MENTAL HEALTH NEEDS OF YOUTH WITH NEURODEVELOPMENTAL DISORDERS

TEXAS
The University of Texas at Austin

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Awareness to Action: Supporting Children with NDD and Mental Health Challenges
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What I hope we can do together: Learning Objectives

1. Recognize mental health concerns alongside developmental needs: Describe common co-occurring mental health conditions and unmet care needs among youth with neurodevelopmental disorders

2. Explain why concerns may go unnoticed or be misattributed: Explain how diagnostic overshadowing and developmental or communication differences can contribute to missed or delayed recognition of mental health concerns

3. Identify ways to make assessment accessible to each child: Identify at least three assessment considerations for a young person with new emotional or behavioral difficulties, including changes from usual functioning, physical contributors, and information across settings.

4. Describe a shared response across home, school, and care: Describe at least two strategies to improve access to individualized mental health care through communication adaptations and collaboration with youth, families, and other professionals.

Ethan, age 7



- Autism with intellectual disability and limited speech. Uses AAC.
- Special education program. Needs extensive daily support.
- New self-injury, aggression, sleep problems, and loss of enjoyment.
- “Something is different.” His family wants to understand why.

Sophia, age 15

- Autism without intellectual disability. Fluent speech. General education.
- Strong academics
- Has some friends, but social interaction takes effort.
- Increasing anxiety, exhaustion, withdrawal, and school avoidance.
- School sees a quiet student. Her family sees growing distress.



What has changed for each child

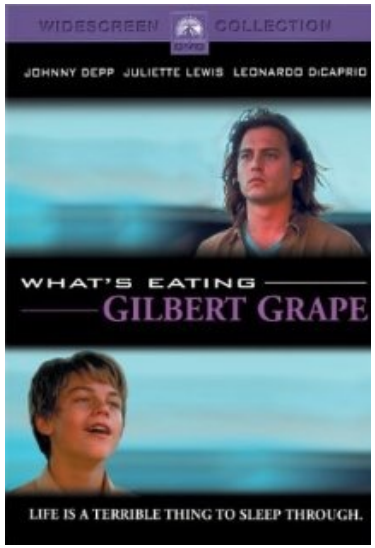
- What is different from this child's usual functioning?
- What might the child be experiencing?
- What do we need to understand before diagnosis and care plan?

Not only emergence of new symptoms (i.e., self-injurious behavior, sleep disruption, anxiety), but changes in functioning and experiences (loss of interests in music, missing schools) provide importance information.

