicated by higher rates of second-tier biologics vs non-ASD IBD patients (Lee et al., 2018)

Kim, J. Y., Choi, M. J., Ha, S., Hwang, J., Koyanagi, A., Dragioti, E., ... & Solmi, M. (2022). Association between autism spectrum disorder and inflammatory bowel disease: A systematic review and meta-analysis. Autism Research, 15(2), 340-352.

Lee, M., Krishnamurthy, J., Susi, A., Sullivan, C., Gorman, G. H., Hisle-Gorman, E., ... & Nylund, C. M. (2018). Association of autism spectrum disorders and inflammatory bowel disease. Journal of autism and developmental disorders, 48, 1523-1529.

Eosinophilic GI Disease (EGID)



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ASD & EGID

Recent systematic review & meta-analysis included six studies consisting of over 700,000 participants

Primary outcome = association between ASD and eosinophilic gastrointestinal diseases

Overall prevalence of ASD in the population with EGID of 21.59% (95% CI: 10.73–38.67)

ASD was significantly associated with EGID

- Any EGID, OR = 3.44, 95%CI 1.25–2.21
- Restricted to EoE, OR = 3.70, 95%CI = 2.71–5.70

Lima, R. V., Muniz, M. C. R., Barroso, L. L., Pinheiro, M. C. A., Matos, Y. M. T., Nogueira, S. B. R., & Nogueira, H. B. R. (2024). Autism in patients with eosinophilic gastrointestinal disease: A systematic review with meta-analysis. Pediatric Allergy and Immunology, 35(4), e14122.

Avoidant/Restrictive Food Intake Disorder (ARFID)

https://www.rcpsych.ac.uk/images/default-source/mental-health-images/arfid-venn-diagram.png?sfvrsn=9c4768be_4

ASD & ARFID

Recent systematic review & prevalence based meta-analysis included 21 studies consisting of over 7,000 participants (Sader et al., 2024)

- Overall prevalence of ASD in the population with ARFID of 16.27% (95% CI: 8.64–28.53)
- Overall prevalence of ARFID in the population with ASD of 11.41% (95% CI: 2.89–35.76)

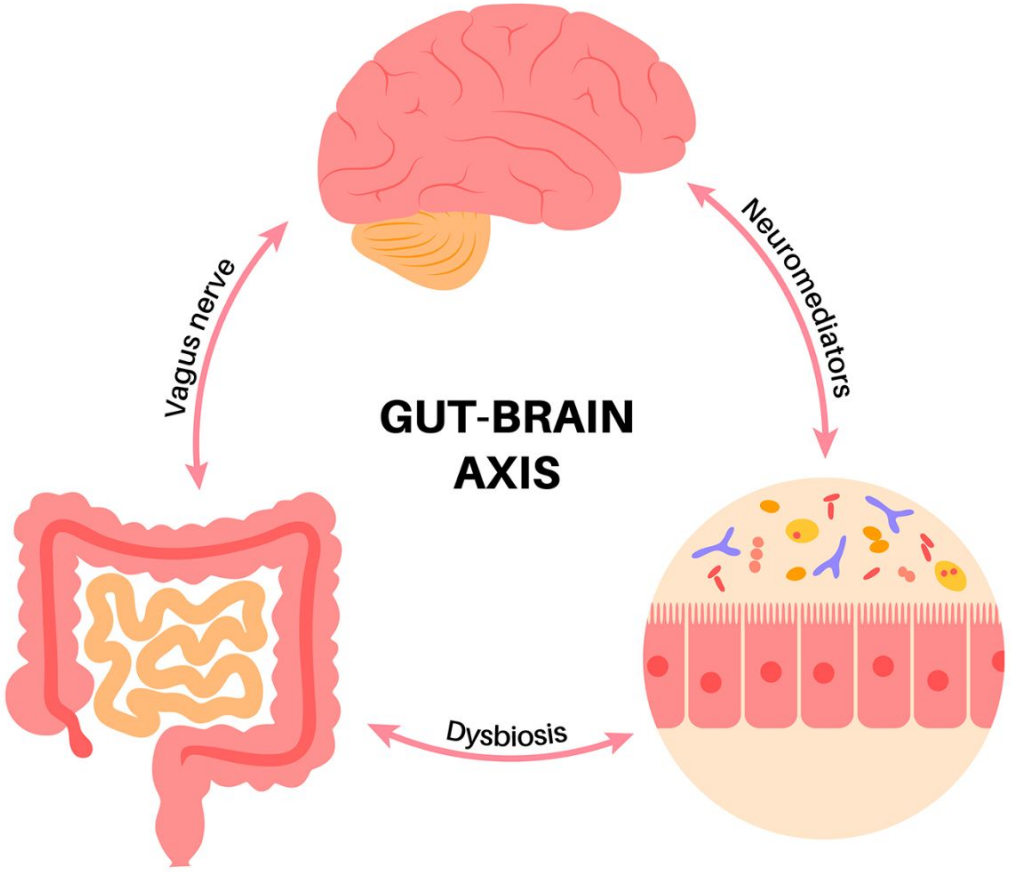
Recent scoping review included 56 studies demonstrated the presence of all three of the main drivers of food avoidance/restriction, although sensory sensitivities are most commonly described in ASD (Bourne et al., 2021)

