Autism Guidebook

for Medical Providers

Children's National

Kelly Register-Brown, M.D. and Anne Inge, Ph.D.
with the Children's National ECHO Autism
Project Team and the Children's National
Center for Autism team

About this Guidebook

The Center for Autism (CASD) at Children's National Hospital is a multidisciplinary team of pediatric autism specialists, including clinical psychologists, neuropsychologists, child and adolescent psychiatrists, developmental pediatricians, social workers and speech/language pathologists. These experts work together to provide the best possible care for autistic youth, and lead research to understand the underpinnings of autism and effective approaches to maximize autistic youth outcomes.

CASD has provided free multidisciplinary autism education and support to over 700 providers via its ECHO Autism (Extension for Community Health Outcomes) project. ECHO Autism creates a virtual learning network that aims to "move knowledge, not patients" using a telementoring format that provides access to a hub of autism specialists to support community providers to diagnose, treat and care for autistic children and their families. Members of the CN CASD ECHO Autism team are:

- Anne Inge, Ph.D. (psychology)
- Kelly Register-Brown, M.D. (child and adolescent psychiatry)
- Shalinee Khurana, M.D. (developmental-behavioral pediatrics)
- Alyssa Ware, MSW, PhD (social work)
- Colleen Morgan, MA, CCC-SLP (speech/language pathology)
- Amanda Hastings, PsyD (psychology and BCBA)
- Angela Bollich, PhD (neuropsychology)
- Chelsea Armour, MA (coordinator)
- Yetta Myrick (parent educator/advocate)
- Elise Horne (parent educator/advocate)
- Lori Kraden (educational specialist)
- Kelly Miller (research assistant)

This guidebook includes a summary of content generated by the CN CASD ECHO Autism team. Funding for CN CASD ECHO Autism was provided by the A. James & Alice B. Clark Foundation, the Alexander and Margaret Stewart Trust, and the RE/MAX Foundation.

This guidebook also includes updated parent handouts from the 2010 CASD parent sourcebook, which included additional authors Lauren Kenworthy, PhD, Jenifer Walkowiak, PhD and Laura Anthony, PhD. and was funded in part by the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA) through the Leadership Education in Neurodevelopmental Disabilities (LEND) program (5-T73-06-001) at Children's National Medical Center, Washington, DC.

Table of Contents

Children's National

INTRODUCTION

This guide is designed to help primary care and specialist providers assess and address the diagnostic and treatment needs of autistic children[1] who are experiencing barriers to accessing specialist autism care. With the increase in autism prevalence (currently at 1 in 36 children according to the CDC)[2] followed by the service disruptions of the COVID-19 pandemic, specialist autism centers have had dramatically increasing numbers of referrals resulting in lengthening wait lists. Children lose valuable intervention time on long wait lists for specialty autism care: critical developmental windows close as children grow, and altered developmental trajectories lead to larger gaps over time between actual and expected development.

Pediatricians report frustration that even in unambiguous cases of autism, insurance requirement of a quantitative medical diagnosis of autism necessitates referral and blocks access to autism-specific treatment like Applied Behavior Analysis.[3] One study found pediatricians report high certainty of the presence or absence of autism in 64% of cases referred for diagnostic testing,[4] suggesting that up to 4% of children in the general population might be appropriate for expedited autism evaluation in the primary care setting.[5] Once a child is diagnosed with autism, a maze of autism services, insurance and educational barriers, and long wait lists for treatment providers often prevent prompt access to evidence-based care. Additionally, navigating this maze has also been reported by pediatricians to be a barrier for making a diagnosis of autism when confidence is high.

Primary care and specialist providers can play a powerful role in connecting neurodiverse children to appropriate diagnostic and treatment services. This guide is intended to provide a practical framework and toolkit for how to support autism families in various medical settings.

---

[1] In line with the current prevailing preference of the autism self-advocate community, this guide uses identity first language (autistic person) rather than person-first language (person-first language). This is in contrast to the prevailing preference of many other patient communities, where person-first language is preferred. Taboas A, Doepke K, Zimmerman C. Preferences for identity-first versus person-first language in a US sample of autism stakeholders. Autism. 2023 Feb;27(2):565-570. doi: 10.1177/13623613221130845. Epub 2022 Oct 13. PMID: 36237135.

[2] Maenner MJ et al. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020. MMWR Surveill Summ. 2023 Mar 24;72(2):1-14..

[3] Hamp N, DeHaan SL, Cerf CM, Radesky JS. Primary Care Pediatricians' Perspectives on Autism Care. Pediatrics. 2023 Jan 1;151(1):e2022057712.

[4] Penner M, Senman L, Andoni L, Dupuis A, Anagnostou E, Kao S, Solish A, Shouldice M, Ferguson G, Brian J. Concordance of Diagnosis of Autism Spectrum Disorder Made by Pediatricians vs a Multidisciplinary Specialist Team. JAMA Netw Open. 2023 Jan 3;6(1):e2252879.

[5] Assuming the 6.2% MCHAT positive rate found in a real-world community setting by Guthrie et al. 2019. Guthrie W, Wallis K, Bennett A, Brooks E, Dudley J, Gerdes M, Pandey J, Levy SE, Schultz RT, Miller JS. Accuracy of Autism Screening in a Large Pediatric Network. Pediatrics. 2019 Oct;144(4):e20183963.

CHAPTER 1: PRACTICAL FRAMEWORK FOR CONCEPTUALIZING AUTISM DIAGNOSIS AND TREATMENT

What instruments/evaluations are required to make a diagnosis of autism?

A **comprehensive autism diagnostic evaluation** includes these 6 elements:

1) a thorough autism developmental history;
2) structured observation of social communication/social skills involving situations designed to elicit autistic traits;
3) adaptive functioning assessment;
4) cognitive/developmental testing;
5) speech/language assessment including pragmatic language assessment;
6) audiology assessment to rule out hearing concerns.

Ideally, every child suspected of having autism would have this full evaluation as soon as developmental concerns were expressed, before any diagnoses were made. In practice, due to factors including limited access to evaluations, this is rare. Children are left waiting on long lists or referred for low intensity, non-specific early intervention targeting symptoms (e.g., speech delay), and miss out on critical specialized interventions designed to shore up foundational social learning skills (e.g., joint attention) that can result in their own positive developmental cascade and contribute to improved long-term outcomes.[6]

*"Given the unprecedented growth and organization of the brain during the **first three years of life**, behavioral interventions initiated in ASD toddlers within this time period result in a range of positive changes including **increases in social attention, language ability, and overall IQ**. However, due to the lag in diagnosis, many children miss the opportunity to receive treatment during this critical period of **neuroplasticity**."*

- Interagency Autism Coordinating Committee, US Department of Health and Human Services

[6] Interagency Autism Coordinating Committee (IACC). 2016-2017 Interagency Autism Coordinating Committee Strategic Plan For Autism Spectrum Disorder. October 2017. Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee website: https://iacc.hhs.gov/publications/strategic-plan/2017/.

Some children have multiple comorbidities and a long differential diagnosis list including autism. These children are best served by the comprehensive evaluation model to improve reliability of the diagnosis of autism and ensure appropriate treatment recommendations (see Chapter 2, Triage for a more detailed discussion). They should be referred to specialist autism centers for full multidisciplinary evaluation as soon as concerns are identified.

However, many children can be confidently diagnosed with autism following just the first two evaluations: a thorough developmental history and structured behavioral observation with elicitation of social behaviors (analogous to the "history" and "physical exam"). The other evaluations, while still important, can be made over time during separate appointments or by outside systems of care (e.g., cognitive evaluation through the school system). If these "less complicated" children can access a rapid abbreviated autism diagnostic evaluation, they can "jump the line" for diagnosis and get started on specialized intervention earlier, thereby improving outcomes.

It is important to note that while structured autism diagnostic instruments like the Autism Diagnostic Observation Schedule – Second Edition (ADOS-2) are helpful for the reliable diagnosis of autism, **no particular instrument or rating scale is clinically necessary to make an autism diagnosis in most cases**. However, families are increasingly finding that they are unable to access autism services with "just" a clinical diagnosis due to insurance-based requirements of quantitative documentation of autism traits via a diagnostic instrument. Therefore, this guide provides information on particular diagnostic instruments that can be used to document autism traits.

Why do children need to be "diagnosed" with autism twice, by the medical and educational systems?

In fact, a child's first diagnosis of autism is only the initial step toward accessing all of the services and supports to which they may be entitled. In the US, autism supports and services are provided through an overlapping maze of public and private entities. Even for highly experienced families and professionals, navigating to appropriate services can be complex, overwhelming, and time-consuming.

In general, each child with autism needs to be "diagnosed" at least twice, by a medical provider, and by the early intervention/school system.[7] The medical diagnosis of autism is necessary for accessing insurance-based services, even for children who already have an educational classification of autism through their school support plan (i.e., Individualized Education Plan (IEP)). The educational classification of autism via an IEP process is necessary to receive most special education supports (even for children who already have a medical diagnosis of autism). The federal/state and nonprofit systems often will accept either a medical or an educational diagnosis, although this can vary.

[7] In some jurisdictions, early intervention will not initiate autism assessment until after age 3, but will accept a medical diagnosis of autism as a basis for providing services.