Why autism receives so much attention



Rain Man



What's Eating
Gilbert Grape

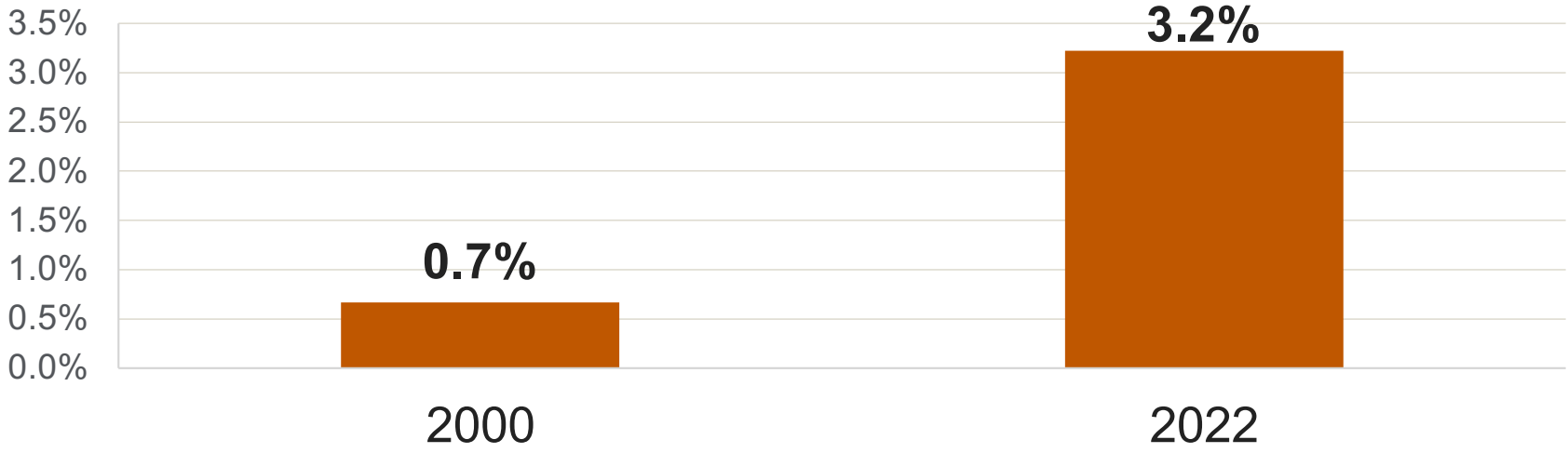


Temple Grandin
Film portrayal



Temple Grandin

More children are being identified

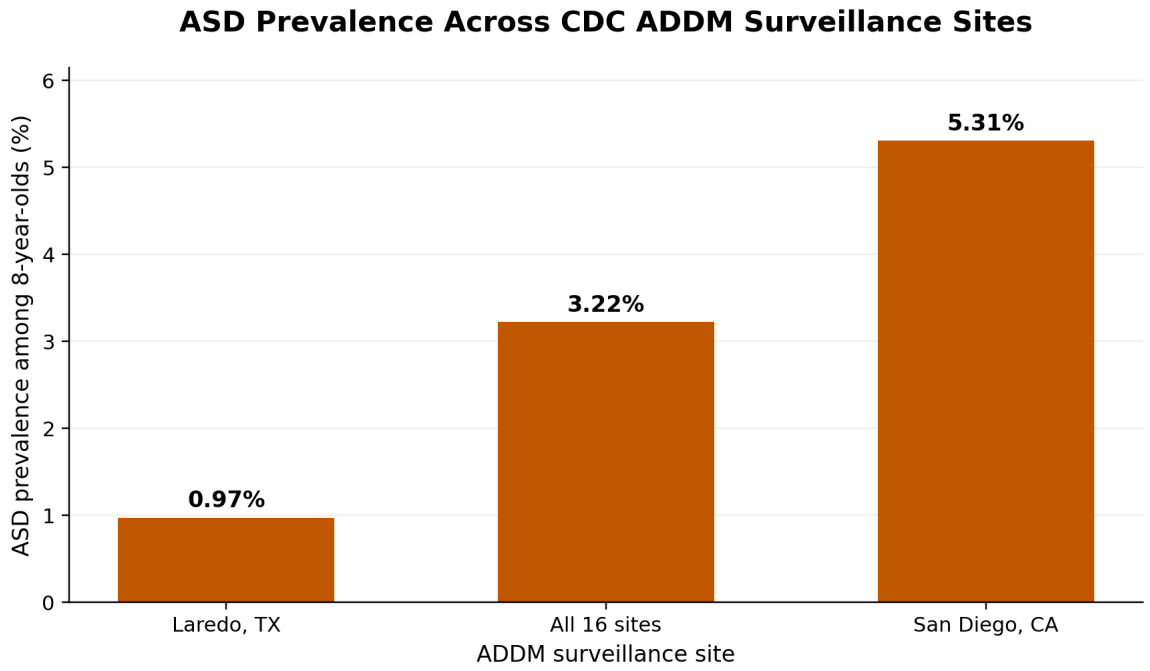


About 1 in 150 in 2000 and 1 in 31 in 2022

8-year-olds in CDC surveillance communities. Sites and methods changed.
These estimates describe identified prevalence, not incidence.

CDC ADDM. Shaw et al., MMWR 2025. 2022 estimate: 16 sites.

2025 CDC Report: Prevalence variation across sites



Source: CDC ADDM Network, 2022 surveillance (published 2025)

CDC ADDM. Shaw et al., MMWR 2025. 2022 estimate: 16 sites.

What changes the numbers we see

- Diagnostic definitions and public awareness influence recognition.
- Screening, records, and access to services affect who is counted.
- Prevalence describes how common autism is in a population.
- An increase in identification alone cannot establish a change in underlying occurrence.

CDC ADDM 2025; Kim et al., JAMA Pediatrics 2026.