While there are no ARFID/ASD specific treatment interventions, several case studies have demonstrated the success of core ARFID treatments may be implementable and effective in ASD

Sader, M., Weston, A., Buchan, K., Kerr-Gaffney, J., Gillespie-Smith, K., Sharpe, H., & Duffy, F. (2024). The Co-Occurrence of Autism and Avoidant/Restrictive Food Intake Disorder (ARFID): A Prevalence-Based Meta-Analysis. International Journal of Eating Disorders.

Bourne, L., Mandy, W., & Bryant-Waugh, R. (2022). Avoidant/restrictive food intake disorder and severe food selectivity in children and young people with autism: A scoping review. Developmental Medicine & Child Neurology, 64(6), 691-700.

Disorders of Gut-Brain Interaction (DGBI)



https://bpb-us-e1.wpmucdn.com/sites.dartmouth.edu/dist/0/2024/files/2024/12/aditi_gutbrainaxis.png

ASD & DGBI

In a retrospective study, nearly ⅓ of patients seen through an ASD-specific clinic were found to have functional GI condition (Penzol et al., 2019)

In a separate retrospective study, 60.3% of patients with ASD who were evaluated in a pediatric GI clinic were diagnosed with a functional GI condition (Mostafavi et al., 2024)

Penzol, M. J., Salazar de Pablo, G., Llorente, C., Moreno, C., Hernández, P., Dorado, M. L., & Parellada, M. (2019). Functional gastrointestinal disease in autism spectrum disorder: a retrospective descriptive study in a clinical sample. Frontiers in psychiatry, 10, 179.

Mostafavi, M., & Sayej, W. (2024). Characterization of Initial Gastrointestinal Evaluation of Children with Autism Spectrum Disorder: A Descriptive Study. Journal of Autism and Developmental Disorders, 1-6.

ASD & Constipation

Predominant GI symptom associated with ASD

Chronic constipation does not appear to be associated with a higher rate of abnormal colonic motility in ASD children than in non-ASD children (Coe et al., 2023)

- Functional constipation

TABLE 1. Rome IV Criteria for the Diagnosis of Functional Constipation[4]

Criteria for Functional Constipation Diagnosis
Onset of constipation symptoms at least 6 months before diagnosis Below criteria met for the past 3 months
I. Two or more of the following criteria must be present: a. Straining with >25% of defecations b. Lumpy or hard stools with >25% of defecations i. Bristol stool form types 1 and 2 c. Sensation of incomplete evacuation with >25% of defecations d. Sensation of anorectal obstruction/blockage with >25% of defecations e. Manual maneuvers required with >25% of defecations i. Eg, digital evacuations, support for the pelvic floor f. Fewer than 3 spontaneous defecations per week
II. Loose stools are rare without administration of laxatives
III. Insufficient criteria for irritable bowel syndrome

Adapted from Lacy BE, Mearin F, Chang L. *Gastroenterology.* 2016;150(6):1393-1407.

Coe, A., Ciricillo, J., Mansi, S., El-Chammas, K., Santucci, N., Bali, N., ... & Williams, K. C. (2023). Evaluation of chronic constipation in children with autism spectrum disorder. Journal of Pediatric Gastroenterology and Nutrition, 76(2), 154-159.

ASD & Constipation

Children with ASD were more likely to visit the ED for constipation-related issues compared to children with other chronic conditions or children with no chronic conditions (1.9% vs 0.6% vs 0.9%; $p < .001$)

ED visits for constipation by children with ASD were 1.5 times more likely than children with other chronic conditions and 12.5 times more likely than children with no chronic conditions to result in hospital admission (15.0% vs 10.6% vs 1.2%; $p < .001$)

Results in significant increase in cost and health care utilization

Sparks, B., Cooper, J., Hayes, C., & Williams, K. (2018). Constipation in children with autism spectrum disorder associated with increased emergency department visits and inpatient admissions. The Journal of Pediatrics, 202, 194-198.