For example, a comprehensive, multidisciplinary autism evaluation by an autism center does NOT entitle a child to special education services. With parent/guardian consent, the IEP team will consider the medical evaluation as part of their determination of eligibility for individualized supports in school (IEP), which involves consideration of both autism diagnostic criteria and presence or absence of related educational impact . A child's autism must "adversely affect educational performance" in order for the child to be entitled to special education supports and services.[8]

> *Autism means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, **that adversely affects a child's educational performance**. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences.*
>
> *- IDEA Sec. 300.8 (c)1a*

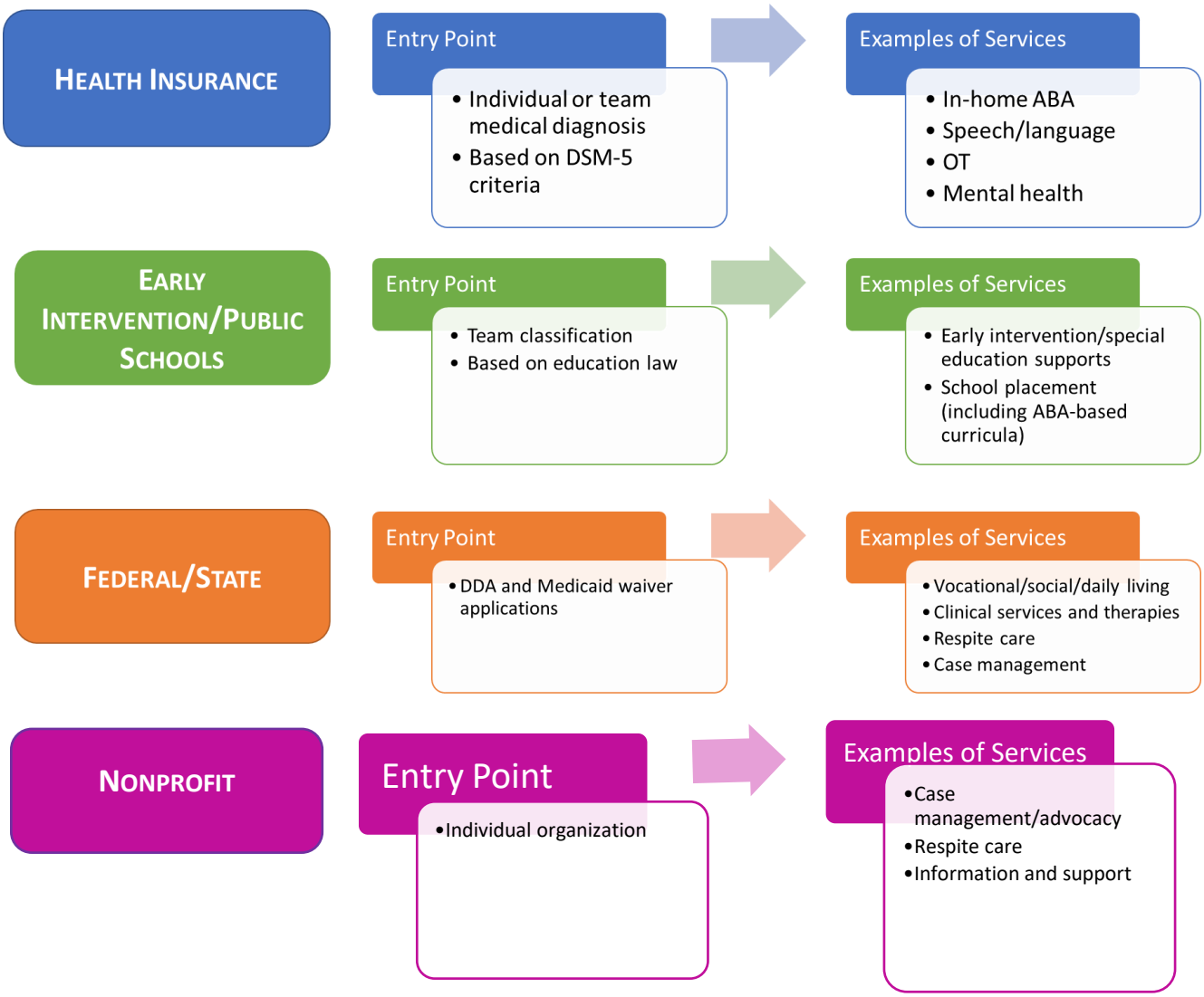
Conversely, a child can be given an educational classification of autism on their IEP, but this does not qualify them to receive autism services like in-home ABA paid for by their medical insurance. Medical autism services require a medical diagnosis of autism, typically involving a quantitative measure of autism traits and increasingly also involving a quantitative measure of adaptive functioning (daily living skills).

What systems of care provide services to autistic individuals in the US?

Below is a simplified framework for categorizing autism services in the US, based on how services are funded. In this framework, there are four main systems of care: 1) medical services paid for by private and public health insurance; 2) early intervention and public school services as mandated under federal IDEA legislation and administered at the local/state level; 3) federal/state services including the state's Administration on Intellectual and Developmental Disability (AIDD) agency, Medicaid waiver services, and state Rehabilitation Services Administration services; and 4) nonprofit agency supports. The entry points, eligibility requirements, and services for each system vary widely by locality.

Our goal in supporting autism families is to 1) ensure that the total of all of a child's assessments in different systems of care is adequate to document all needs and meet service eligibility requirements; and 2) optimize access to services in each of these systems of care. Often this requires redundant services (e.g. being "diagnosed" with autism by a medical provider and a school team team) and multiple referrals or cross-collaboration (e.g., leveraging school-based cognitive and adaptive functioning evaluation as part of medical autism diagnostic testing/evaluation).

[8] Sec. 300.8 (c) - Individuals with Disabilities Education Act


HEALTH INSURANCE
Entry Point
• Individual or team medical diagnosis
• Based on DSM-5 criteria
Examples of Services
• In-home ABA
• Speech/language
• OT
• Mental health
EARLY INTERVENTION/PUBLIC SCHOOLS
Entry Point
• Team classification
• Based on education law
Examples of Services
• Early intervention/special education supports
• School placement (including ABA-based curricula)
FEDERAL/STATE
Entry Point
• DDA and Medicaid waiver applications
Examples of Services
• Vocational/social/daily living
• Clinical services and therapies
• Respite care
• Case management
NONPROFIT
Entry Point
•Individual organization
Examples of Services
•Case management/advocacy
•Respite care
•Information and support

CHAPTER 2. TALKING ABOUT, SCREENING FOR, AND SOMETIMES PERFORMING AN ABBREVIATED MEDICAL EVALUATION FOR AUTISM.

Overview of Autism Screening, Referrals, and Diagnosis

The AAP recommends universal screening for autism at the 18 and 24 month well child visits.[9] When a provider and/or family have concerns about autism for a child, referring to an autism specialist[10] **AND** to the Early Intervention/public school team for further evaluation is almost always preferable to taking a "wait and see" approach. The AAP writes:

> *Take parents' developmental concerns seriously. Remember, 80% of parents' developmental concerns are correct and associated with a developmental delay or risk. In particular, consider ASD anytime a parent mentions concerns about language delay, eye contact, social skills, hearing problems, or repetitive behaviors/interests.*[10]

In some settings and cases, a provider may also wish to perform an abbreviated autism diagnostic evaluation, so that if the diagnosis is positive the child can access autism services rather than waiting, potentially many months, for evaluation. The AAP added a tip sheet for providers on Autism Diagnosis in Primary Care to its website in September 2023.[11]

This chapter outlines the steps in an abbreviated autism diagnostic evaluation, from introducing the idea of autism to a family, through screening, diagnosis, feedback, and documentation.

Primary care ASD diagnosis has some benefits, including:
- Reducing wait times for your patients
- Improving continuity of care
- Reducing disparities in access to diagnostic services
- Assisting families in better understanding their child's strengths and needs for support

It is important for primary care physicians to be prepared with the content knowledge and documentation abilities to make sure that their diagnoses are accurate and well-documented to support children on the autism spectrum.

- AAP, Autism Diagnosis in Primary Care website

[9] Autism Spectrum Disorder (aap.org)
[10] Medical autism specialists work within a range of specialties, most commonly psychology and developmental-behavioral pediatrics.
[11] AAP Autism Toolkit: How Can I Improve Access to Autism Spectrum Disorder Care for My Patients?
[12] Autism Diagnosis in Primary Care (aap.org)

Talk about the possibility of autism with families.

Language matters.
As clinicians who screen for and diagnose autism, we are often among the first people to have detailed conversations about autism with families. The language we use matters profoundly. We are often among the first "outsiders" to whom families and patients reveal concerns about how their child is learning and growing. This is a vulnerable moment for families; almost universally, families love their children and want to protect them, and detailing a child's struggles to a stranger can feel like a betrayal. Deliberately using neutral and strengths-based language rather than deficits-based clinical language can help frame a developmental interview as a mutual problem-solving session rather than as an enumeration of deficits, or even an attack. Many autism self-advocates suggest clinicians use words like "traits" instead of "symptoms", "intensity" instead of "severity," and "difference" rather than "deficit."