What our Korean study adds





Earlier community study

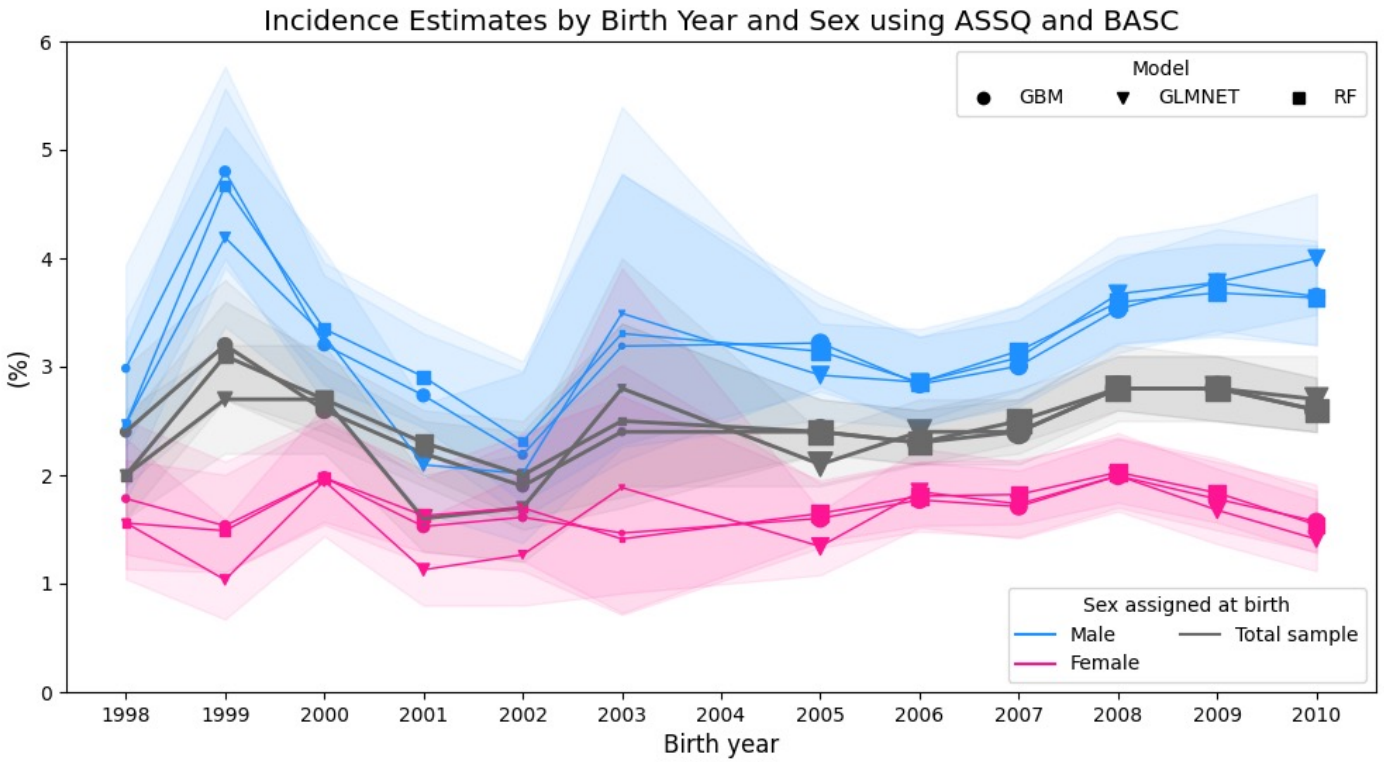
12 consecutive birth cohorts assessed at age seven

Relatively stable cumulative incidence and prevalence (1.9-3.2%)

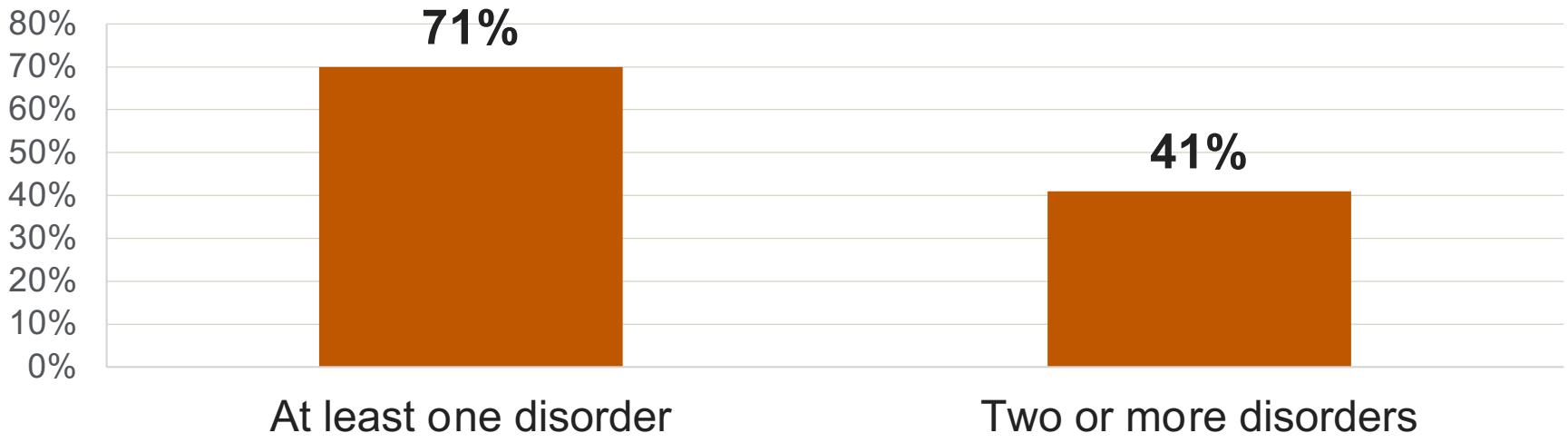
Consistent community ascertainment reaches beyond service records