Recommendations for Evaluation and Treatment of Common Gastrointestinal Problems in Children With ASDs

AUTHORS: Timothy Buie, MD,[a,b,c] George J. Fuchs, III, MD,[d] Glenn T. Furuta, MD,[e,f] Koorosh Kooros, MD,[g] Joseph Levy, MD,[h] Jeffery D. Lewis, MD,[i] Barry K. Wershil, MD,[j] and Harland Winter, MD[a,c]

[a]Department of Pediatrics, Harvard Medical School, Boston, Massachusetts; [b]Learning and Development Disabilities Evaluation and Rehabilitation Services, Lexington, Massachusetts; [c]Division of Pediatric Gastroenterology and Nutrition, MassGeneral Hospital for Children, Boston, Massachusetts; [d]Division of Pediatric Gastroenterology, Hepatology, and Nutrition, University of Arkansas for Medical Sciences, UAMS College of Medicine and Arkansas Children's Hospital, Little Rock, Arkansas; [e]Keck School of Medicine of USC, Los Angeles, California; [f]Section of Pediatric Gastroenterology, Hepatology and Nutrition, Children's Hospital Denver, Aurora, Colorado, Department of Pediatrics, National Jewish Health, Denver, Colorado; and Department of Pediatrics, University of Colorado Denver School of Medicine, Aurora, Colorado; [g]Division of Pediatric Gastroenterology and Nutrition, Golisano Children's Hospital at Strong, University of Rochester Medical Center, Rochester, New York; [h]Department of Pediatrics (Administration), NYU Lagone Medical Center, New York University School of Medicine, New York, New York; [i]Children's Center for Digestive Health Care, LLC, Atlanta, Georgia; and [j]Division of Gastroenterology, Hepatology and Nutrition, Children's Memorial Hospital, Northwestern University's Feinberg School of Medicine at Northwestern, Chicago, Illinois

KEY WORDS

autism spectrum disorder, abdominal pain, constipation, diarrhea, gastroesophageal reflux disease

abstract

Children with autism spectrum disorders (ASDs) can benefit from adaptation of general pediatric guidelines for the diagnostic evaluation of abdominal pain, chronic constipation, and gastroesophageal reflux disease. These guidelines help health care providers determine when gastrointestinal symptoms are self-limited and when evaluation beyond a thorough medical history and physical examination should be considered. Children with ASDs who have gastrointestinal disorders may present with behavioral manifestations. Diagnostic and treatment recommendations for the general pediatric population are useful to consider until the development of evidence-based guidelines specifically for patients with ASDs. *Pediatrics* 2010;125:S19–S29

Buie, T., Fuchs III, G. J., Furuta, G. T., Kooros, K., Levy, J., Lewis, J. D., ... & Winter, H. (2010). Recommendations for evaluation and treatment of common gastrointestinal problems in children with ASDs. Pediatrics, 125(Supplement_1), S19-S29.

TABLE 4 Differential Diagnosis of Constipation

- Nonorganic
  - Developmental
    - Cognitive handicaps
    - Attention deficit disorders
  - Situational
    - Coercive toilet training
    - Toilet phobia
    - School bathroom avoidance
    - Excessive parental interventions
    - Sexual abuse
    - Other
  - Depression
  - Constitutional
    - Colonic inertia
    - Genetic predisposition
  - Reduced stool volume and dryness
    - Low fiber in diet
    - Dehydration
    - Underfeeding or malnutrition
- Organic
  - Anatomic malformations
    - Imperforate anus
    - Anal stenosis
    - Anterior displaced anus
    - Pelvic mass (sacral teratoma)
  - Metabolic and gastrointestinal
    - Hypothyroidism
    - Hypercalcemia
    - Hypokalemia
    - Cystic fibrosis
    - Diabetes mellitus
    - Multiple endocrine neoplasia type 2B
    - Gluten enteropathy
  - Neuropathic conditions
    - Spinal cord abnormalities
    - Spinal cord trauma
    - Neurofibromatosis
    - Static encephalopathy
    - Tethered cord
  - Intestinal nerve or muscle disorders
    - Hirschsprung disease
    - Intestinal neuronal dysplasia
    - Visceral myopathies
    - Visceral neuropathies
  - Abnormal abdominal musculature
    - Prune belly
    - Gastroschisis
    - Down syndrome
  - Connective tissue disorders
    - Scleroderma
    - Systemic lupus erythematosus
    - Ehlers-Danlos syndrome
  - Drugs
    - Opiates
    - Phenobarbital
    - Sucralfate
    - Antacids
    - Antihypertensives
    - Anticholinergics
    - Antidepressants
    - Sympathomimetics
  - Other
    - Heavy-metal ingestion (lead)
    - Vitamin D intoxification
    - Botulism
    - Cow's milk protein intolerance

Reprinted, with permission from Constipation Guidelines Committee of the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition. *J Pediatr Gastroenterol Nutr*. 2006;43(3):e6.