Consider the following two descriptions of the restrictive, repetitive behaviors of autism, the first a clinical definition from the DSM-5, and the second a celebration of neurodiversity from an autism self-advocate:[12]

"Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests)." **–DSM 5**	"The way I love? It is deep. Autism is deep love. People write it off as special interest or obsession, but even if it's not something I can excel at, I can excel at loving what I love, loving what I do, loving who I love. Autism is being able to be consumed by love and interest; it is giving 100% because it is an insult to the thing one loves to give any less. Autism is going big or going home." **-Kassiane**

When clinicians show confidence that children are the same amazing individuals full of potential regardless of their "labels," we model attitudes that help build children's self-esteem. Our hope (borne out by a small but growing literature)[13] is that this strengths-based approach can help "bubble wrap" children's mental health as they approach the vigorous social demands of adolescence, and thereby help build resilience against anxiety, depression, suicidality, and other mental health problems that are more common among autistic individuals.

Common parent question	**Sample response**
What is autism?	Autism is a brain-based difference in the way a person learns, socializes, communicates, reacts to changes,

[12] Resource Library - Autistic Women & Nonbinary Network (AWN) (awnnetwork.org)
[13] Oredipe, T., Kofner, B., Riccio, A., Cage, E., Vincent, J., Kapp, S. K., Dwyer, P., & Gillespie-Lynch, K. (2022). Does learning you are autistic at a younger age lead to better adult outcomes? A participatory exploration of the perspectives of autistic university students. Autism, 0(0). https://doi.org/10.1177/13623613221086700

Common parent question	**Sample response**
	and experiences their environment including sensory input like sounds and lights. See the Appendix for family handouts on autism.
Why is autism becoming more common?	Autism is being diagnosed more often now because: 1) although there are still major barriers, people in underserved populations are more likely to be able to access autism evaluation and be counted as having autism 2) we are looking for autism in populations where we previously had low concern, like girls and women 3) we are now identifying autism more in young children and in adults, not just in preschoolers 4) we are recognizing that some kids with intellectual disability or a medical/genetic disorder also have autism; and 5) we are recognizing that some kids we used to just call "quirky" actually have autism, and would benefit from autism therapy, especially while they are young.
Why is it important to screen young children for autism?	Evidence-based autism therapies like social communication interventions and Applied Behavior Analysis improve foundational social learning skills, social interaction skills, language and communication skills, and IQ in autistic children. The earlier autistic children are identified, the more therapy can help.
What might the benefits of an autism diagnosis be for older teens or adults?	Getting the diagnosis of autism can help individuals understand themselves and their loved ones, access new strategies and services, and reach a community of people with similar experiences. Teenagers with autism are more likely to develop mental health problems like anxiety, depression, and suicidality. Research suggests that a supportive environment including access to positive autistic communities and role models can help build self-esteem and mental wellness.

Screen for autism using an evidence-based, age-appropriate tool.[14]

Free autism screening instruments for patients of all ages are available online. The MCHAT-R/F, used for children aged 16-30 months, is widely used in primary care (https://mchatscreen.com/mchat-rf/). For younger children, consider using the CSBS Checklist (valid for ages 6-24 months, https://firstwords.fsu.edu/pdf/ checklist.pdf). For children aged 4 to adults, a free screener is the AQ (https://psychology-tools.com/test/autism-spectrum-quotient).
Useful proprietary screens include the Social Responsiveness Scale – Second Edition and the Social Communication Questionnaire (both available on CHADIS)

AAP Recommendations

The AAP recommends that all children be screened for ASD at ages 18 and 24 months, along with regular developmental surveillance. Toddlers and children should be referred for diagnostic evaluation when increased risk for developmental disorders (including ASD) is identified through screening and/or surveillance. Children should be referred for intervention for all identified developmental delays at the time of identification and not wait for an ASD diagnostic evaluation to take place.

CAUTION: If the screening tool you use is negative but you and/or the family are concerned about a child's development, further evaluation and referral is always warranted. Autism screening tools, in particular the MCHAT-R/F, have high false negative rates for autism, and are likely to miss children who would benefit from early intervention.[15] However, screening tools are still more accurate than unstructured interview alone, and are also helpful for picking up other developmental delays that would benefit from intervention. **Do not "wait and see" if you and/or the family are concerned, because the child may miss out on the opportunity for intervention during critical periods of early development.**

[14] Autism Spectrum Disorder (aap.org)

[15] A 2019 study examining records of 26,000 cases in a real-world urban setting found that the MCHAT-R/F had a sensitivity of 38.8% and a positive predictive value of 14.6% for autism, and a sensitivity of 11.8% and positive predictive value of 72% for any developmental delay. Children who screened positive were diagnosed with autism 7 months earlier than children who screened negative. Guthrie W, Wallis K, Bennett A, et al. Accuracy of Autism Screening in a Large Pediatric Network. Pediatrics. 2019;144(4):e20183963.

Suggested Scripts for Discussing MCHAT Results with Parents

Positive MCHAT	Although your child's MCHAT was positive, this does not necessarily mean that s/he has autism. I still suggest we refer for medical AND educational evaluations because s/he probably needs extra help to stay on track.
Negative MCHAT but parent or clinician concerns	Although your child's MCHAT was negative, this test misses almost 60% of kids with autism. Since we have concerns, I still suggest we refer for medical AND educational evaluations.

Triage the probability of autism and the complexity of the case overall.

Biostatistics tells us that when there is a high pretest probability of a patient having a disease, we can still be reasonably confident in our test results even if the test has a relatively unfavorable sensitivity and specificity.[16] For example, if a child has all of the classic signs of a pharyngeal strep infection and a strep positive sibling (high pretest probability), we are not relying heavily on a rapid strep test to inform treatment decisions. However, if our suspicion of strep is low, we might perform a rapid strep test and wait for confirmatory test results before making a final treatment decision.

Similarly, diagnosing autism can sometimes be relatively straightforward and sometimes be very tricky. Some children who have all of the classic signs of autism throughout development (e.g., restricted repetitive interests and behaviors, interference due to sensory regulation needs, functional communication weaknesses including language delay and problems with nonverbal strategies such as pointing and gesture use), as well as a positive family history, younger age, and no suspected complicating comorbidity (e.g. global developmental delay,

Clinical Implications: CARS-2 and ADOS-2 Summary Statistics

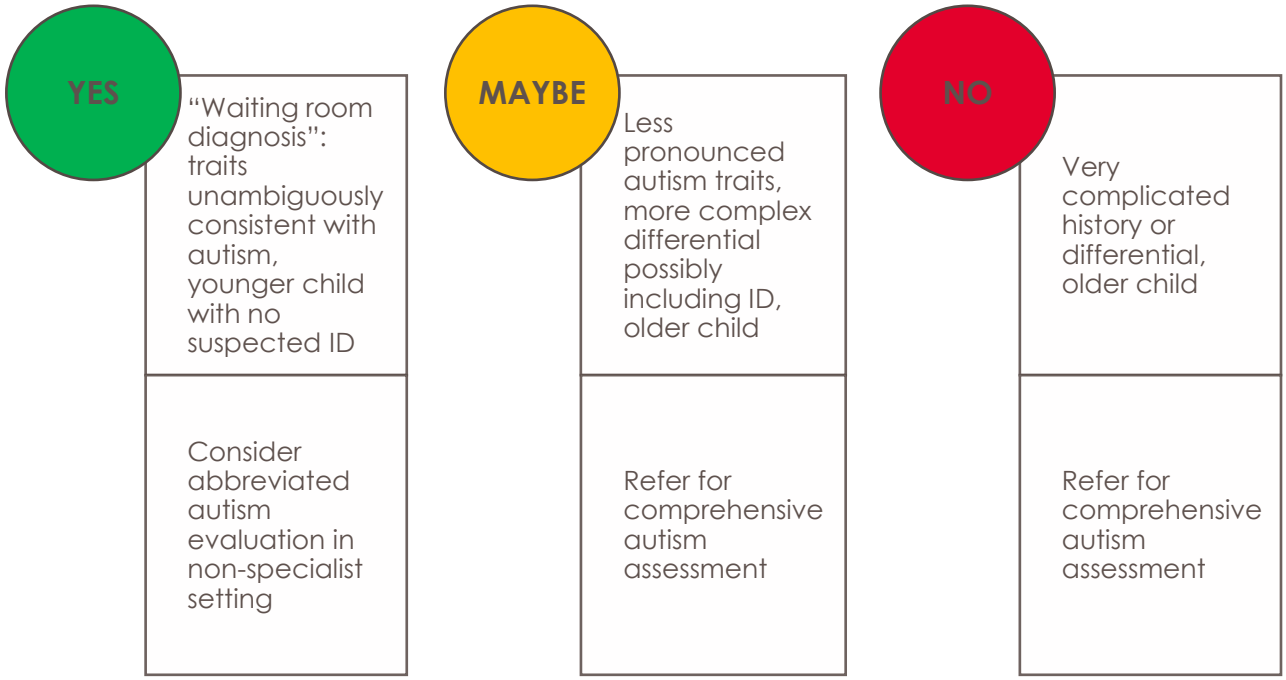
- *The ADOS-2 is the comprehensive instrument for eliciting and rating autism traits, and should be used for yellow and red cases when possible. The CARS-2 is an older, more feasible, and less sensitive instrument than the ADOS-2, and may be appropriate for some green cases.*
- *The CARS-2 is good for ruling in autism (same specificity as ADOS-2 means same likelihood of false positives).*
- *CARS-2 is not great for ruling out autism (lower sensitivity than ADOS-2 means more false negative results).*
- *It's reasonable to use the CARS-2 to rule in autism if you clinically suspect autism (high pretest probability).*
- *The CARS-2 is not as helpful if you don't have a strong suspicion for autism (low pretest probability).*
- *Don't trust a negative CARS-2 if you clinically suspect autism.*

[16] Why Pretest and Posttest Probability Matter in the Time of COVID-19 (asm.org)

trauma history, mood disorder, etc.), have a low overall diagnostic complexity and have a high pretest probability of autism. They could be evaluated in a non-specialist setting using a test with relatively lower sensitivity such as a clinician-administered autism diagnostic rating scale with a streamlined protocol. In this guidebook, we refer to such situations as **green cases**.

