



Caring for Children with Autism in the Medical Home: Beyond the Diagnosis

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Disclosures

- Nothing to disclose



Learning Objectives

- Analyze the heterogeneous nature of the autism spectrum
- Evaluate the efficacy and appropriateness of various therapeutic interventions
- Identify and manage common medical comorbidities in children with ASD

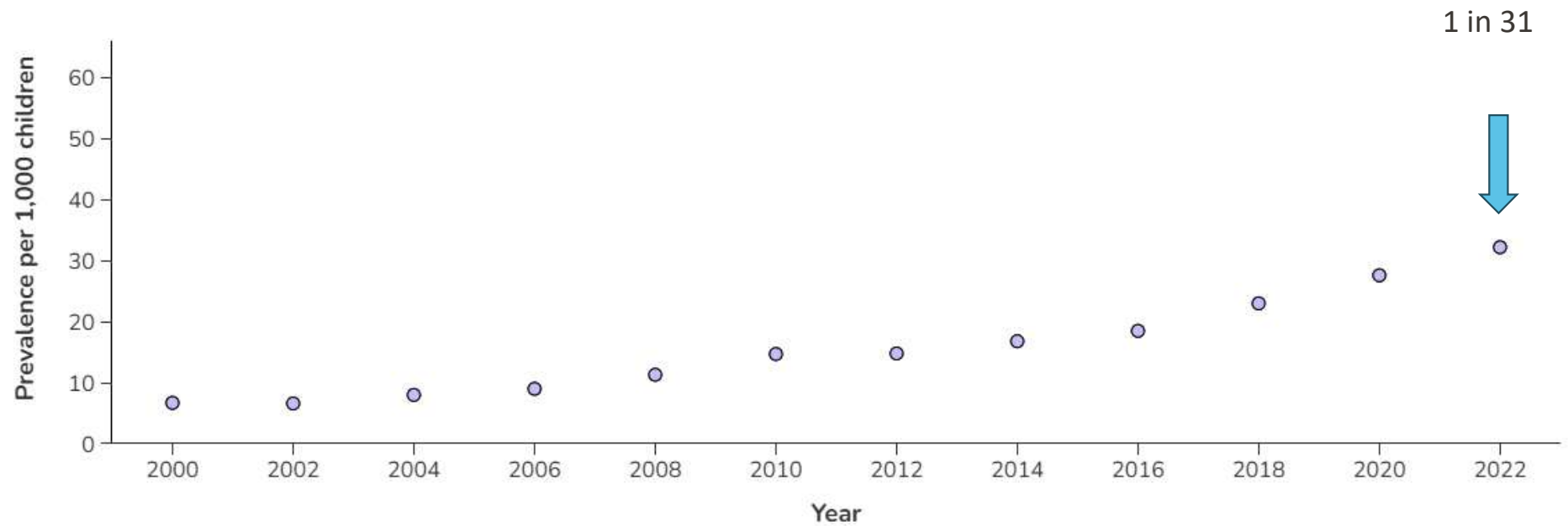




JUST DIFFERENT
NOT LESS



Prevalence of autism over time



<https://www.cdc.gov/autism/data-research/autism-data-visualization-tool.html>

Increasing prevalence

- Diagnostic and Ascertainment Factors
 - Ongoing revisions of the Diagnostic and Statistical Manual of Mental Disorder (now on DSM-V TR)
 - Increased public awareness of diagnosis and symptoms
 - Universal screening (M-CHAT R/F)
- Possible true increase in prevalence?
 - Genetic factors
 - Epigenetic factors



Language Matters

- Identity- & Person-First
 - Autistic person
 - Person with autism
- Preferences often differ based on functional impairment, culture, identity development, etc.

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RESEARCH ARTICLE

Autism-related language preferences of English-speaking individuals across the globe: A mixed methods investigation

Connor Tom Keating¹ | Lydia Hickman¹ | Joan Leung² | Ruth Monk³ |
Alicia Montgomery⁴ | Hannah Heath¹ | Sophie Sowden¹

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DOI: 10.1002/aur.2876

COMMENTARY

A full semantic toolbox is essential for autism research and practice to thrive

Alison Singer¹ | Amy Lutz² | Jill Escher³ | Alycia Halladay^{1,4}

e.g., Barnes (2020); Billawalla & Wolbring (2014); Botha et al. (2023); Bottema-Beutel et al. (2021); Keating et al. (2023); Kenny et al. (2016); King, B. J. (2016, February 25); Lord et al. (2022); Shakespeare (2006); Singer et al. (2022); Vivanti (2020); Woods (2017)

History of autism

- **Leo Kanner – 1943** “Infantile autism”
 - He described:
 - autism—or severe problems in social interaction and connectedness from the beginning of life
 - resistance to change/insistence on sameness.
- **Hans Asperger – 1944** “broader phenotype”
 - He described
 - Social difficulties
 - Circumscribed interests
 - Good verbal skills



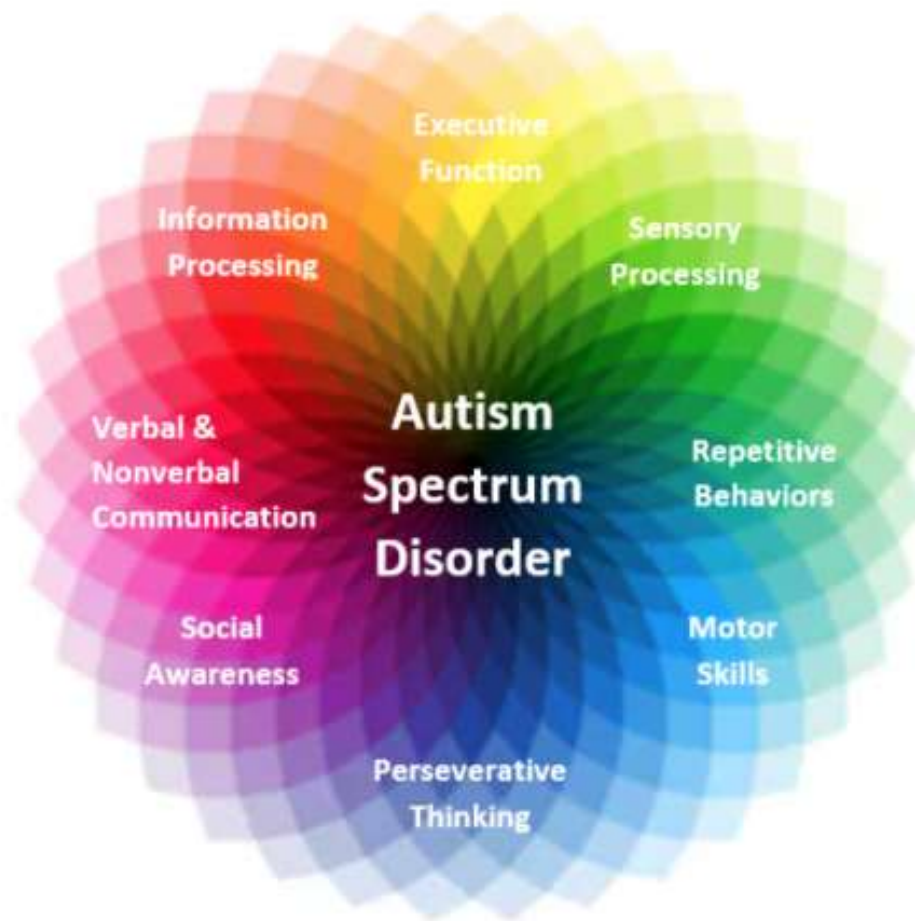
Diagnostic and Statistical Manual of Mental Health Disorders (DSM)



What changed?