TABLE 5 Physical Examination of Children With Constipation

- General appearance
- Vital signs
  - Temperature
  - Pulse
  - Respiratory rate
  - Blood pressure
  - Growth parameters
- Head, ears, eyes, nose, throat
- Neck
- Cardiovascular
- Lungs and chest
- Abdomen
  - Distension
  - Palpable liver and spleen
  - Palpable mass
- Anal inspection
  - Position
  - Stool present around anus or on clothes
  - Perianal erythema
  - Skin tags
  - Anal fissures
- Rectal examination
  - Anal wink
  - Anal tone
  - Fecal mass
  - Presence of stool
  - Consistency of stool
  - Other masses
  - Explosive stool on withdrawal of finger
  - Occult blood in stool
- Back and spine examination
  - Dimple
  - Tuft of hair
- Neurologic examination
  - Tone
  - Strength
  - Cremasteric reflex
  - Deep tendon reflexes

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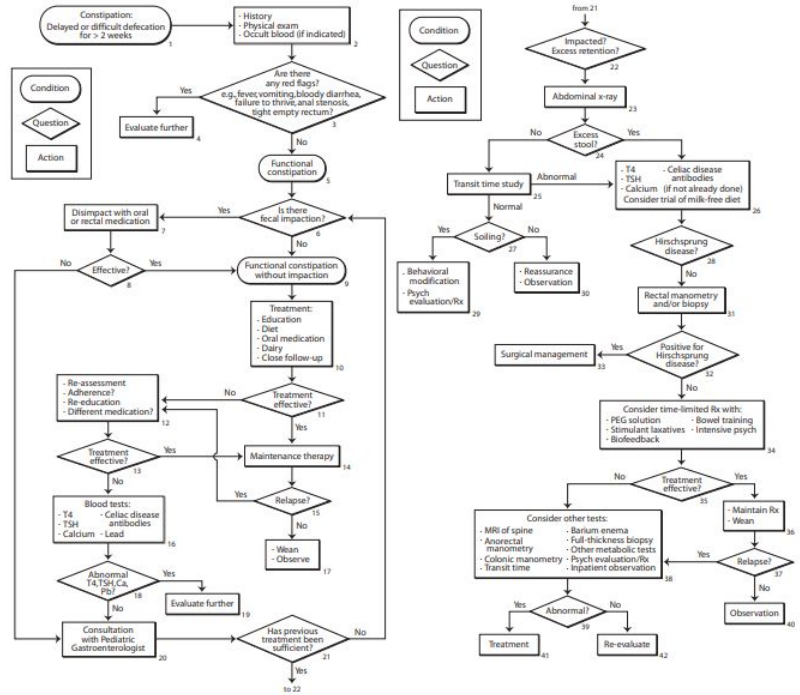


FIGURE 1
Algorithm for the management of constipation in children 1 year of age and older. T4 indicates thyroxine; TSH, thyroid-stimulating hormone/thyrotropin; Ca, calcium; Pb, lead; Rx, therapy; psych, psychological management. (Reprinted with permission from Constipation Guidelines Committee of the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition. *J Pediatr Gastroenterol Nutr*. 2006;43(3):e3.)

TABLE 6 "Red-Flag" Findings in Mitochondrial Disease

Organ System	Selected Findings
Neurologic	Cerebral stroke-like lesions in nonvascular pattern
	Basal ganglia disease
	Encephalopathy
	Neurodegeneration
	Myoclonus
Cardiovascular	Hypertrophic cardiomyopathy with rhythm disturbance
	Unexplained heart block in child
	Cardiomyopathy with lactic acidosis (>5 mM)
	Dilated cardiomyopathy with muscle weakness
Ophthalmologic	Retinal degeneration with signs of night blindness, color-vision deficits, decreased visual acuity
	Ophthalmoplegia/paresis
	Fluctuating, disconjugate eye movements
	Ptosis
Gastrointestinal	Unexplained or valproate-induced liver failure
	Severe dysmotility
	Pseudo-obstructive episodes
Other	Unexplained hypotonia, weakness, FTT, and a metabolic acidosis (particularly lactic acidosis) in newborn, infant, or young child
	Hypersensitivity to general anesthesia

FTT indicates failure to thrive.
Adapted with permission from Haas RH, Parikh S, Falk MJ, et al. *Pediatrics*. 2007;120(6):1326–1333.