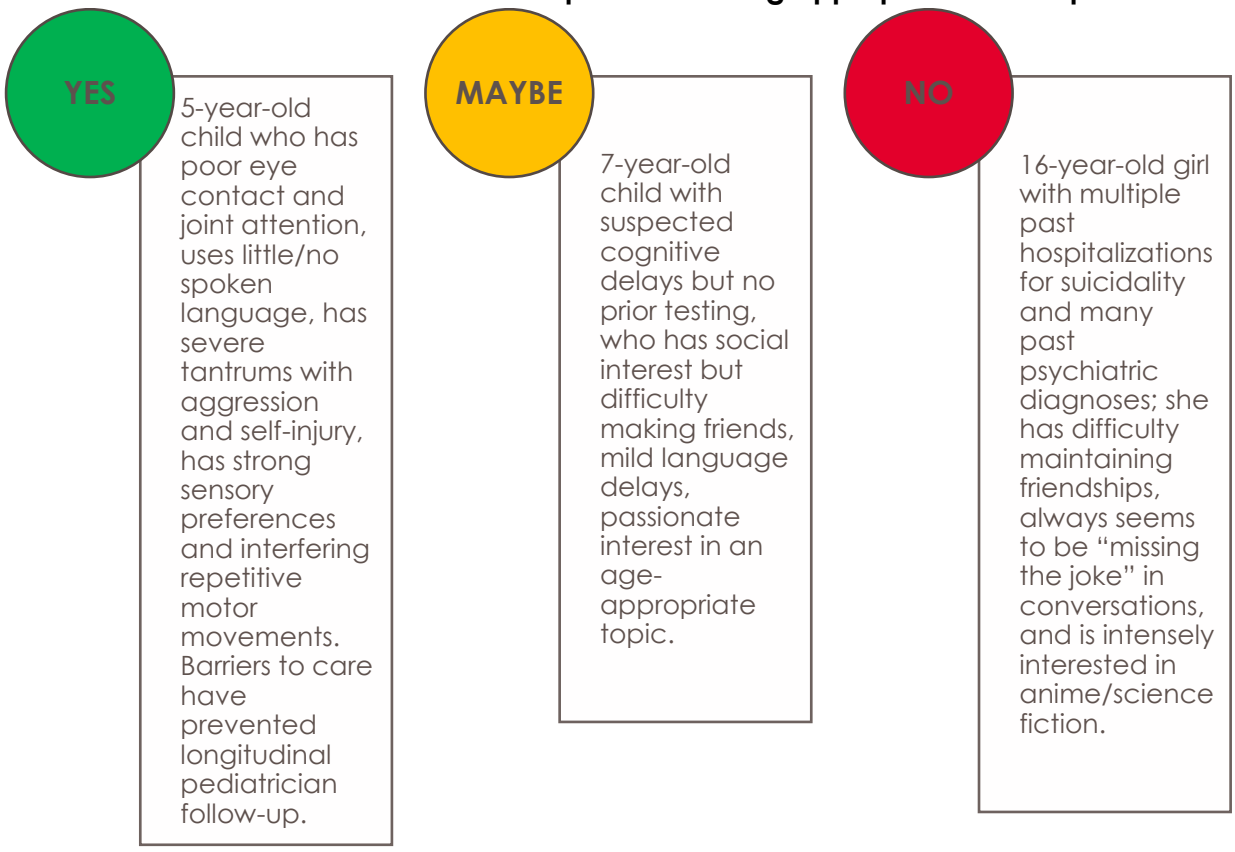
Other youth may have a complex range of comorbidities and a broad differential diagnosis including autism. These youth will often have an extensive history of neurodevelopmental and psychiatric diagnoses including language delay, behavioral regulation difficulties (including problems with flexibility), attention and learning disorders, trauma and attachment disorders, anxiety/depression, seizures and other neurological conditions, and prodromal psychotic disorders. They often will be relatively older and have an extensive list of past diagnoses, evaluations, and/or treatment trials. These youth have a lower pretest probability of autism, and require a more extensive diagnostic evaluation in an autism specialist setting before any diagnosis is made. These **yellow** and **red cases** would not be appropriate for evaluation in the non-specialist setting.[17]

Is autism evaluation in the primary care setting appropriate for this patient?



[17] For a review of the summary statistics for the CARS-2 versus the ADOS-2 in preschool children, see Randall M, Egberts KJ, Samtani A, Scholten RJ, Hooft L, Livingstone N, Sterling-Levis K, Woolfenden S, Williams K. Diagnostic tests for autism spectrum disorder (ASD) in preschool children. Cochrane Database Syst Rev. 2018 Jul 24;7(7):CD009044. doi: 10.1002/14651858.CD009044.pub2.

EXAMPLES: Is autism evaluation in the non-specialist setting appropriate for this patient?



For uncomplicated ("green") cases only: Elicit an autism developmental history and a "good" behavioral sample from the child using a set of materials/toys and protocol.

A comprehensive autism diagnostic evaluation, which **yellow** and **red** cases will likely require, involves a multidisciplinary evaluation as described in Chapter 1. However, for **green cases**, an autism diagnosis can reliably be made with a thorough history of autism traits and clinical observation involving elicitation of social behaviors (analogous to a "physical exam").

What are the elements of a thorough autism developmental history?

Autism developmental history should focus on social-communication skills and restrictive/repetitive behaviors and interests over the course of a child's development, with particular focus on the toddler through preschool years and currently. The comprehensive instrument for this is the Autism Diagnostic Interview-Revised (ADI-R). In the non-specialist setting for green cases, a thorough parent interview

can be sufficient. At Children's National, the Cerner dot phrases **=psCARS2ST** and **=psCARS2HF** contain prompts for taking an autism developmental history.

In general, an autism developmental history should focus on qualitative aspects of development including:

- Development of social communication skills (e.g., eye contact, pointing, joint attention, gesture use, facial expressions, range of pragmatic contexts/for what purpose does the child communicate) vs language milestones (e.g., age of first words and phrases)
- Social milestones (e.g., social affect, social responsiveness, social approach/initiation, reciprocity, imitation of others)
- Play interests and how the child plays (e.g., repetitive and/or sensory exploration of objects, reciprocity in play)
- Repetitive interests, behavior, and language

The interviewer should anchor ALL concerns to the child's development by asking when the behavior started and how it has changed over development.

What are the elements of a "good" behavioral sample in an autism diagnostic evaluation?

Unstructured play with a child, without strategically giving a child the opportunity to demonstrate characteristic autistic or non-autistic behaviors, provides less information about the presence or absence of autism traits, and therefore clouds clinical decision-making. For example, a characteristic autism trait in younger children is problems shifting from self-directed to examiner/caregiver-led activities or play, even after being prompted by an adult. If the interviewer does not press for a skill (e.g., such as set-shifting or imitation), then the interviewer may not be able to comment adequately on key behaviors relevant to autism.

Therefore, many autism diagnostic instruments, such as the ADOS-2, provide a script and a series of tasks for the interviewer to strictly follow. This increases sensitivity and specificity, but makes the instrument less feasible for use outside of autism specialty clinics. Other instruments, such as the CARS-2 and the Autism Mental Status Exam, provide considerable latitude for the behavioral sample on which the diagnosis is based.

In general, regardless of what instrument is being used for an autism diagnostic evaluation, the interviewer should be specifically probing for the following conceptual domains with varying diagnostic relevance depending on age, verbal, and cognitive level:

Conceptual Domain	Sample Items/Activities
Social orienting	Response to name when engaged in an activity, joint attention
Social initiations	Free play; communicative temptations; social use of language; overtures including showing, giving, asking, commenting
Social responsiveness	Prompts for imitation, following the examiner's lead in play and conversation, brief reciprocal acts in play and interactions
Social reciprocity	Shared enjoyment and participation in back-and-forth activities involving objects/toys and conversational attempts/exchanges

Conceptual Domain	Sample Items/Activities
Social thinking (perspective taking, insight, theory of mind, understanding of nonverbal cues)	Interpretation of social scenes; insight-oriented questions related to social awareness and understanding, responsibility, self-advocacy; interview with child/adolescent about their subjective experience of social interactions
Communication skills (speech/vocal quality, functional vs. non-functional; pragmatic skills and range; repetitive features)	Communicative temptations; Story telling tasks; Response to questions and bids for conversation in structured and unstructured formats
Nonverbal communication skills	Eye gaze preferences including gaze shifting from objects and interests to others; use of pointing, gestures, and range and directedness of facial expressions
Play skills (level, symbolic use of objects; object preference and unique object interests)	Various toys scaled up in functional play level (e.g., cause and effect, construction, vehicles, objects for functional and representational play); access to objects via breaks or other tasks
Repetitive tendencies (e.g., language, play, social style including inflexibility)	Language quality (e.g., echolalia), evidence of strong interests, ability to transition with objects and between activities, insistence on sameness/rigidity
Sensory regulation differences and repetitive behaviors	Use of high arousal activities; sensory-related toys or activities; interview with child/adolescent about their sensory experience of the environment

Rate autism traits quantitatively using an established autism diagnostic instrument.