- Significant variability in number and severity of autism symptoms between and among subcategories with similar core symptoms
- Poor diagnostic clarity between subgroups
- Increased stigma or restrictions on eligibility for treatment





<https://carmenbpingree.com/blog/what-is-autism-spectrum-disorder/>

What is Autism Spectrum Disorder?

- A neurobiological developmental disorder
 - ‘Persistent deficits in social communication & social interactions’
 - ‘Restricted, repetitive patterns of behavior, interests, or activities’
- A **constellation** of differences in social interaction, communication, & behavior that can present in a **variety** of ways

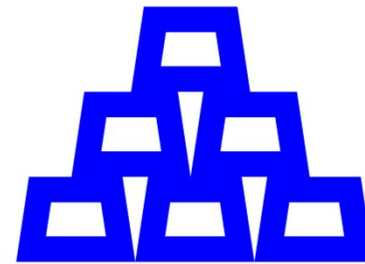


Core criteria



Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history

Social-emotional reciprocity
Nonverbal communication
Relationships



Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history

Stereotyped or repetitive behaviors
Insistence on sameness
Focused interests
Sensory differences

DSM V TR

- Updates to the DSM V – Text Revision (TR)
- Not much
- **From: Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history**
- **To Persistent deficits in social communication and social interaction across multiple contexts, as manifested by ALL OF THE following, currently or by history**

Social Communication

Persistent deficits in social communication and interaction across multiple contexts, as manifested by ***all*** of the following, currently or by history:

1. Deficits in social-emotional reciprocity
2. Deficits in nonverbal communicative behaviors used for social interaction
3. Deficits in developing, maintaining, and understanding relationships



Social Emotional Reciprocity

- Abnormal social approach
- Failure of normal back and forth conversation
- Reduced sharing of interest, emotions, or affect
- Failure to initiate or respond to social interactions



- Shared Enjoyment



Nonverbal communication

- Poorly integrated verbal and nonverbal communication
- Abnormalities in eye contact and body language
- Deficits in understanding and use of gestures
- Lack of facial expressions
- Lack of nonverbal communication

- Nonverbal communication skills

Relationships

- Difficulties adjusting behavior to suit various social contexts
- Difficulties in sharing imaginative play
- Difficulty making friends
- Absence of interest in peers



- Play Skills

Restricted Interests and Repetitive Behavior (RRBs)

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at ***least two*** of the following, currently or by history:

1. Stereotyped or repetitive motor movement, use of objects, or speech
2. Insistence on sameness, inflexible adherence to routine, or ritualized patterns of verbal/nonverbal behavior
3. Highly restricted, fixated interests that are abnormal in intensity or focus
4. Hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment



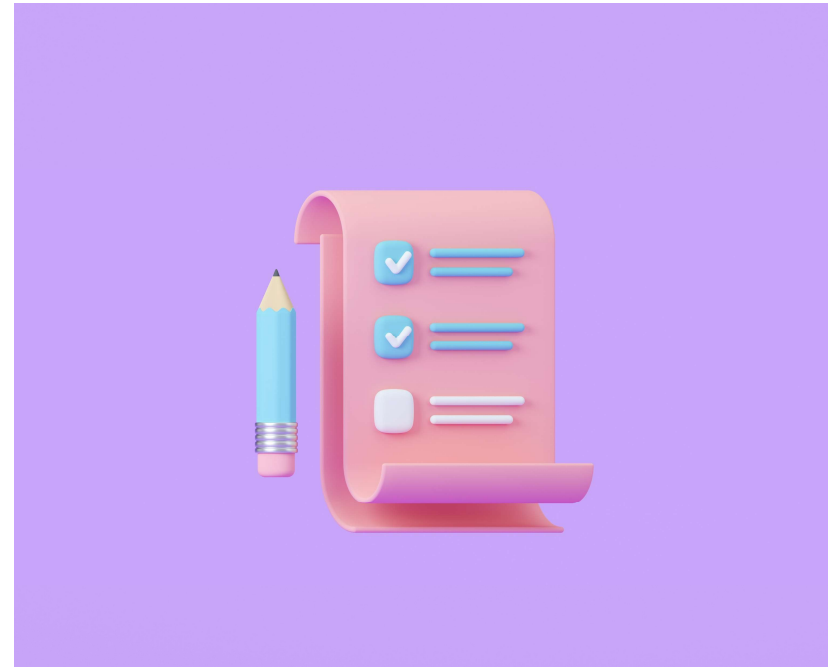
Repetitive behavior

- Stereotyped or repetitive motor movements (hand flapping, rocking back and forth, clapping hands)
- Repetitive use of an objects (lining up toys, putting objects in and out of containers)
- Repetitive language (echolalia, idiosyncratic phrases, jargoning)



Insistence on Sameness

- Need to adhere to routine
- Extreme distress with small changes
- Difficulty with transitions
- Rigid thinking patterns
- Greeting rituals
- Food preference



Restricted Interests

- Focused interests
- Strong attachment to unusual objects
- Perseverative interests