TABLE 7 Baseline Screening Tests For Mitochondrial Disease: Initial Evaluation

Metabolic Screening of Blood and Urine for All Patients	Assessment of Systemic Involvement for All Patients	Metabolic Screening of Spinal Fluid for Patient With Neurologic Symptoms	Clinical Neurogenetic Evaluation for Patient With Developmental Delay
Basic chemistries	Echocardiogram	Lactate and pyruvate	Karyotype
Liver enzymes and ammonia	ECG	Quantitative amino acids	Fragile X syndrome testing
CBC	Ophthalmologic examination	Routine studies, including cell count, glucose, and protein measurement	Child neurology consult
Creatinine kinase	Audiology testing		Genetics consult
Blood lactate, pyruvate, and lactate/pyruvate ratio	Brain MRI		
Quantitative blood amino acids			
Quantitative urine organic acids			
Plasma acylcarnitine analysis			

Negative test results have a high false-negative rate. Thus, if the results are abnormal or if mitochondrial disease is still suspected, refer the patient to a mitochondrial center. CBC indicates complete blood count; ECG, electrocardiogram; MRI, magnetic resonance imaging.
Adapted with permission from Haas RH, Parikh S, Falk MJ, et al. *Pediatrics*. 2007;120(6):1326–1333.

TABLE 8 Medications for Use in Treatment of Constipation in Children

Medication	Dosage	Comments
Lactulose (70% solution)	1–3 mL/kg per d in divided doses	Well tolerated
Sorbitol (70% solution)	1–3 mL/kg per d in divided doses	Similar to lactulose but less expensive
Magnesium hydroxide (400 mg/5 mL, 800 mg/5 mL, or tablets)	3 mL/kg per d	Monitor for Mg toxicity, hypophosphatemia, hypocalcemia
Magnesium citrate (liquid, 16.17% Mg)	<6 y of age: 1–3 mL/kg per d; 6–12 y of age: 100–150 mL/d in single or divided doses; >12 y of age: 150–300 mL/d in single or divided doses	Monitor for Mg toxicity, hypophosphatemia, hypocalcemia
PEG 3350	1–1.5 g/kg per d for 3 d; maintenance: 1 g/kg per d (usual dose 17 g/d)	Palatable (can be dissolved in most fluids); not approved for use in infants
Phosphate enemas	<2 y of age: to be avoided; ≥2 y of age: 6 mL/kg up to 135 mL	May be psychologically traumatic; may damage rectal wall; may cause abdominal distention or vomiting; tetany with hyperphosphatemia/hypocalcemia; avoid if renal disease is present
PEG electrolyte solution	For disimpaction: 25 mL/kg per h (maximum: 1000 mL/h) via nasogastric tube until clear; maintenance: 10 mL/kg per d	Taste is an issue; may cause nausea, bloating, cramps, vomiting
Mineral oil	<1 y of age: not recommended; >1 y of age: maintenance 1–3 mL/kg per d	Safe alternatives are available; should be used only if other agents fail; lipoid pneumonia if aspirated; leakage of stool; concern about impairing absorption of fat-soluble vitamins has not been substantiated clinically
Senna (syrup, 8.8 mg sennosides per 5 mL)	2–6 y of age: 2.5 mL/d; >12 y of age: 5–15 mL/d	May cause permanent nerve or muscle damage, hepatitis, melanosis coli
Bisacodyl suppository (10 mg)		May irritate rectal mucosa
Bisacodyl tablets (5 mg)		Abdominal pain, diarrhea, hypokalemia
Glycerin suppositories		Minimal adverse effects except for stress caused from insertion

Mg indicates magnesium.
Adapted with permission from Constipation Guidelines Committee of the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition. *J Pediatr Gastroenterol Nutr*. 2006;43(3):e1–e13.

Potential Aspects of GI Evaluation

- History & Physical Exam
  - Critical to determining what work is indicated
- Laboratory Studies
  - Blood work
  - Stool studies
- Imaging Studies
  - X-ray
  - Ultrasound
  - Cross-sectional imaging (CT scan or MRI)
- Endoscopic Studies
  - Esophagogastroduodenoscopy (EGD)
  - Video capsule endoscopy
  - Sigmoidoscopy
  - Colonoscopy

Endoscopy Social Story

PEDIATRIC GASTROENTEROLOGY AND NUTRITION

MassGeneral Hospital *for* Children

SOCIAL STORY:

I am going to have an endoscopy

A note to caregivers:

This social story outlines a general visit to our pediatric endoscopy unit at Mass General Hospital *for* Children where we perform upper endoscopy (EGD) and colonoscopy procedures. However, the steps may vary depending on your child's medical history and needs. As such, not all sections may apply to your child. For any specific concerns, please reach out to your medical provider to discuss prior to your child's procedure.