The "comprehensive" instrument for eliciting and rating autism traits is the Autism Diagnostic Observation Schedule-2 (ADOS-2). However, the ADOS-2 is generally not feasible in non-specialist settings due to cost of materials, training requirements, and administration and scoring time. Feasible alternative diagnostic instruments with acceptable sensitivity/specificity for **green cases** include:

	Free Instruments	Proprietary Instruments
Younger and/or less verbal children	ASD-PEDS (online training available)[18] Autism Mental Status Exam (online training available)[19]	STAT (online training available)[20] CARS-2 ST (training required; available in CHADIS)
Older children who speak in sentences and do not have ID	Autism Mental Status Exam	CARS-2 HF (training required; available in CHADIS)

[18] Vanderbilt TRIAD Autism Tool: TELE-ASD-PEDS (vumc.org)
[19] Autism Mental Status Exam
[20] https://vkc.vumc.org/vkc/triad/stat/

To obtain insurance coverage of medically necessary services like ABA therapy, some children will also need adaptive functioning testing. Some suggested instruments follow, which range in scope and time intensity for families to complete: Vineland Adaptive Behavior Scales- Third Edition (VABS-3), Adaptive Behavior Assessment Scales- Third Edition (ABAS-3), Diagnostic Adaptive Behavior Scale (DABS), and the Adaptive Function subscale of the Developmental Profile – Fourth Edition.[21]

Consider alternative explanations for the historical and behavioral data, generate a differential diagnosis, and diagnose autism if indicated.

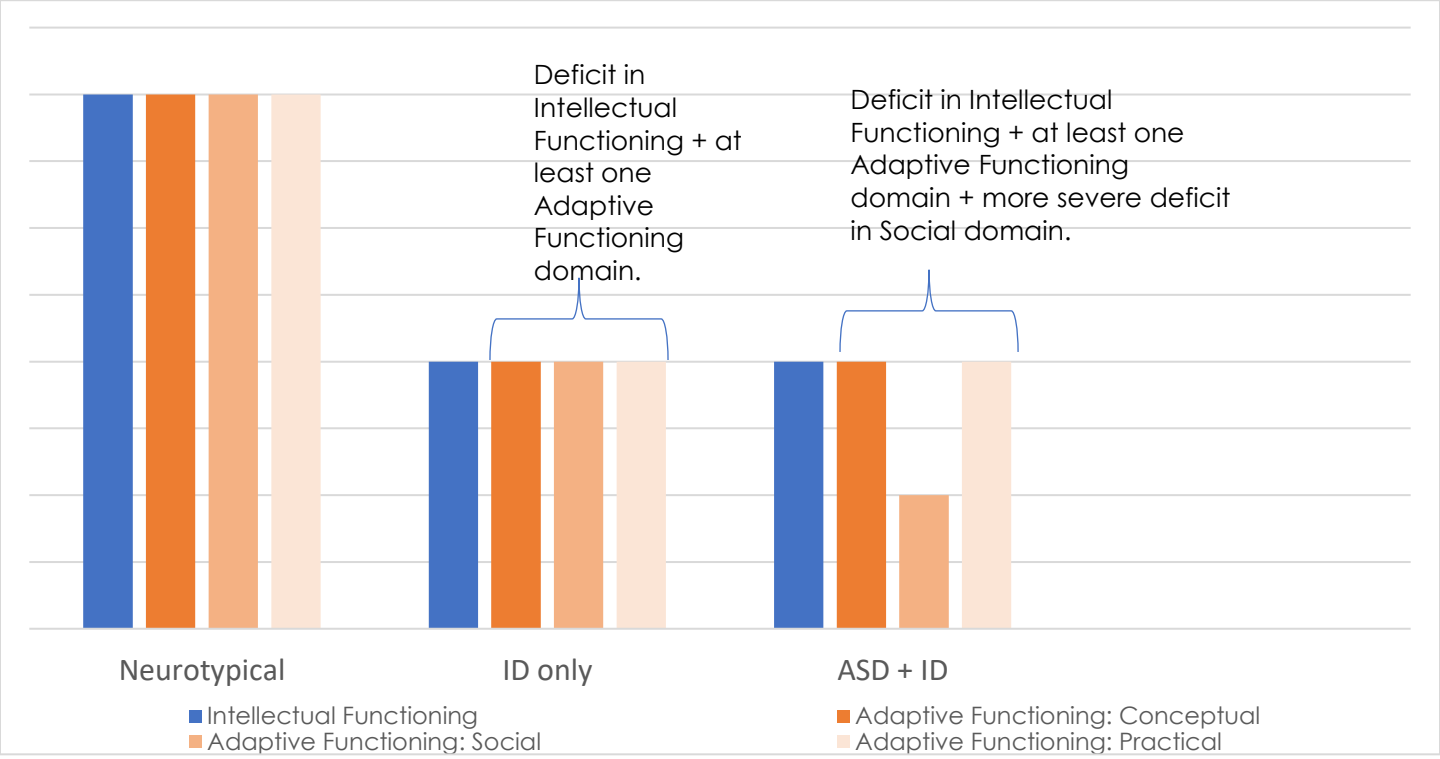
Key distinguishing features of common pediatric mental health concerns versus autism include:

Clinical concern	Similarities to autism	Differences from autism
Speech/language (S/L) disorders	S/L disorders including expressive and receptive language disorders and pragmatic language disorders are common in autistic individuals.	Children with S/L disorders typically: • compensate through nonverbal communication (typical response to name, social overtures, facial expressions, gestures, and eye contact), and • have a typical range of interests and behaviors without repetitive or sensory-related interference
Intellectual Disability	About 31% of autistic children have ID, and an additional 25% have "borderline IQ."	In individuals with ID but not autism, social communication & interaction are generally commensurate with *the* individual's developmental/cognitive level
Anxiety disorders	Most common co-occurring anxiety disorders in ASD: • Social Anxiety Disorder • Generalized Anxiety Disorder • Specific Phobia	Anxiety symptoms are less pronounced or disappear in familiar settings.
Depression	Many depression symptoms may be difficult to differentiate from autism, e.g. • Flat affect • Anhedonia • Social withdrawal • Sleep problems	Depression typically involves a change from baseline and a loss of functioning.
ADHD	Both autism and ADHD can involve difficulty keeping	Children with ADHD generally have few problems with social understanding and

[21] DABS (aaidd.org)

Clinical concern	Similarities to autism	Differences from autism
	friends, emotional dysregulation, poor organization, and sensory difficulties.	nonverbal communication like eye contact and gestures. Social reciprocity is generally intact, though problems with impulsivity/behavioral regulation can interfere.
Psychotic disorders	Schizophrenia and related disorders often include social deficits, poverty of speech, unusual use of language, blunted affect, and overvalued ideas.	Autism has age of onset in early childhood, but psychotic disorders typically occur in older teens and young adults.

A note on autism and intellectual disability: For a child to qualify for diagnoses of both autism and intellectual disability, social functioning must be more impaired than the other domains of functioning. Determining and comparing level of functioning in multiple domains is typically outside the scope of evaluations done in non-specialist settings (which is why known or suspected ID generally puts children at least in the yellow/intermediate complexity triage category). It is also important to keep in mind that about a third of autistic people also have intellectual disability, so it is important to verify that an autistic patient has had a cognitive evaluation, including an evaluation for intellectual disability if there is clinical suspicion.



Children's National

Write a brief report for family and put a copy in the medical record.

Following an autism evaluation, families should be given documentation of test scores, diagnosis, and primary recommendations so they can be shared with their child's insurance company, school, state department of disability services, etc. if they so choose.

At Children's National, the Cerner dot phrases **=psCARS2ST** and **=psCARS2HF** contain templates for this documentation. The dot phrases can be used to document findings in Cerner. The text can then be copied onto letterhead (e.g., using the Letter function in Cerner) so families can be provided with a copy.

Discuss your findings with the family via a feedback session.