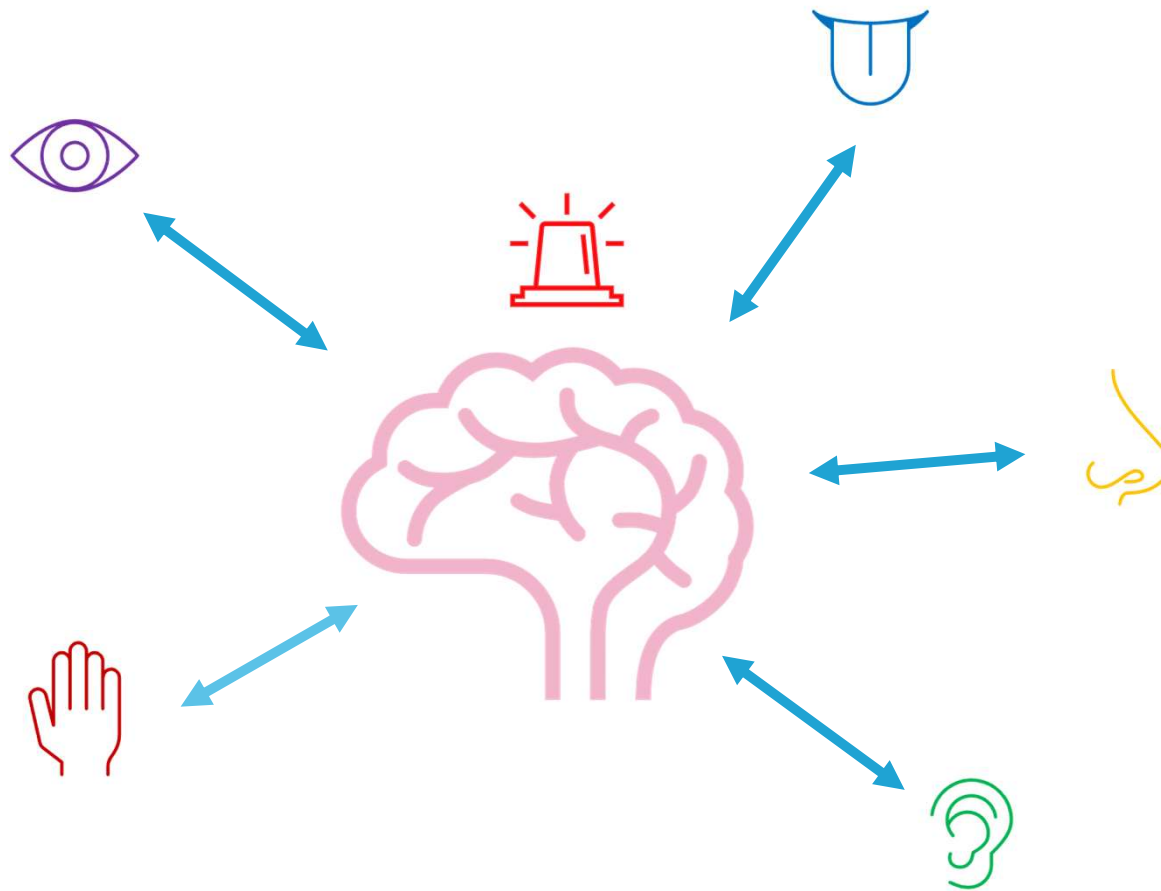


Sensory processing differences

- Hyperreactive to sensory input
 - Loud noises
 - Pain
 - Tactile sensitivity (hair brushing, teeth brushing, tags)
- Hyporeactive to sensory input
 - High pain tolerance
 - Toe walking
 - Deep pressure
- Unusual interest in sensory aspects of the environment
 - Visual inspection

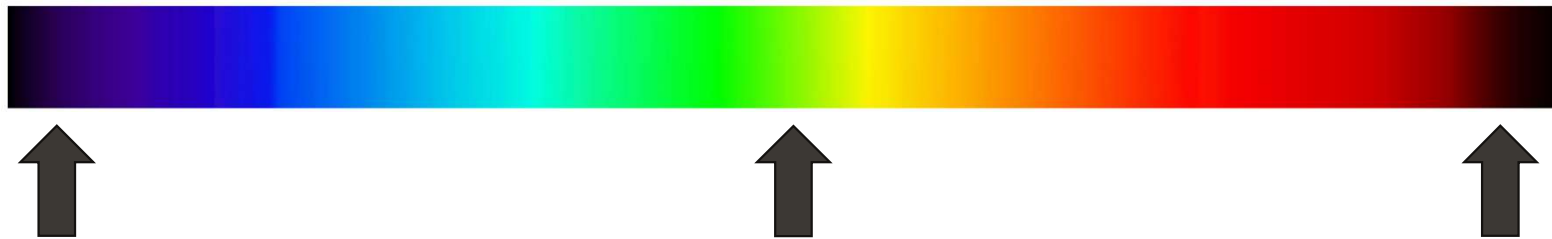


Sensory Processing Differences



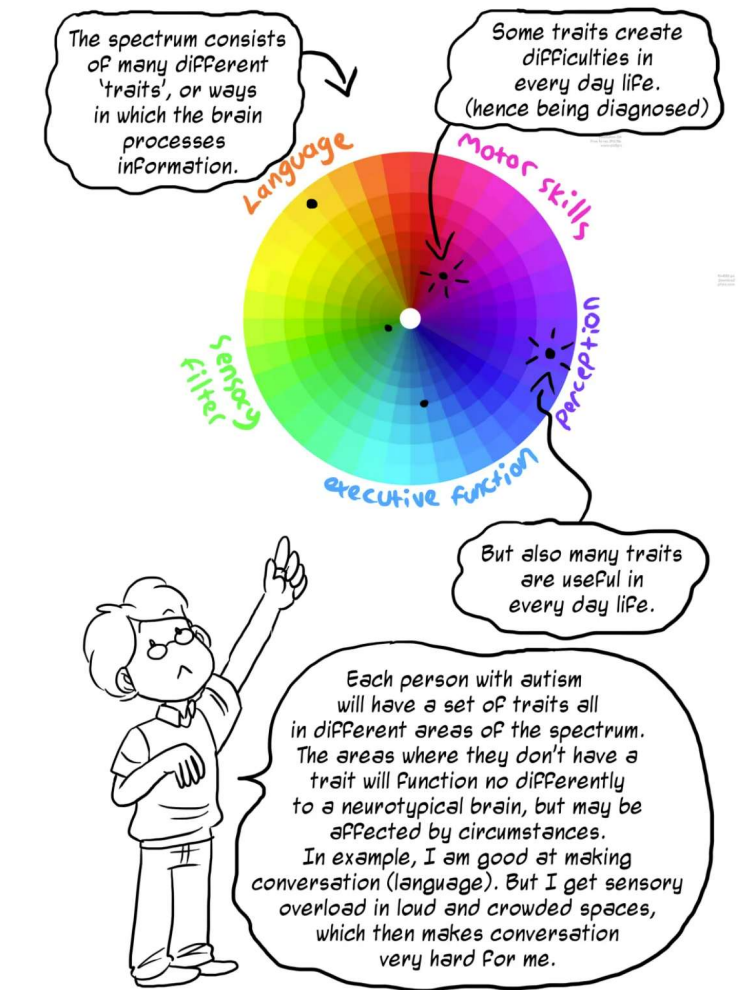
Where is my child “on” the spectrum?