You know your child best. This social story was created as a tool to aid in preparing your child for their upcoming procedures. We recommend that you read this first and choose what information you think will be helpful for your child. Please feel free to use and modify this in conjunction with language and other tools your child is familiar with. For instance, the phrase "I am safe" may not be the most successful language in reassuring your child. An abridged daily schedule is provided at the end of this social story. For some, it can additionally be helpful to practice modifications of these steps at home or come for a pre-visit tour. For additional information, please contact your medical provider.

Many children benefit from the use of positive reinforcers, or rewards, after completing a task such as this. We have small prizes for patients to select from to take home. Please feel free to bring additional rewards from home that you feel will be reinforcing for your child. One way to present the idea of a reward to your child is through a token-based system. Please see the customizable tool on the last page of this story that can assist with this.

We understand that coming to the doctor and undergoing a procedure can be stressful. Please bring any comfort items you feel your child would benefit from.

We are committed to ensuring both you and your child have the best experience possible. Please do not hesitate to let us know how we can best support you and your child.

Sincerely,

Your Pediatric Gastroenterology Team at Mass General Hospital *for* Children

Endoscopy Social Story

We are going to drive the car to Mass General Hospital.

We will park the car. We will walk inside the building.

The nurse will check my weight.

I will take off all my clothes. I will put on a hospital gown. I may feel cold. I can use a warm blanket.

IF HAVING ANESTHESIA VIA INTRAVENOUS (IV) LINE

The nurse will push on my hand or arm. The nurse will wrap a blue rubber band around my arm. This will feel tight.

The nurse will clean my arm with a swab. This will feel cold and wet.

Endoscopy Social Story

https://bit.ly/endoscopysocialstory

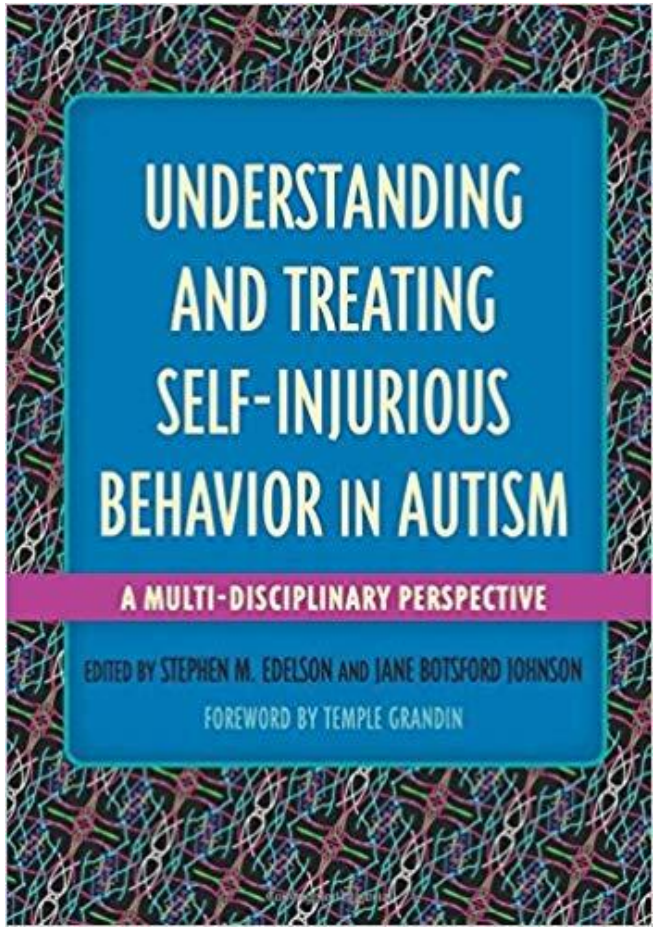
ASD: Non-core features

Includes:

- Irritability
- Oppositional behavior
- Meltdowns
- Self-injurious behavior (SIB)
- Aggression

Generally recognized as common by families and providers

Difficult to characterize and thus poorly evaluated scientifically



Causes of SIB & Aggression

Both physiologic and social/behavioral causes of SIB and aggression in ASD exist, including:

- ***Pain***
- Sensory overload
- Extreme form of self-stimulation
- Autonomic dysfunction (increased reactivity)
- Difficulty and frustration with communication
- Response to behavioral antecedent

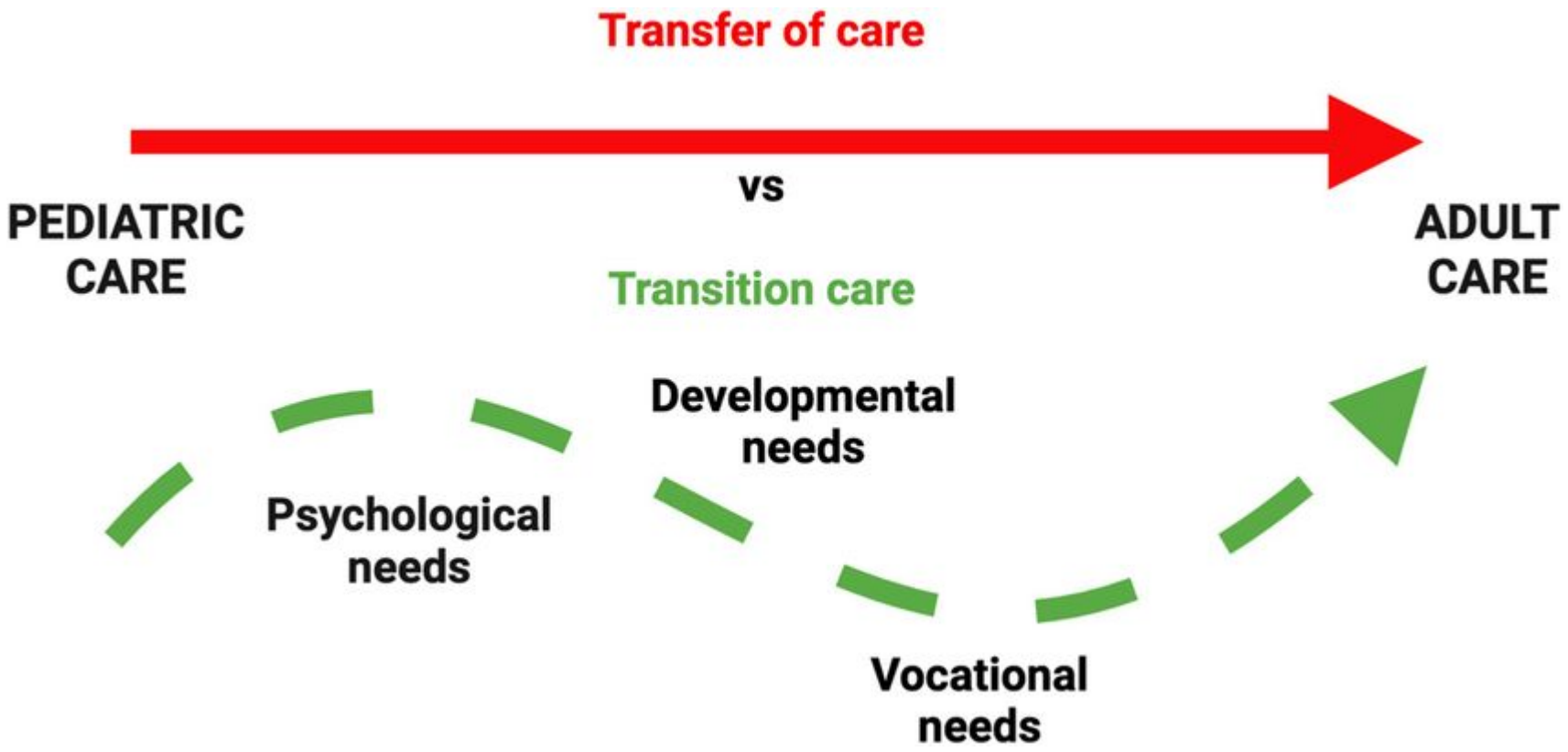
Misinterpreted Behaviors

- Self-injurious behaviors
- Aggression
- Meltdowns
- Gulping or grimacing
- Tapping the chest or stomach
- Pressing on the abdomen
- Refusing to sleep
- Repetitive motions

Causes of SIB & Aggression

A single individual can demonstrate one or many forms of behavioral disturbance, with variable frequency, intensity, duration and causation