The appointment at which a child is diagnosed with autism is almost universally momentous for families; completing online modules and seeking clinical supervision before giving the diagnosis is highly recommended.[22] Bringing a child for developmental evaluation can be terrifying for parents, who are being asked (often by a stranger in a position of authority) to describe in detail every possible weakness of a child they love dearly. The clinician's task in a feedback session is to partner with families to contextualize their child's developmental difficulties via the diagnostic conceptualization. This includes using the family's language for behavior when possible and sharing recommendations for treatment while assessing a family's comfort, willingness and ability to carry them out on a daily basis. Genuinely sharing joy in the child's strengths, potential, and individuality with the family, and allowing them time and conversational space to react without their child

Autistic Self Advocacy Network Statement on Neurodiversity

Neurodiversity means that no two brains are exactly the same. Every person has things they are good at and things they need help with, and there is no such thing as a "normal" brain. The neurodiversity movement says that people with brain-based disabilities (like autism, intellectual disabilities, learning disabilities, or mental health disabilities) should be accepted and included in society just like neurotypical people (people without brain-based disabilities). The neurodiversity movement also says that we shouldn't try to cure or get rid of autism. Autistic people should be allowed to exist, and we should work to make sure that everyone gets the accommodations we need to reach our full potential. ASAN believes in the ideas of the neurodiversity movement, and works to make sure all autistic people are celebrated for our differences instead of excluded.

What We Believe - Autistic Self Advocacy Network (autisticadvocacy.org)

[22] Autism Speaks Providing Feedback Toolkit and Video Guide to Delivering Feedback.pdf (autismspeaks.org). CDC Providing Feedback for Developmental Tools https://www.cdc.gov/ncbddd/actearly/autism/case-modules/diagnosing.html

in the room, can be critical for expediting next steps for the family. The feedback session should set the tone for the family's interactions with systems of autism care, providing critical education related to their child's rights (e.g., school setting, mental health parity in insurance-based settings) and a parent's key role as advocate for their child.

Parent reactions to being told a new autism diagnosis vary widely, and include shock, anger, sadness, validation ("finally someone is listening"), and acceptance ("I don't care what we call this – she's still the same kid – how can I help her?"). Parents should be encouraged to seek out positive, strengths-based, evidence-based sources of information and supports about autism (see the "Advice from Experienced Autism Parents" handout in the Appendix).[23]

In particular, the potential for stigma should be addressed by exploring how the autism diagnosis fits in their social and cultural context. Key questions and counseling points include:

Topic	**Sample Language**
Definitions and orientation	What does the word "autism" mean to you? Do you know anyone with autism?
Normalizing neurodevelopmental differences	Neurodiversity adds to our collective social progress. There is a long history of contributions and accomplishments made by people with brain-based differences including autism. You can try searching the internet for "autism role models" and "autism self advocates" to learn more.
Educating families about variability in outcomes	Autism makes social learning hard, but it does not mean children cannot learn. Autistic people often excel at self-directed learning and may be very strong in some areas of learning. Each autistic child is unique. Dr. Stephen Shore, an autistic autism researcher and advocate, famously said "If you've met one person with autism, you've met one person with autism."[24] Now that your child has an autism diagnosis, we can work together on building a plan to maximize their learning by using their strengths.
Providing a clear path forward	You are receiving a lot of advice and information today. I recommend that your top priority in the next month should be _____.

[23] Other strengths-based resources for families, written by autistic self-advocates, include the Autistic Self Advocacy Network books (Books - Autistic Self Advocacy Network (autisticadvocacy.org)), the Neurodivergent Narwhal (The Signs of Autism (wordpress.com)), and the Autistic Women and Nonbinary Network (Resource Library - Autistic Women & Nonbinary Network (AWN) (awnnetwork.org)).

[24] Flannery, Kathleen A, and Robert Wisner-Carlson. "Autism and Education." *Child and adolescent psychiatric clinics of North America* vol. 29,2 (2020): 319-343.

Consider potential disparities, biases, and barriers.[25]

Currently, parents of children across racial and ethnic backgrounds report concerns about their child's development at similar ages, and there is no compelling evidence that rates of autism or presentation of core autism symptoms differ in different racial or ethnic groups.

Historically, autism was under-diagnosed in diverse populations. In recent years, differences in prevalence rates between diverse groups have diminished.[26] However, disparities in access to care, and the downstream effects of these disparities, continue to exist. Minoritized children are more likely to be diagnosed late/after three years of age, less likely to be referred for a developmental evaluation, more likely to receive a non-autism diagnosis prior to being diagnosed with autism, and more likely to face barriers in accessing high-quality health care services.[27] Minoritized children are also less likely to receive intensive services.[28] Restricted access to early diagnosis and intensive supports, in turn, may be responsible for the higher rates of accompanying intellectual disability in black children compared to white children.[29]

A variety of factors may contribute to these disparities. For the primary care clinician, close attention should be paid to:

- The family's access to information about developmental disorders, including autism. Minoritized families may have limited access to accurate, evidence-based information about developmental disorders.[30]
- Bidirectional factors within the family-provider relationship. Consider the family's cultural experience with healthcare providers, and any biases the clinician may hold.

[25] Section author: Kirsty Coulter, PhD.

[26] Maenner, Matthew J et al. "Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2016." *Morbidity and mortality weekly report. Surveillance summaries (Washington, D.C. : 2002)* vol. 69,4 1-12. 27 Mar. 2020.

[27] Miller, Lauren E et al. "Characteristics of toddlers with early versus later diagnosis of autism spectrum disorder." *Autism : the international journal of research and practice* vol. 25,2 (2021): 416-428. Mandell, David S et al. "Disparities in diagnoses received prior to a diagnosis of autism spectrum disorder." *Journal of autism and developmental disorders* vol. 37,9 (2007): 1795-802. Bishop-Fitzpatrick, Lauren, and Amy J H Kind. "A Scoping Review of Health Disparities in Autism Spectrum Disorder." *Journal of autism and developmental disorders* vol. 47,11 (2017): 3380-3391. Magaña, Sandra et al. "Racial and ethnic disparities in quality of health care among children with autism and other developmental disabilities." *Intellectual and developmental disabilities* vol. 50,4 (2012): 287-99.

[28] Yingling, Marissa E et al. "Treatment Utilization Trajectories among Children with Autism Spectrum Disorder: Differences by Race-Ethnicity and Neighborhood." *Journal of autism and developmental disorders* vol. 49,5 (2019): 2173-2183. Tomczuk, Liza et al. "Who gets coached? A qualitative inquiry into community clinicians' decisions to use caregiver coaching." *Autism : the international journal of research and practice* vol. 26,3 (2022): 575-585.

[29] Constantino, John N et al. "Timing of the Diagnosis of Autism in African American Children." *Pediatrics* vol. 146,3 (2020): e20193629.

[30] Iadarola, Suzannah et al. "Understanding stress in parents of children with autism spectrum disorder: A focus on under-represented families." *International journal of developmental disabilities* vol. 65,1 (2019): 20-30.

- Some minoritized families may be less likely to report autism-specific concerns outside of the context of an autism-specific structured interview.[31]
- Families may also worry about stigma or discrimination towards their child or family when sharing concerns about their child's development.

To reduce disparities, clinicians are encouraged to use similar procedures for determining if a child needs a referral for further evaluation, and to take care that neurodevelopmental causes of behavioral symptoms are considered in all children.

Resources in Other Languages

The CDC Learn the Signs Act Early materials are available in multiple languages: Get Free "Learn the Signs. Act Early." Materials | CDC. The Autism Speaks 100 Day Kit has been translated into 13 languages: Non-English Resources | Autism Speaks.

The following books and websites in Spanish may be helpful for some families:

- Organization for Autism Research Recursos en español: https://researchautism.org/families/spanish-language-resources/
- Autismo: Guía para Padres y Profesionales by Matías Cadaveira and Claudio Waisburg
- Diez cosas que todo niño con autismo desearía que supieras by Ellen Nothbom
- Child Mind: https://childmind.org/es/temas/autismo/
- Recursos TEA: https://recursostea.com/.
- Padres Sin Límites: https://padressinlimites.com/..
- Autismo Diario: www.autismodiario.com
- Autism Speaks: www.autismspeaks.org (Haga clic en "en español")
- We're Amazing, 1 2 3! (Sesame Street book for children) – disponible en español
- Just Right for You by Melanie Heyworth (book for children) – disponible en español

[31] Donohue, Meghan Rose et al. "Race influences parent report of concerns about symptoms of autism spectrum disorder." *Autism : the international journal of research and practice* vol. 23,1 (2019): 100-111.

CHAPTER 3: BUILDING AN AUTISM TREATMENT PLAN.

Assess for missing elements of the autism diagnostic evaluation, and refer as needed.