Kim et al., JAMA Pediatrics 2026. 12 cohorts assessed at age seven.

Annual ASD Incidence of 1998-2010 Birth Cohortd



Co-occurring psychiatric conditions in autism



The Special Needs and Autism Project Sample in US: n = 112, ages 10–14

Simonoff et al., 2008

Children identified outside clinical care

Selected measure	Clinical ASD	Non-clinical ASD
SRS T-score	77 ± 17	66 ± 14
Performance IQ	82 ± 25	97 ± 17
Intellectual disability	33%	6%

Service populations do not capture the full range of children in the community.

Kim et al., JAMA Pediatrics 2026. 12 cohorts assessed at age seven.

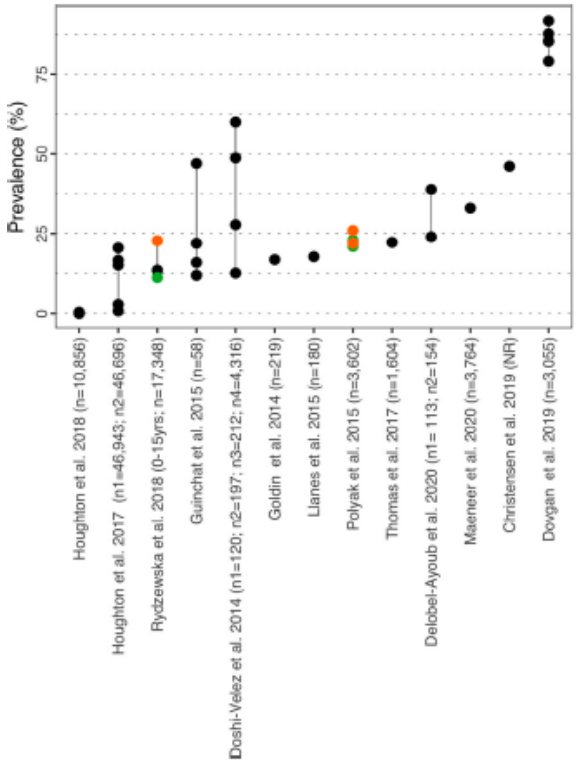
Psychiatric symptoms beyond clinical care

Clinical ASD: n = 105 Non-clinical ASD: n = 342

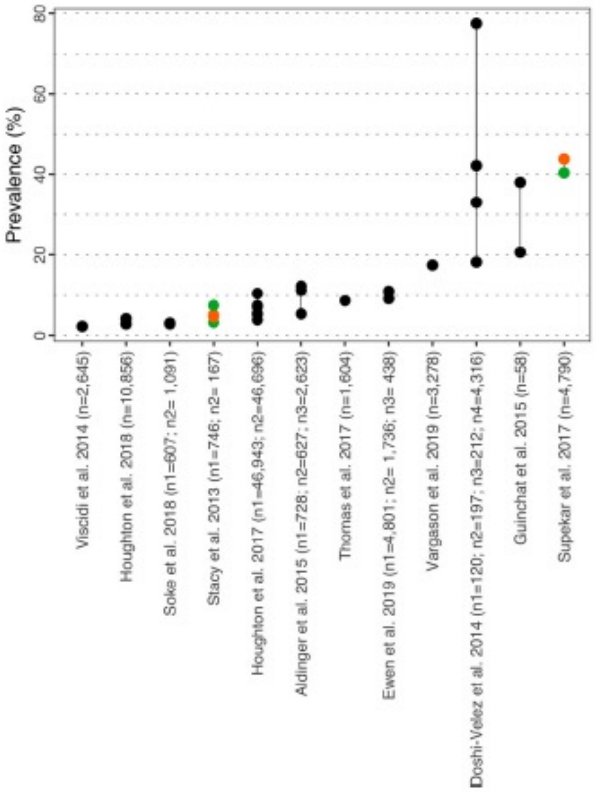
Comorbid Conditions	Clinical ASD	Non-clinical ASD
Mood/Anxiety Disorder	17%	29%
Disruptive Behavior Disorder	61%	48%
Speech Language Disorder	30%	7%

Kim et al., JAMA Pediatrics 2026. 12 cohorts assessed at age seven.