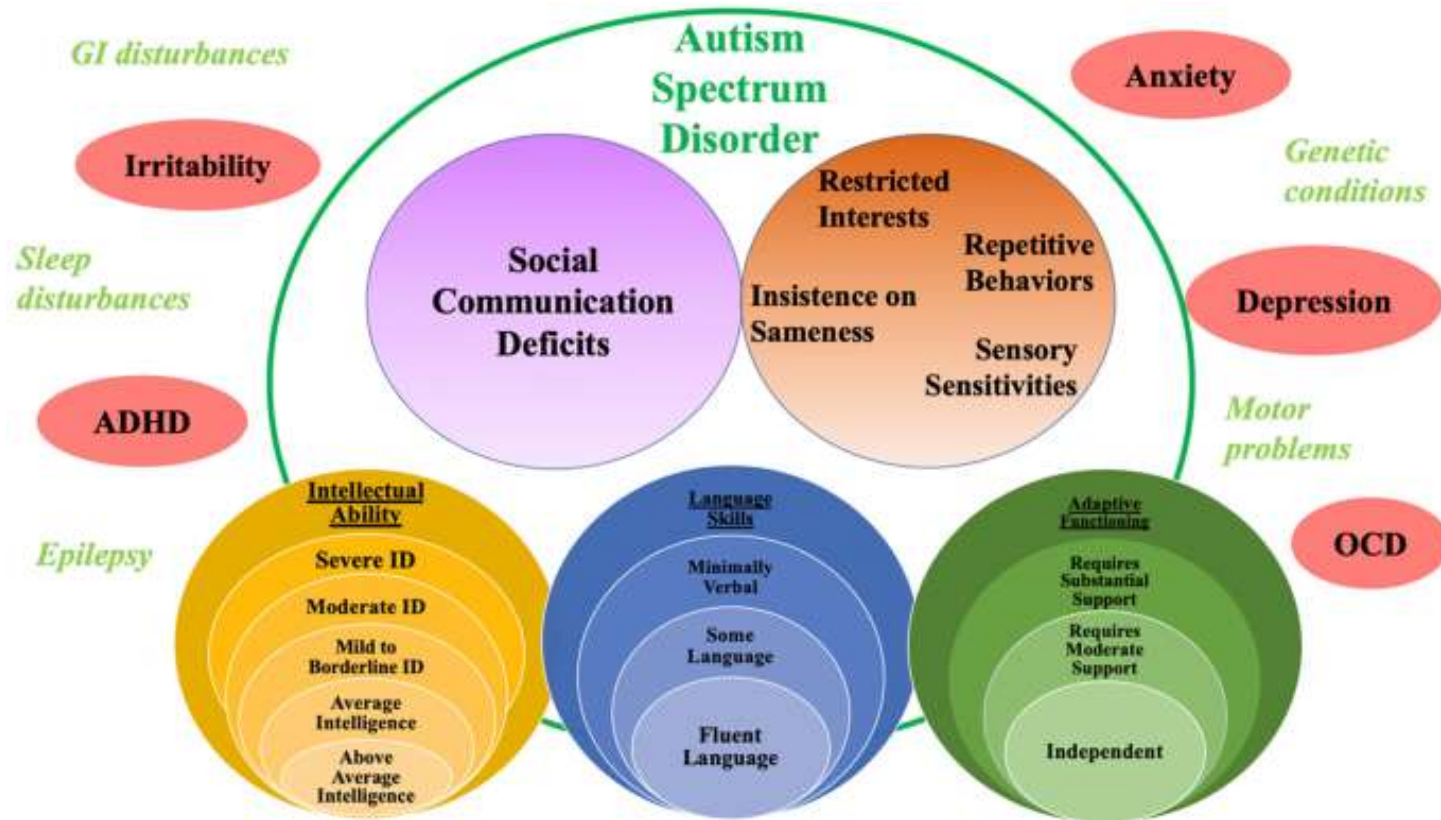
- “Severity Levels” are meant to be assigned separately for both criterion:
‘**Persistent deficits in social communication & social interactions**’
‘**Restricted, repetitive patterns of behavior, interests, or activities**’
 - Level 1: Requiring Support
 - Level 2: Requiring Substantial Support
 - Level 3: Requiring Very Substantial Support



A word on this matter

- These are NOT intended to be
 - A determination of “where” on the spectrum a child is
- Levels of support are
 - Dynamic
 - Moderated by environmental factors and interventions received





Rosen, N. E., Lord, C., & Volkmar, F. R. (2021). The diagnosis of autism: From Kanner to DSM-III to DSM-5 and beyond. *Journal of autism and developmental disorders*, 51, 4253-4270.

Early Detection

- AAP recommends universal screening at 18 and 24 months of age
- Early interventions give the best start possible
- Early interventions improve long term outcomes
 - Maximize developmental gains
 - Reduction in symptom severity
 - Shown to improve effective communication & social reciprocity
- Reach the highest potential

Early Intervention

- Goals may include:
 - Communication skills
 - Cognitive skills
 - Social skills
 - Emotional/behavioral regulation skills
 - Adaptive/Self help skills



Speech therapy

- Expressive and receptive language
 - Vocabulary building
 - Sentence structure
 - Understanding language
- Pragmatic language skills
 - Conversation turn taking
 - Understanding nonverbal cues
 - Using language appropriately in social situations
- Verbal apraxia
 - Specialized techniques for motor planning
- Augmentative and Alternative Communication Device (AAC)
 - PECS
 - Speech Generating Device
 - Sign Language



Illustration by Lindsay Dale-Scott from Denise Underkoffler's book "Everybody Needs a Turn.")

Occupational Therapy

- Sensory integration
 - Sensory diet
 - Hypo/hyper-reactivity to sensory input
- Motor skills
 - Hand strength , dexterity, coordination
 - Core strength
- Activities of Daily Living
 - Toileting
 - Dressing/Grooming
 - Eating
- Emotional Regulation
 - Impulse control
 - Cognitive flexibility
 - Coping strategies
- Visual Perception

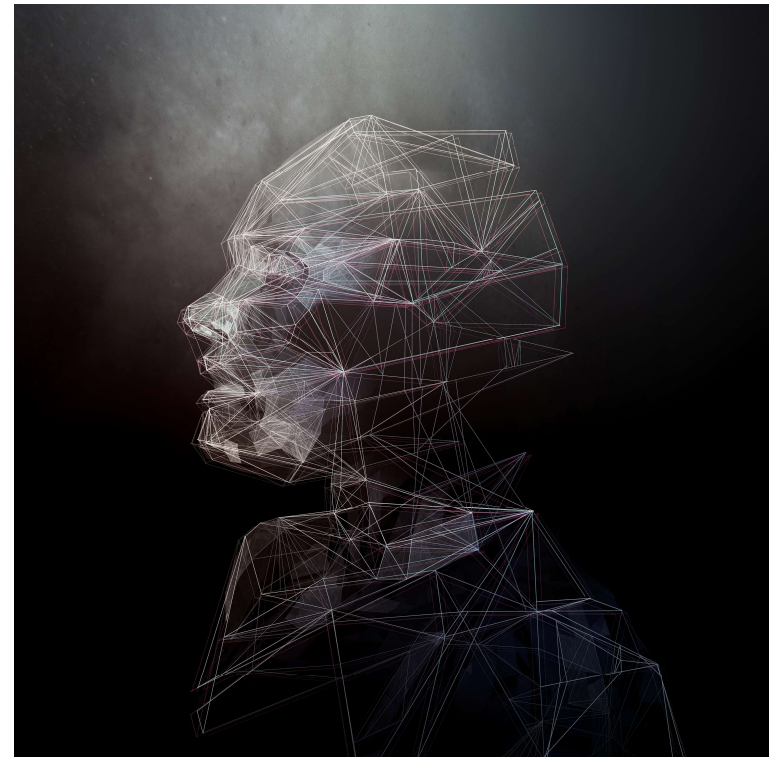
ABA therapy

- Developed in the 1960s
 - Discrete trial training – created to teach skills and modify behavior
- Traditionally recommended for 25-40 hours per week
- Goals to acquire new skills and reduce unwanted behavior over time



But...