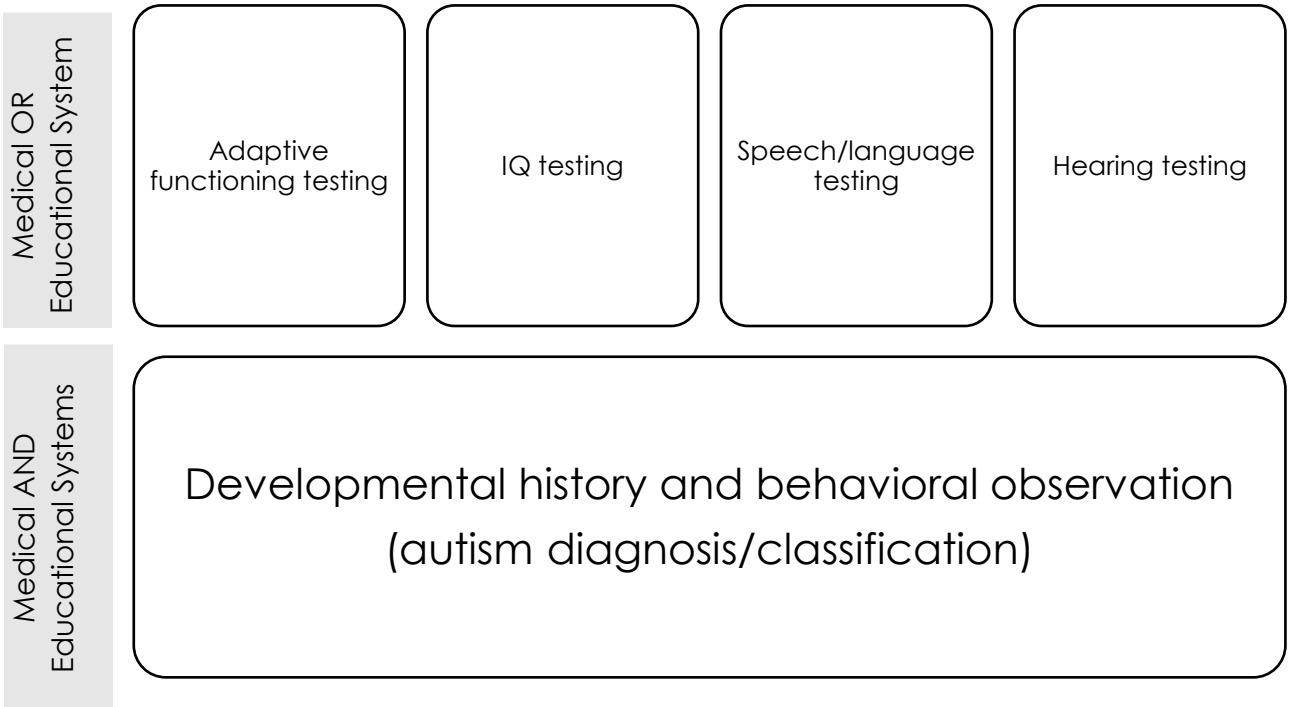
When assessing whether an autistic child is receiving appropriate services, it is helpful to first assess whether they have received a thorough diagnostic evaluation. Consider three main questions:

Has the child gone through the entry point ("front door" initial application process) for at least the medical, educational, and federal/state systems of care? Typically this entails a medical diagnosis of autism, an eligibility evaluation via early intervention programming or the school setting to obtain specialized supports and/or accommodations (e.g., IFSP, IEP, 504 Plan), and parent-submitted AIDD (DDA) and Medicaid Waiver applications.

Has the child been referred for all of the elements of the comprehensive diagnostic evaluation for autism (history, behavioral observation, adaptive functioning measurement, cognitive (IQ) testing, speech/language testing, hearing testing)? These evaluations do not all need to be done in the same system of care. For example, often autism is first diagnosed by a medical provider, and the school system then does speech/language and cognitive testing as part of the IEP evaluation.

Has the etiology for autism been considered (e.g. via referral to Genetics)? The possibility of genetic testing should be discussed with autism families; often this is most thoroughly accomplished through referral to Genetics.

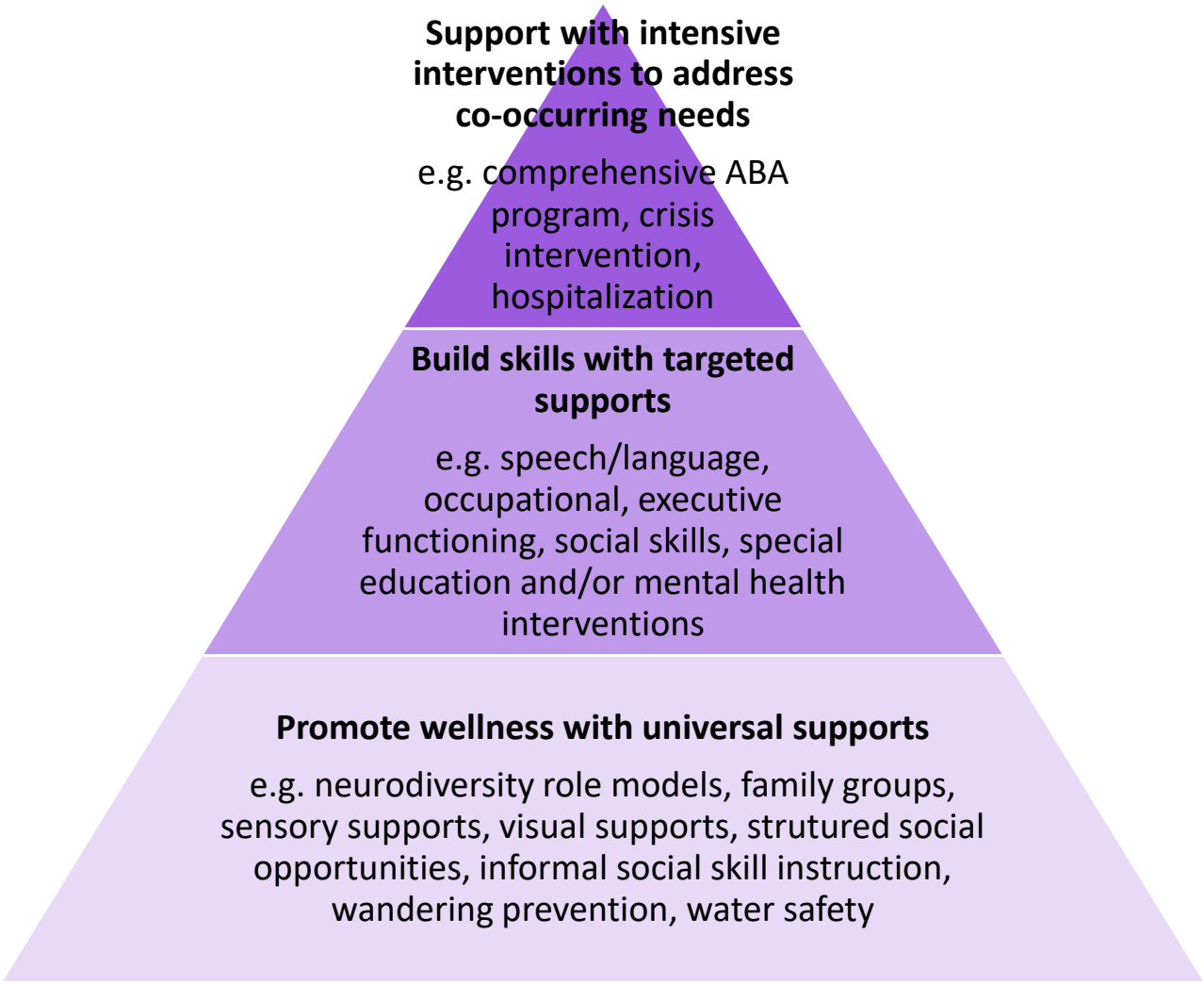
Elements of the Full Autism Diagnostic Evaluation



Case management support can be invaluable in making sure that these diagnostic referrals do not get lost in the flurry of treatment referrals, which often appropriately feel more urgent to families of newly diagnosed children. However, the diagnostic evaluations are the foundation of a comprehensive treatment plan. Because some wait lists stretch for years, supporting overwhelmed families to follow through with multiple referrals can be critical to optimizing outcomes and accessing resources when the child is older.

Triage the intensity of the family's needs.

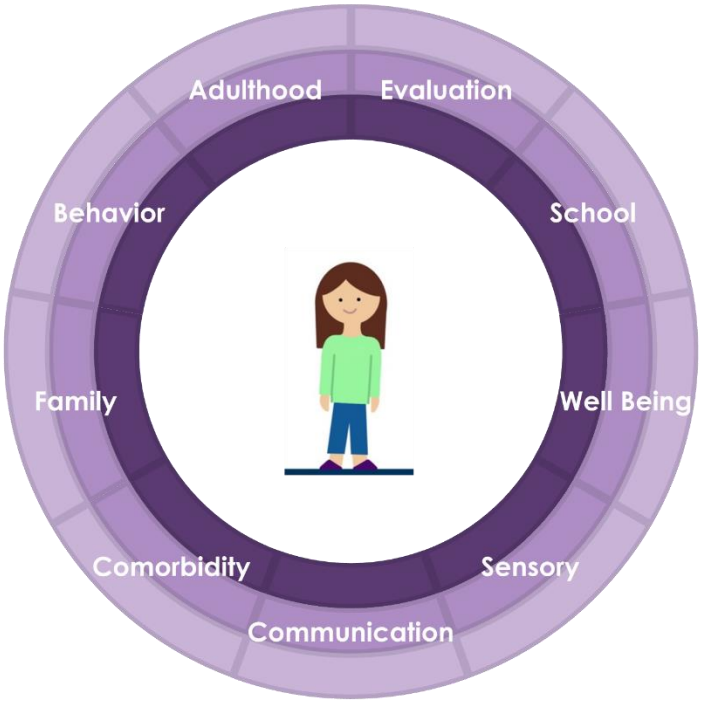
Virtually all autism families can benefit from low intensity supports including social skills instruction, visual supports like social stories for non-routine events, and anticipatory guidance around safety and future developmental touchpoints. Some autism families benefit from additional targeted supports, which can be achieved in low intensity outpatient settings, to address areas of need like speech/language disorders, motor coordination problems, learning disabilities, and mental health problems that would benefit from therapy and/or medication treatment. At times, autism families may present with intensive support needs related to skill development, co-occurring behaviors,



coping difficulties, or safety, potentially including self-contained and/or highly specialized/therapeutic classroom placements, comprehensive treatment programs (e.g., 15-20 hours per week), and a higher level of care, such as hospitalization, for stabilization when in crisis. Families often move back and forth along this continuum depending on developmental stage, environmental stressors, protective factors, and support availability. Determining the present intensity of needs guides treatment planning.