Intellectual disability and epilepsy in autism



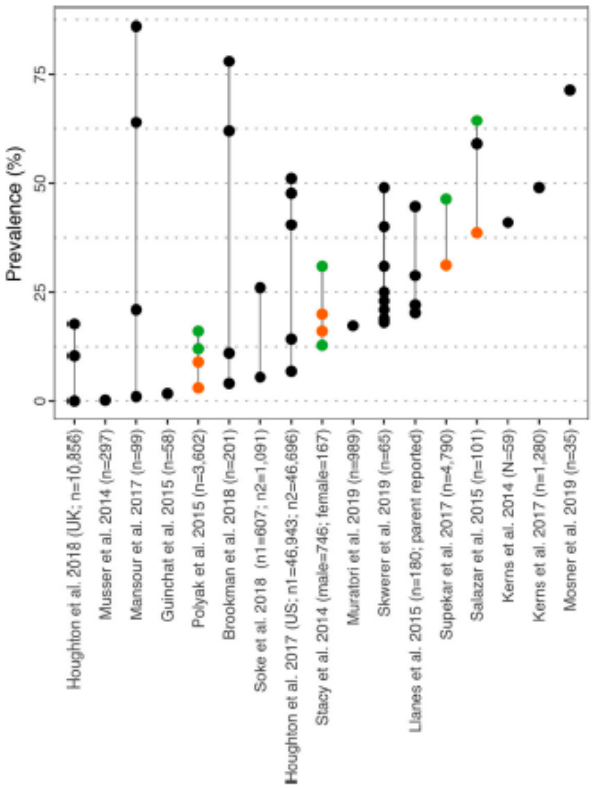
ID: 0–91.7%



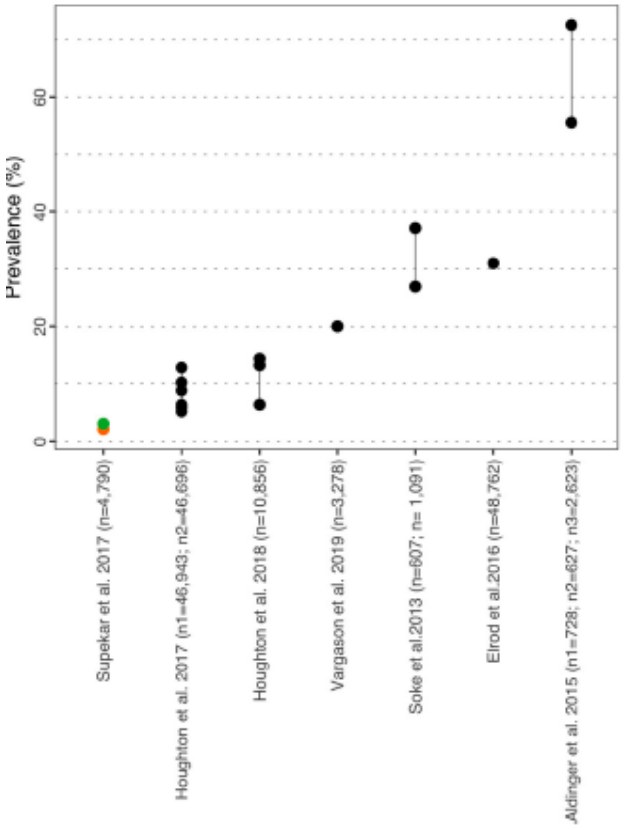
Epilepsy: 2.8–77.5%

Bougeard et al. Front Psychiatry. 2021;12:744709.