- Autistic adults reported:
 - Traumatic experiences
 - Felt that they were being made to be more like their peers
 - Describe mental health concerns and negative consequences
 - Higher rates of masking
 - Did not help build independence



Anderson, 2022

ABA now

- Improvement in cognitive abilities and adaptive skills
- Better understanding of amount of therapy needed
 - Not ALWAYS 40 hours per week
- Naturalistic
 - Child-led
 - Play based
 - Natural consequences
- Neurodiversity affirming
- Developmentally appropriate

- Of note – not all therapists/therapies are created equal
 - Conversation/education with families

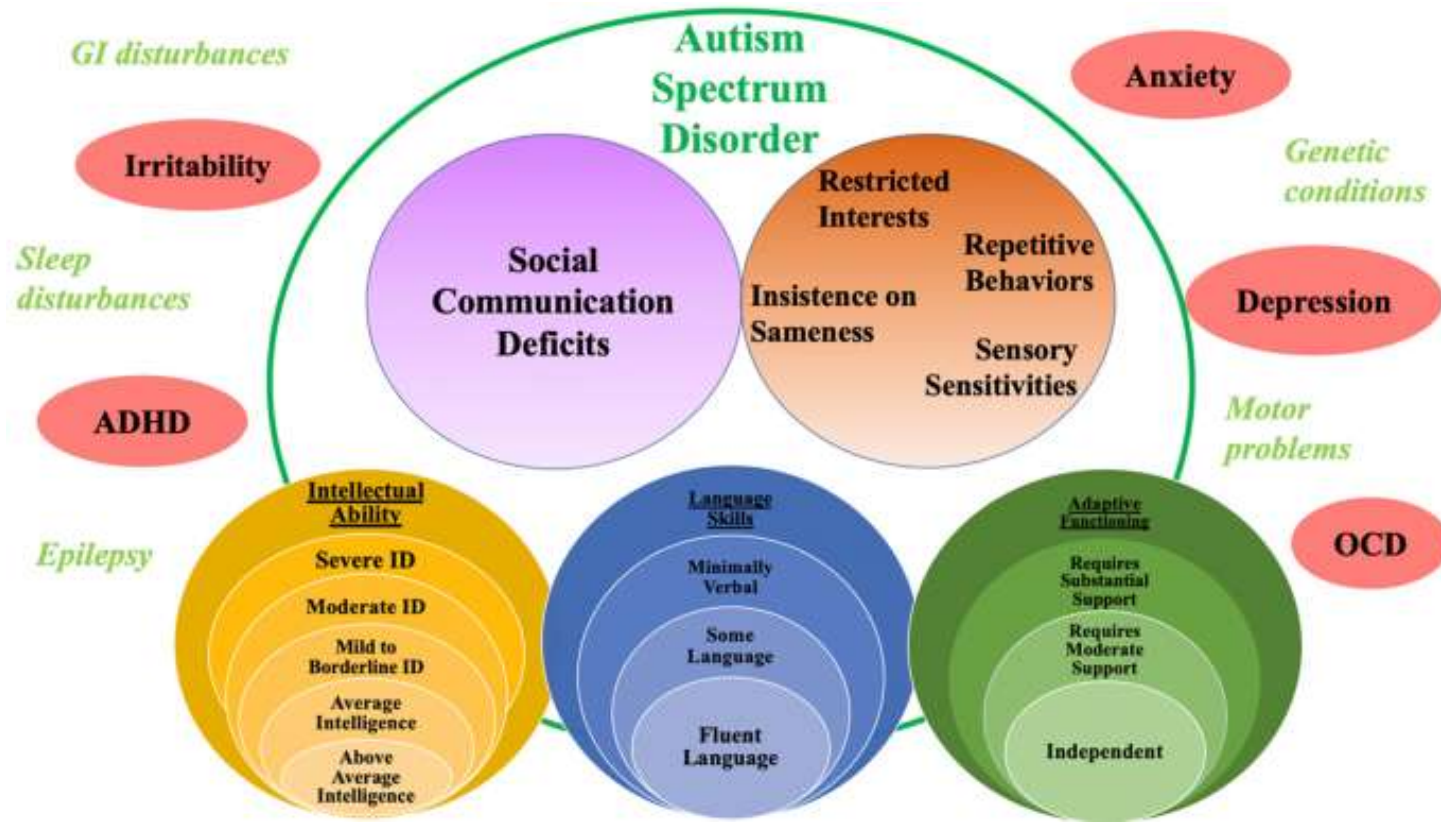
Additional therapies

- Physical therapy
- Feeding/Eating Therapy
- Equine/Hippotherapy
- Music Therapy



Autism and Co-occurring conditions





Rosen, N. E., Lord, C., & Volkmar, F. R. (2021). The diagnosis of autism: From Kanner to DSM-III to DSM-5 and beyond. *Journal of autism and developmental disorders*, 51, 4253-4270.

Understanding co-occurring conditions

- Diagnostic overshadowing
- Behavior is a form of communication
 - Pain
 - Discomfort
 - Feeling unwell
- Any sudden change in behavior should warrant investigation



GI symptoms and Autism

- Relationship between GI issues and autism is well-documented
- Range of symptoms – constipation, diarrhea, abdominal pain, reflux
- Can lead to increased irritability, self-harm, and sleep problems
- Studies looking into microbiotia and genetic factors



<https://blog.prismahealth.org/what-to-do-if-your-child-has-stomach-pain/>

Restrepo et.al., 2020, Hung and Margolis, 2024

Autism and Sleep

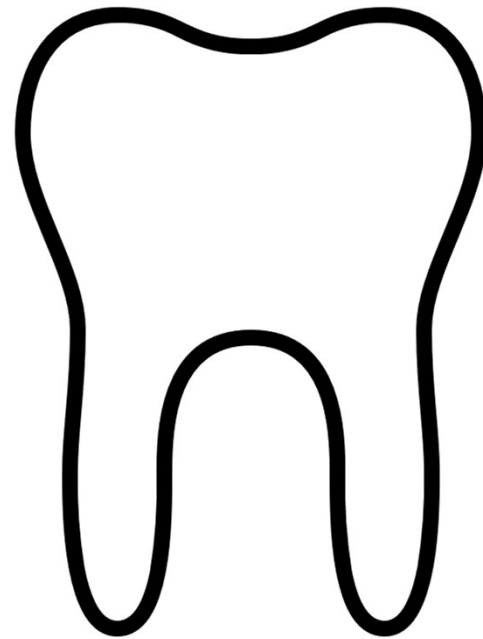
- Sleep disorders are common in children with autism
- 44-83% of children and adolescents with autism report sleep difficulties
- Can have significant impact on day-to-day functioning
- Increasing irritability, behavior concerns, self injurious behaviors, etc.
- Impact on caregivers



Reynolds and Malow, 2011, Buckley et.al., 2020,

Dental concerns in autism

- Sensory sensitivities
 - Challenges with oral health and hygiene
- Dentist offices
 - Sensory overload
- Processed food intake
- Dental health
 - Poorer overall oral health status
 - Higher rates of dental caries
 - Bruxism