Adults with ASD & Transition



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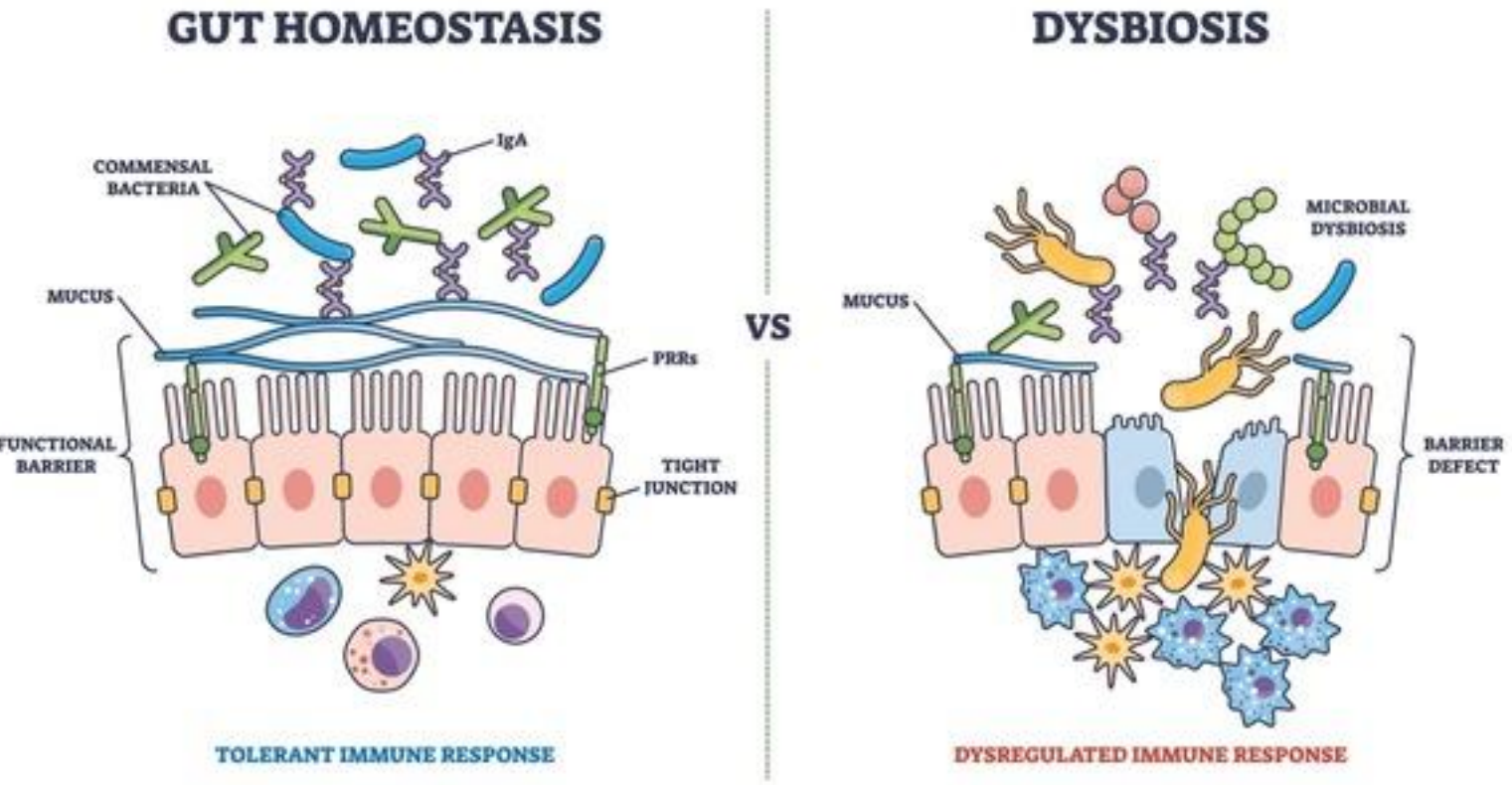
Why the association?



Conclusions

- The majority of individuals with ASD do have associated medical comorbidities, including GI-related symptoms and conditions
- The most frequently associated GI condition are DGBIs; however, other conditions such as GERD, IBD, EGID, and ARFID are also more commonly identified in individuals with ASD
- Comprehensive evaluation of symptoms with the guidance of a gastroenterologist is often necessary, and may be challenging based on the needs of the individual
- Children with ASD become adults with ASD and have unique health needs
- The reason for the association between ASD and GI conditions remains an area of important research

Questions?

Healthcare Equity and Access Concerns in Autism

Free webinar at 1 p.m. Eastern time (US), Wednesday, May 21, 2025

Tune in for a discussion on how to achieve healthcare equity for all persons, including those with autism spectrum disorder and other neurodevelopmental conditions, through effective self-advocacy for providers, patients, and families, while addressing the urgent need for systemic change.

next up...