ADHD and sleep problems in autism



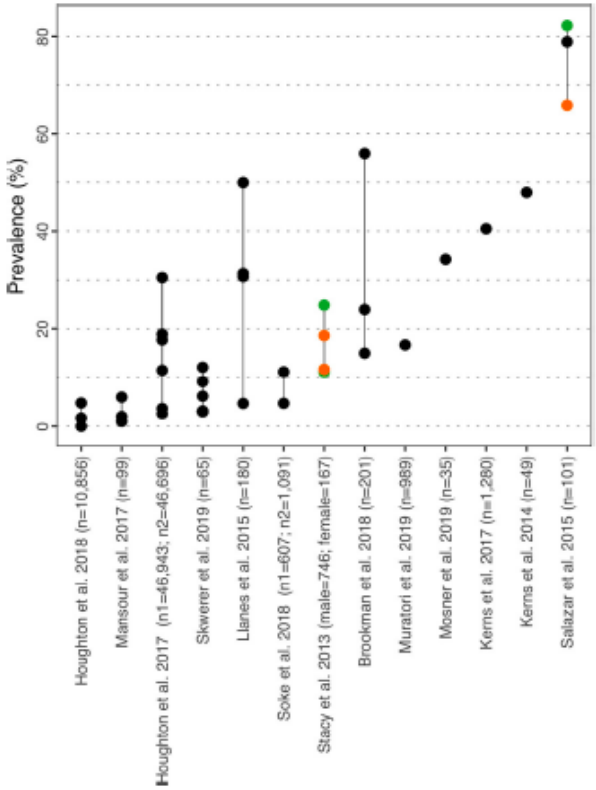
ADHD:
0–86.0%



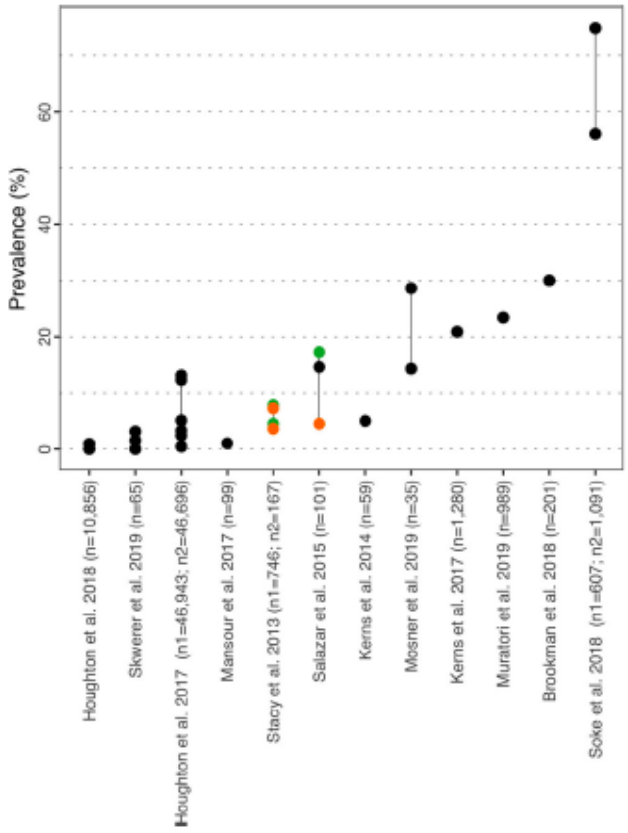
Sleep disorders:
2.08–72.5%

Bougeard et al. Front Psychiatry. 2021;12:744709.