Motor Coordination Difficulties

- Risk for motor impairment was present in most children with ASD (86.9%)
- Few were receiving or received physical therapy (31.69%)
- Up to 88% of children with autism have motor impairments
 - <25% receiving therapy
- Motor skills can closely tie into social communication skills
 - Walking → sharing objects with caregiver
 - Head motions → looking toward people
 - Arm movements → pointing and gesturing
- Early intervention in motor coordination can facilitate growth in social/communication skills

Motor coordination in autism

- Evidence supports early access to physical therapy services
- As autistic children get older they would benefit from recreational therapies
 - Yoga
 - Dance
 - Adaptive/recreational sports
 - Outdoor play



Attention Deficit Hyperactivity Disorder (ADHD)

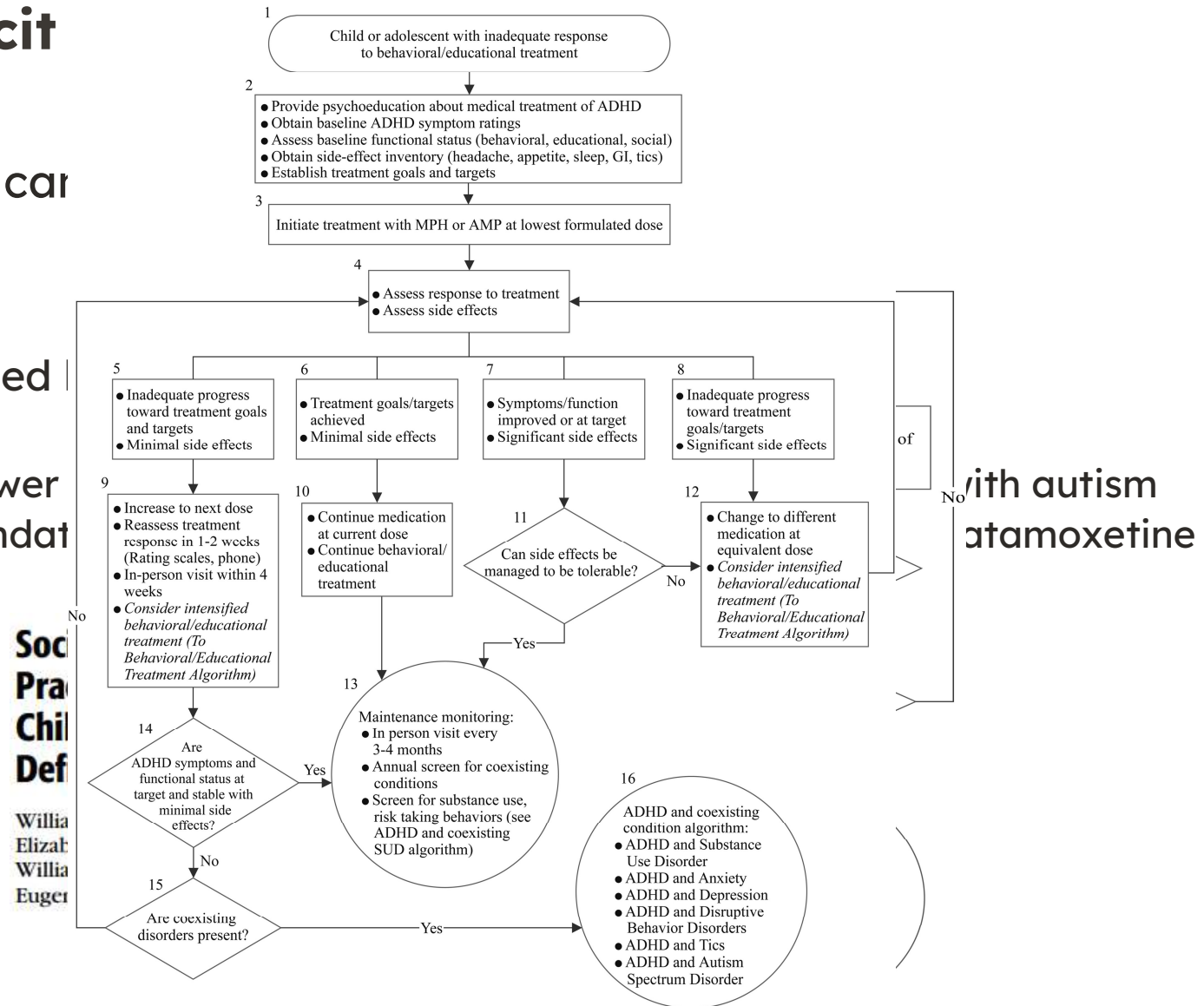
- DSM IV to DSM V → autism and ADHD CAN occur together
- Can sometimes be hard to distinguish
- Standardized tools are not validated in autism
 - Can be used to determine impact of symptoms
 - Monitor progress over time
- For children with autism – ADHD can cause functional impairments
- Important to rule out other factors
 - Speech impairment causing inattention
 - Perseverative interests causing internal distraction



Attention Deficit

- Dual diagnosis car
- Treatment
 - Evidence based
 - Medication
 - Can see lower
 - Recommendation

Complex ADHD General Medication Treatment (Age ≥ 6 years)



Anxiety

- Anxiety disorders seen in children with autism
 - Diagnosis can be more difficult
 - Overlapping symptoms
 - Cognitive and/or language impairments
 - Difficulty reporting of emotions
 - Can manifest as:
 - Behavioral challenges
 - Increased perseverative or stereotyped/repetitive behaviors
 - GI or Sleep disturbances

Anxiety

- Treatment
 - Behavioral interventions are highly valuable

- Various factors

- Medication

- SSRIs are

- Studies
 - Rule of
 - Hyperc
 - *always

- Alpha adrenergic

- Some benefit but not as great as SSRIs

Anxiety, depression	SSRIs ^{469,628}	Anxiety relief has been reported in trials of citalopram and buspirone, with fluvoxamine revealing some effect in female patients with ASD; documented utility in children and youth without ASD
	α-adrenergic (clonidine, guanfacine)	Hyperactivation is an adverse effect of SSRIs in children and youth with ASD that may result in stopping the medication
		The anxiety disorders most amenable to treatment are generalized anxiety disorder, separation anxiety disorder, and social phobias

ety

Complimentary Alternative Treatments

- Alternative treatments have always been part of the autism landscape, and it is important for us to continue to have conversations about this
- List of alternative treatments will not be exhaustive



Important Reminder:

Families are trying to do all that they can do to help their children

They don't want to leave any stone unturned

They are hearing lots of information from LOTS of sources

They need help understanding what they are hearing



Sources of information

- Medical sources
 - Pubmed
 - JAMA
 - AAP (other professional societies)
 - Cochrane



PEDIATRICS®

- Other sources



<https://www.cleanpng.com/png-social-media-icons-social-media-icons-floating-on-8076190/>

Understanding Complimentary Alternative Treatments



We will not cover ALL options



[Home](#) > [Health Information](#) > [Autism](#)

Autism

[NIH CAM Autism](#)

Health Topics A-Z

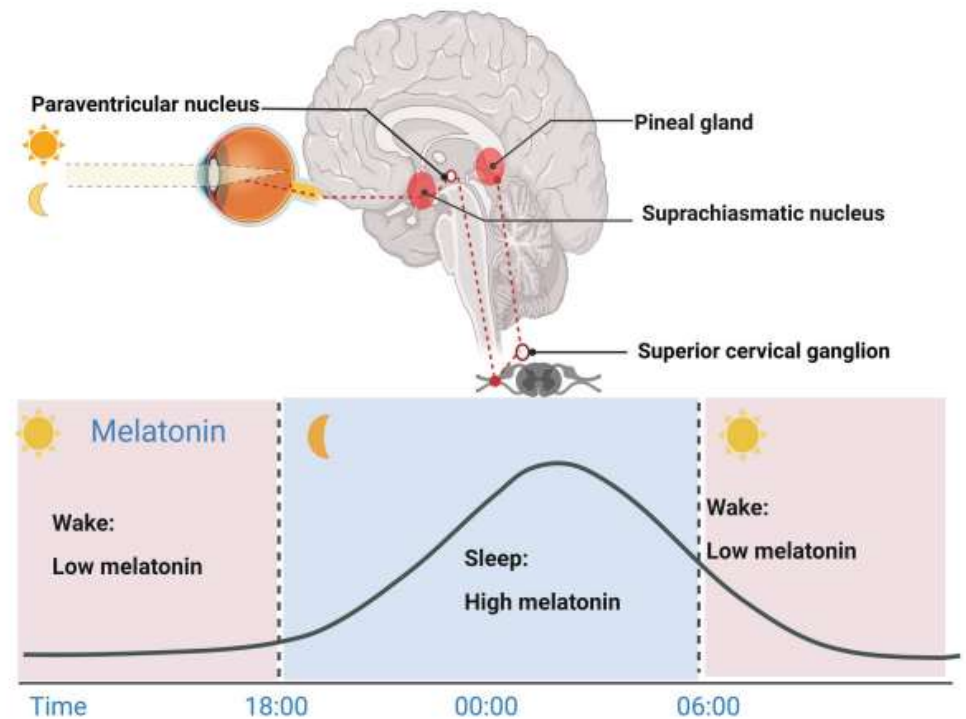
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- [Acai](#)
- [Acupuncture](#)
- [Aloe Vera](#)
- [Alzheimer's Disease](#)
- [Antioxidants](#)
- [Anxiety](#)
- [Are You Considering a Complementary Health Approach?](#)
- [Aromatherapy](#)
- [Ashwagandha](#)
- [Asian Ginseng](#)
- [Asthma](#)
- [Astragalus](#)

Melatonin and Sleep

- Hormone secreted mainly from the pineal gland
- Production is suppressed by light
- Regulator of circadian rhythm



Zhu et.al., 2023

Autism and Melatonin

- Improved sleep onset in children with neurological diagnoses
- Neutral evidence for total sleep time or awakenings
- No long term safety data beyond 3 years, need close monitoring
- Compared to cognitive behavioral therapy, parent-based sleep education, weighted blankets, south to sleep mattress technology
 - Melatonin beneficial after behavioral strategies exhausted
- Sustained Release melatonin safe and effective in children with autism
- Reduced sleep latency and improved sleep time

Buckley, et.al. 2020; Gringras et.al., 2017 ; Kacht, et.al. 2026;
; Malow et.al, 2021

Table 1 Evidence summary for interventions targeting sleep disorders in children and adolescents with autism spectrum disorder (ASD)^a

	Bedtime resistance	Sleep onset latency	Sleep continuity: sleep efficiency	Sleep continuity: WASO, night awakenings	Total sleep time	Daytime behavior
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Table 3 Recommendation statements for care of children and adolescents with autism spectrum disorder (ASD) and sleep disturbance regarding melatonin use

Poss effect	Recommendation number	Recommendation statement and level
	3a	Clinicians should offer melatonin to children and adolescents with ASD if behavioral strategies have not been helpful and contributing coexisting conditions and use of concomitant medications have been addressed (Level B).
Poss ineff	3b	Clinicians offering melatonin for sleep disturbance in children and adolescents with ASD should write a prescription for melatonin or recommend using a high-purity pharmaceutical grade of melatonin when available (Level B).
Insu evid	3c	Clinicians offering melatonin for sleep dysregulation in children and adolescents with ASD should start by initiating a low dose (1–3 mg/d), 30–60 minutes before bedtime, and titrate to effect, not exceeding 10 mg/d (Level B).
	3d	Clinicians offering melatonin for sleep disturbance in children and adolescents with ASD should counsel children and adolescents with ASD and sleep disturbance (as appropriate) and their parents regarding potential adverse events of melatonin use and the lack of long-term safety data (Level B).

Abbr
° Spe
text :

American Academy of Neurology, upon request; for interventions for which there are multiple conclusions for a single sleep category, conclusions with the highest degree of confidence and potential benefit are reflected here.

^a Other outcomes for this intervention and this sleep category show either no benefit or have insufficient evidence.

Buckely, et.al. 2019

Gluten Free and Casein Free Diet

Gluten-Containing Grains and Their Derivatives

- Wheat
- Varieties and derivatives of wheat such as:
 - wheatberries
 - durum
 - emmer
 - semolina
 - spelt
 - farina
 - farro
 - graham
 - KAMUT® khorasan wheat
 - einkorn wheat
- Rye
- Barley
- Triticale
- Malt in various forms including: malted barley flour, malted milk or milkshakes, malt extract, malt syrup, malt flavoring, malt vinegar
- Brewer's Yeast
- Wheat Starch that has not been processed to remove the presence of gluten to below 20ppm and adhere to the Labeling Law¹



Common Foods That Contain Gluten

- **Pastas:**
 - raviolis, dumplings, cous
- **Noodles:**
 - ramen, udon, soba (thos noodles and mung bean
- **Breads and Pastries:**
 - croissants, pita, naan, b
- **Crackers:**
 - pretzels, goldfish, graha
- **Baked Goods:**
 - cakes, cookies, pie crust
- **Cereal & Granola:**
 - corn flakes and rice puf
 - oats
- **Breakfast Foods:**
 - pancakes, waffles, frenc
- **Breading & Coating Mixes:**
 - panko breadcrumbs
- **Croutons:**
 - stuffings, dressings
- **Sauces & Gravies** (many u:
 - traditional soy sauce, cr
- **Flour tortillas**
- **Beer** (unless explicitly glut
- information on alcoholic be
- **Brewer's Yeast**
- Anything else that uses "wi

What foods contain casein?