Anxiety and depression in autism



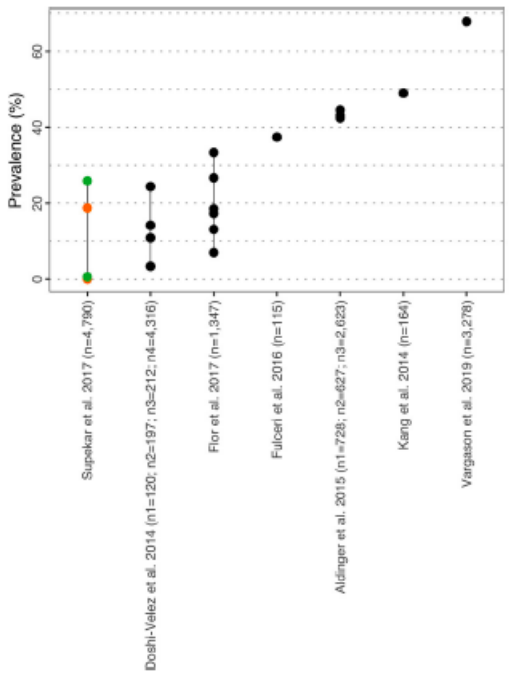
Anxiety:
0–82.2%



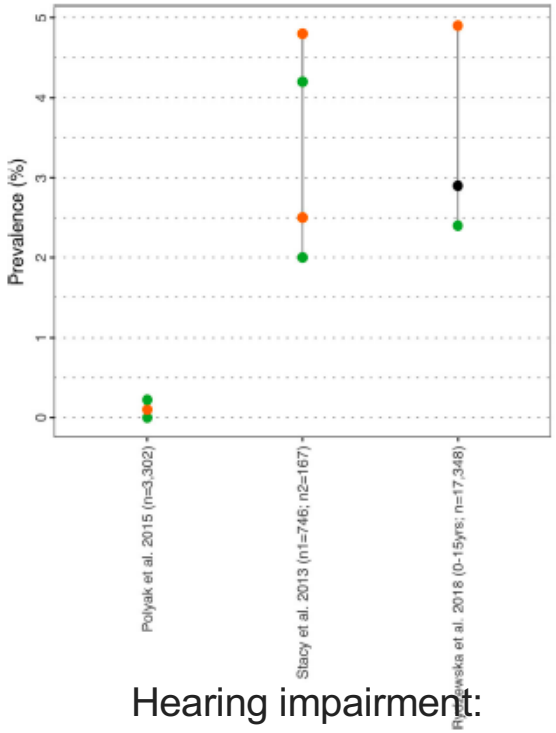
Depressive:
0–74.8%

Bougeard et al. Front Psychiatry. 2021;12:744709.

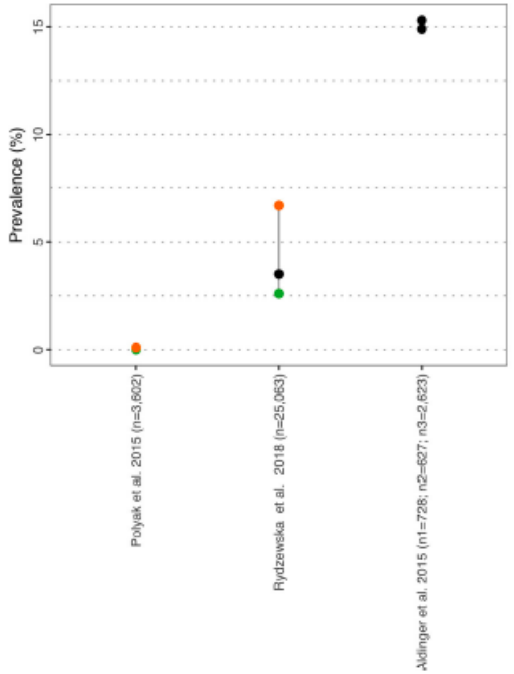
Gastrointestinal and sensory conditions in autism



GI conditions:
0–67.8%



Hearing impairment:
0–4.9%



Vision impairment:
0–14.9%

Bougeard et al. Front Psychiatry. 2021;12:744709.

Syndromic conditions associated with autism

Condition	Chr. / gene	Condition	Chr. / gene
Down	Trisomy 21	Noonan / related RASopathies	SOS1, RAF1, BRAF, KRAS, MAP2K1
Turner / Klinefelter	45,X / 47,XXY	CHARGE	CHD7
Williams	7q11.23	Angelman	UBE3A
DiGeorge / VCFS	22q11.2	Rett	MECP2
Phelan-McDermid	22q13	Creatine transporter deficiency	SLC6A8
Smith-Magenis / Potocki-Lupski	17p11.2	Lesch-Nyhan	HPRT1
Fragile X	FMR1	2q23.1 deletion	MBD5
Tuberous sclerosis	TSC1 / TSC2	Sotos	NSD1
PTEN-related conditions	PTEN	Cortical dysplasia / focal epilepsy	CNTNAP2
Timothy	CACNA1C	Pitt-Hopkins	TCF4
Smith-Lemli-Opitz	DHCR7	Lujan-Fryns	MED12
Phenylketonuria	PAH	ARX-related disorders	ARX

Associations and clinical features vary. An individual assessment remains essential.

Why psychiatric comorbidities matter

- Autism does not protect a child from psychiatric illness.
- Overlapping symptoms can make diagnosis difficult, including OCD and stereotypies.
- Medication needs a clear target linked to distress or impaired functioning.
- Treatment principles may be similar, with adaptations for the individual child.

Why children sometime do not access to appropriate care

- A developmental diagnosis may overshadow a new concern.
  - Limited speech can make distress harder to understand.
  - Diagnostic overshadowing: worsening of ASD symptoms
  - Strong grades may reassure adults while an adolescent struggles.
  - Medical, psychiatric, or environmental contributors may receive too little attention
- Families may have to navigate separate systems to find help.

Understanding Ethan's new distress

- When did the episodes begin? What happens around them?
- What has changed in his physical health or sleep?
- What has changed at home, at school, or in his supports?
- How can Ethan tell us what he is experiencing?

Understanding Sophia's distress

- Direct and private conversation with her
  - What does it take for her to get through the school day?
  - Ask about anxiety, mood, bullying, exhaustion, relationship, and safety
- Multiple informants (teachers, parents) information
  - Different demands in different settings
  - teachers see efforts
  - Parents see exhaustion

The child's usual functioning

- What is difference for Ethan or Sophia?
    - When did the change begin, sudden/gradual
    - how much does it affect daily life, only in certain setting or everywhere, impact
- What is different in sleep, enjoyment, participation, or routines compared to their baselines?
- What does the child say or show us?

Similar behavior, different explanations

- **School avoidance** may involve anxiety, bullying, sensory demands, pain, safety issues, or low mood.
- **Repetition** needs context. Is it familiar, comforting, or linked to distress?
- **Inattention** may have several contributors.

The assessment clarifies underlying causes for seemingly identical behavioral presentation, providing clues for interventions.

Hyman SL, Levy SE, Myers SM et al.

Making assessment accessible for each child

- Child's direct participation in assessment:
  - Offer AAC, visual information, clear questions, and processing time as needed
  - Safety assessment: self-harm, SI, abuse
- Use multi-source caregiver information
- Use developmentally, cognitively and language-wise appropriate measures
- Best estimate clinical diagnosis and treatment plan

NICE guidance

A shared understanding of the problem (clinical formulation)

- Separate what we know from what we still need to assess.
  - Ethan: onset of new symptoms (self-injury and sleep disruption), need to address safety, physical discomfort, changes in his environment
  - Sophia: increasing anxiety, withdrawal and onset of school avoidance, need to address her mood, school stress and experiences
- Agree on the next step and who will take it.
  - Further information gathering from caregivers, interview/observations in other settings, testing, collaborations with other specialists
- Choose goals that matter to the child and family.

Care that the child can use: Treatment Plans

- Treat the medical and psychiatric conditions the assessment identifies:
  - Psychological treatment, medication, communication support, changes in environment
- Adapt the intervention to the child's communication and development.
  - Eg) Adapted DBT, CBT for autism and neurodiverse population
- Make the plan workable in the child's everyday settings.
  - Intervention availability, parents can manage schedule, realistic recommendations?
- Review benefit, adverse effects, and progress toward agreed goals.
  - Scarcity of available evidence in specific populations, children and adolescents

An example of adapted treatment and its evidence

- RCT of 167 autistic children, ages 7–13, with interfering anxiety and IQ ≥70.
- Autism-adapted CBT improved the primary anxiety outcome more than standard CBT or usual care.
- The trial does not directly establish effectiveness for Ethan's profile or Sophia's age.

Wood JJ, et al.

Ethan's care plan

- Address safety and assess physical discomfort and sleep and treat them
    - Maybe more than one contributing factors to the new symptoms
- Keep his communication supports available and consistent across settings.
- Assess psychiatric concerns and patterns around behavior.
- Medical Home: Agree on follow-up across home, school, and clinical care.

NICE guidance

Sophia's care plan

- Hear her own experiences:
  - Mood, anxiety, school stress, and safety.
- Select treatment that fits her assessment and development.
  - Medication, CBT, Trauma-informed CBT, DBT, etc.
- Choose school accommodations with Sophia and her family.
  - Right school choice, difficulties related to specific parts, classes, teachers, peer groups, adults/peer support availability, anticipatory anxiety
- Medical Home: Review wellbeing, participation (school, peer and social interaction, family activities), and symptoms.

Improvement in everyday life: Care is helping!

- Ethan: safer days (fewer self-injurious behaviors), more comfortable sleep, and enjoyment of familiar activities (music, bath).
- Sophia: manageable and less missing school days, less distress, reduced anxiety, more energy for what she values, can ask for help.
- Ask the child and family what improvement would mean to them.
- Review symptoms and daily life together.

What I hope you will remember

- Mental health concerns can occur across developmental profiles.
- A change in functioning deserves careful attention.
- Assessment needs to give each child a way to participate.
- Care needs to fit the condition and the child's developmental and functional level.
- A shared plan across patient, caregivers, and clinicians: no single person has every answer, and it takes a village to raise a child
    - Clinician: attention to new concerns alongside developmental history
    - Caregiver in school/community setting: observations across diverse settings
    - Family member: knowledge of the child's usual life and usual functional capacity

The conversation continues today

- Whose mental health needs might we be missing?
- What would make it easier for this child to receive care?
- How will the young person and family tell us whether it helps?

Discussion

Questions and reflections

Selected references

Simonoff E, et al. Psychiatric disorders in children with autism spectrum disorders. JAACAP. 2008;47:921–929.

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