Most dairy products will contain some amount of casein. These include:

- Milk
- Cheese
- Cream
- Yogurt
- Butter
- Cream cheese
- Ice cream
- Custard
- Pudding

Casein can also be used in products that you wouldn't expect to have dairy —

Source: MedicineNet

Source: Celiac Disease Foundation

Gluten Free Casein Free (GFCF) and Autism

- No significant effects on behavior, autism core symptoms, or function when on a GFCF diet
- Restricts potentially already restricted diet
- Expensive/time consuming
- Current recommendation is that GFCF should NOT be recommended universally

Keller et.al., 2022 ; Yu et.al., 2022; Quan et.al., 2022; Gonzalez-Domenech et.al., 2020



Chelation therapy

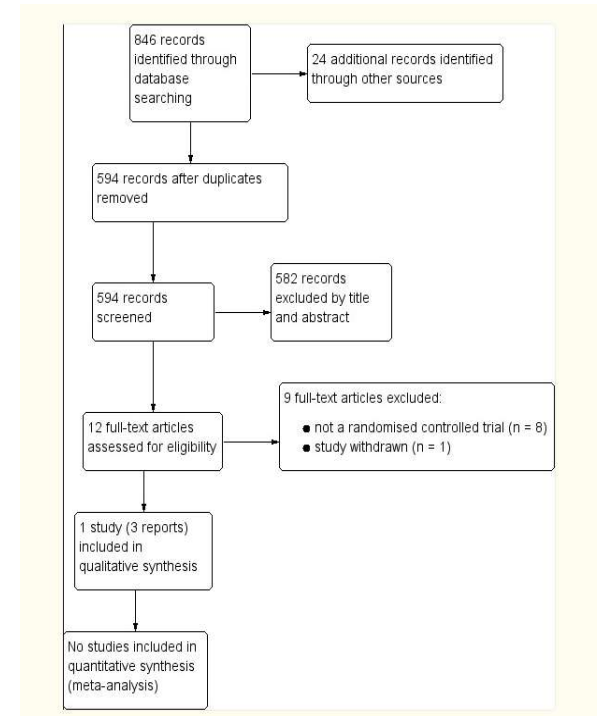
- Chelating substances are used to bind to heavy metals
- Excreted in the urine
- Some FDA approved uses for chelation: lead poisoning (DMSA), hypercalcemia (emergency treatment – EDTA)**
 - ** under constant monitoring
- Not approved for use in autism
- No evidence to suggest increased heavy metals in individuals with autism

Chelation in Autism

- James et.al., 2015 – Cochrane Review
 - Looked at all randomized control trials
 - Only one study was included
 - No evidence to suggest any benefit

There have been reports of serious adverse effects from chelation.

RISK outweighs any possible benefits



Leucovorin

- Folinic acid – reduced form of folic acid
- FDA approved uses for leucovorin
 - Methotrexate rescue
 - Treatment of megaloblastic anemia
 - Combined with 5-fluorouracil to prolong survival in advanced colorectal cancer

Cerebral Folate Deficiency and autism

- Cerebral folate deficiency
 - Low CSF folate levels with normal serum folate levels
 - Characterized by (OMIM, 2020):
 - Developmental regression, severe
 - Neurodegeneration
 - Seizures
 - Motor dysfunction
 - Decreased CSF MTHF
 - Rare - Three patients reported as of Oct 2009
- Mixed findings about levels of folate receptor antibodies in children with autism (Shit et al. 2024)
- Unclear data on folate receptor antibodies and clinical presentation

Leucovorin and Autism

- Studies so far are limited
 - Small sample sizes
 - Short treatment durations
 - Variable outcomes measures that show possible improvement
- Retraction of randomized trial from 2024
- Major pediatric societies do NOT recommend use of leucovorin in autism
 - AAP statement 10/2025 **“At this time, the American Academy of Pediatrics (AAP) does not recommend the routine use of leucovorin (folinic acid) for autistic children.”**
 - SDBP statement 09/2025 **“Right now, there is not enough strong research to know if taking Leucovorin, a form of folate, is safe or helpful for autistic people.”**

Something we all know

- Vaccines do not cause autism
- Plenty of research with thousands of participants supports this
 - Hviid et.al. 2019
 - Studied over 650,000 children born in Denmark up until age 31
 - Large observational study
 - Danish Civil Registration System
 - Looking at MMR vaccine
 - MMR does not increase risk of autism

Followed until end of study ($n = 650\,943$)
No autism: 644 426
Autism: 6517

- Jain et.al. 2015
 - Retrospective Cohort study
 - Over 95,000 children
 - No increased risk of autism with MMR

Health Care for Youth With Neurodevelopmental Disabilities: A Consensus Statement

Carol Weitzman, MD,^{a,*} Cy Nadler, PhD,^{b,*} Nathan J. Blum, MD,^c Marilyn Augustyn, MD,^d
on behalf of the Supporting Access for Everyone Consensus Panel**

Pediatrics. 2024;153(5). doi:10.1542/peds.2023-063809

American Academy
of Pediatrics



DEDICATED TO THE HEALTH OF ALL CHILDREN®

Foundational Premises of SAFE Care

SAFE care is:

- Care that individuals understand and want;
- Individualized and evolving with the changing needs of a person;
- Accessible throughout the entire lifespan;
- Equitable and respectful;
- Defined and measured by patient experience, quality of care, and psychological well-being of patients and caregivers, and not solely by narrow interpretations of safety, efficiency, and remuneration.

SAFE care reduces or eliminates:

- Risk of physical and emotional harm to people, including accident, injury, restraint, and seclusion;
- Poor quality, inadequate, and incomplete care;
- Foregone care, which results in untreated healthcare conditions and increased morbidity.

EXECUTIVE SUMMARY

Healthcare for Youth with Neurodevelopmental Disabilities:

A Consensus Statement



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Screenshot taken on 11/03/2024 from Executive Summary Health Care for Youth with Neurodevelopmental Disabilities: A Consensus Statement: <https://safedbp.org/>

Bill of Rights

American Academy
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From: **Health Care for Youth With Neurodevelopmental Disabilities: A Consensus Statement**

Pediatrics. 2024;153(5). doi:10.1542/peds.2023-063809

NDD Healthcare Bill of Rights

Individuals with NDDs are human beings who are entitled to human rights and dignity. This **NDD Healthcare Bill of Rights** articulates that people with NDDs have the right to:

- Give or refuse consent/assent and participate in shared or supported decision-making.
- Access care that is proactively adapted to meet their needs.
- Use their preferred mode of communication (spoken words, sign language, AAC, etc.) and be communicated with in a format they can understand, with the support and technology they need.
- Receive effective pain and anxiety management.
- Advocate for their own needs and best interests.
- Receive care that is not traumatizing.
- Be treated as a person, not simply a diagnosis.
- Experience timely, courteous, and respectful care.
- Be free from restraint, coerced care, and maltreatment.

Figure Legend:

NDD Health Care Bill of Rights.



Conclusion

- Autism prevalence is increasing
- So is our understanding of the heterogeneity
- Neurodiversity affirming care is paramount
- Early intervention $\square$ improved outcomes
- Every autistic child deserves the chance to reach their highest potential





**Phoenix
Children's[®]**

Thank you!

draz1@phoenixchildrens.com

Autism Educational Summit

Provider Day

Friday, September 25, 2026

Learn More:



<https://AutismSummit.eventbrite.com>



Phoenix Children's

- Kanner L. Autistic disturbances of affective contact. *Nervous Child*. 1943;2(3):217–250.
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