Build a treatment plan leveraging all systems of care.

Treatment plans for autistic children should be as individual as children themselves. Initial diagnosis of autism allows providers to specify areas of need that should be addressed by specialist providers (e.g., speech-language therapy, ABA, occupational therapy, feeding therapy, physical therapy); however, individualization of intervention targets is accomplished through careful, data-driven assessment of needs by providers within their specialty area. This includes specification of level of intensity for intervention. It is a diagnostician's role to outline the scope of treatment, involving all systems of care if necessary, and educate families about the steps necessary to obtain these supports. Key domains of functioning to consider include:



More specifically, support needs in each domain will continually vary, from minimal (universal) support needs to maximum (intensive) supports, depending on the interplay between the child's and family's needs and the fit with the ever-changing environmental demands. An autism treatment

plan should be dynamic, responding to challenges and developmental issues as they arise. Specifically the following supports can be considered:

Domain of Need	Intensive Supports	Targeted Supports	Universal Supports
Evaluation Needs	Psychoeducational/ neuropsychological evaluation to address learning and/or behavior needs and revise treatment and educational programming; psychiatric/psychological evaluation of comorbidities to build treatment plans	Periodic (often annual) evaluation using standardized measures to track progress and update treatment goals (Speech, OT, PT, at times achievement)	Medical and educational evaluation to document needs related to autism
Communication Needs	High frequency SLT through school and insurance-based programming (2-3/week) or specialized interventions including addressing potential comorbidities (e.g., apraxia, selective mutism)	Weekly speech therapy to address core (including AAC) and/or higher-order language needs; Parent-mediated interventions to teach and support social communication	Visual supports, total communication approaches including emphasis on non-speaking communication approaches, accommodations including reduced language use and complexity in social and learning settings
Behavioral, Social, and Executive Functioning Needs	Comprehensive and/or high intensity interventions to address social learning and executive needs, coping problems, and interfering behaviors	Individual and/or group intervention to address social skill, executive function, and social learning needs; Parent-mediated interventions to teach social learning, flexibility, and executive supports, and play skills	Visual supports, flexibility from adults, deciphering *can't vs. won't* when conflicts arise,[32] accommodations and understanding of autistic differences (allowing breaks, differences in eye contact patterns), use of student's interests to support learning and behavior
Sensory Needs	High frequency OT to address the intersection of sensory regulation problems, motor coordination and adaptive functioning weaknesses which may include in-home supports; intensive OT via summer programming	Weekly occupational therapy in school or clinic settings to address sensory regulation, motor skills, and (often) planning and organization weaknesses impacting adaptive skills	Accessible and inclusive environments at home, school, & in the community; Accommodations for sensory overload in all settings; opportunity for sensory-based coping in all settings

[32] Distinguishing when a child "can't" do a target behavior because of brain-based differences, versus when they "won't" do the behavior because of defiance, is a powerful framework for determining effective behavioral approaches.

Domain of Need	Intensive Supports	Targeted Supports	Universal Supports
School Needs	Specialized educational placement for comprehensive support of learning, social, and behavioral needs; Home/Hospital programming, BIP/FBA, crisis management services	Specialized instruction to address learning needs associated with ASD-related weaknesses in attention, EF (including flexibility), language, social cognition, and emotional coping	Visual supports, flexible school team that understands autistic students needs, use of student's interests to support learning and behavior
Co-occurring Conditions and Safety Needs	Multidisciplinary team-based therapy and family supports to address unsafe and interfering behaviors or maladaptive coping strategies which may include psychiatric treatment, intensive feeding intervention, social work support, comprehensive ABA programming, crisis management and intervention services, hospitalization	Individualized and/or group-based outpatient therapy to address co-occurring problems (sleep, feeding, toileting, psychiatric, problem behaviors), which may include problem-focused ABA program, CBT, medication treatment, and ongoing consultation with developmental specialists	Safety protocols including adequate home locks and door alarms, water safety protocols including regular and special needs swim instruction, appropriate adult supervision, ID bracelets and tracking devices particularly for non-speaking youth
Well-Being Needs	See above; Intensive supports for emotional distress/acute coping difficulties including multidisciplinary team-based therapy and family supports, psychiatric treatment, crisis management and intervention services, hospitalization	Self-directed learning via literature written by autistic authors, participation in autistic identity affirming social skills groups, individualized therapy and/or counseling with trusted adults to support identity development and if present, co-occurring problems that can be managed through weekly outpatient therapy (e.g., anxiety)	Acceptance and Integration in accessible and inclusive environments at home and in the community (including school); Integrated healthy autistic identity which includes recognition of personal strengths and the importance of self-advocacy for needs; Understanding of neurodiversity frameworks
Family Support Needs	Respite services, case management services for resource navigation, educational advocacy and legal support when experiencing school, insurance, or agency-based barriers	Self-directed learning via autism-focused literature; Participation in state and local parent support programming; Coping supports including therapy for parents; Parent coaching to develop therapeutic skills to address autism-related weaknesses in communication, play, executive skills, and behavior	Education about autism with a knowledge base stemming from evidenced-based research, the lived experience of autistic people and their families, and neurodiversity frameworks; Opportunities for self-care; Acceptance and Integration in accessible and inclusive environments; Connection to specialized health insurance for Medicaid families and state and

Domain of Need	Intensive Supports	Targeted Supports	Universal Supports
			federal resource programs (waivers)
Transition to Adulthood Needs	Comprehensive ABA or high intensity OT targeting life skills at home and in the community; Participation in specialized internship programs such as Project Search; Participation in supported living experiences via summer or college programming	Individual or group-based intervention programs focused on the intersection of social, executive function, and adaptive skills; participation in vocational programming with integrated job coach; weekly OT or problem-focused ABA targeting life skills development	Comprehensive transition plan via IEP; Transition plan for medical care from pediatric to adult settings; Connection to state-based programming such as Department of Rehabilitative Services; Access to state and federal financial resources if eligible (DDA); Parent/caregiver education

Evidence-Based Interventions

Guiding families to the right programs and providers can be daunting. There are a large number of overlapping evidence-based autism therapies (and many more non-evidence-based autism therapies), covered to various degrees by different insurances, with varying geographic availability and wait lists. Broadly categories of evidence-based interventions include:

Type of Therapy	Sample Language for Describing the Therapy to Families	Example Programs
Applied Behavior Analysis (ABA)	Understanding what happens just before and just after a child's behavior helps adults know how to respond. For example, if a child gets a reward every time they do something, they are more likely to repeat it.	General ABA programs Pivotal Response Training* Discrete Trial Teaching Early Start Denver Model*
Naturalistic Developmental Behavioral Approaches[33]	Intervention focusing on techniques to increase motivation and performance (child-preferred activities in the natural environment, incidental teaching, consideration of developmental prerequisites). Informed by ABA methods.	Early Start Denver Model* Pivotal Response Training* Early Achievements Program Joint Attention Symbolic Play Engagement and Regulation (JASPER)* Project ImPACT*
Developmental Approaches	Focus on improving certain skills, like motor, communication, or daily living skills, in a way that is appropriate for the child's age and level of development.	Speech/language therapy Occupational therapy Physical therapy
Educational Approaches	Deliberate modifications to the classroom environment, materials, demands, and instruction to accommodate needs of autistic students with	Treatment and Education of Autistic and Related Communication-Handicapped Children (TEACCH)

[33] Schreibman L, Dawson G, Stahmer AC, Landa R, Rogers SJ, McGee GG, Kasari C, Ingersoll B, Kaiser AP, Bruinsma Y, McNerney E, Wetherby A, Halladay A. Naturalistic Developmental Behavioral Interventions: Empirically Validated Treatments for Autism Spectrum Disorder. J Autism Dev Disord. 2015 Aug;45(8):2411-28.

Type of Therapy	Sample Language for Describing the Therapy to Families	Example Programs
	weaknesses in social learning and promote new skill/content acquisition	
Social Approaches	Teaching children what to expect in social situations can help improve relationships and reduce stress.	Social Stories Social Thinking Social skills groups like PEERS
Cognitive Behavioral Therapy Informed Interventions	Thoughts, feelings, and behaviors are all related. Helping a child see a new way of thinking about a situation can help them feel and act differently.	Facing Your Fears (for anxiety) Unstuck and On Target (for cognitive inflexibility)
Parent-Mediated Intervention	Parent training and coaching to provide consistent intervention for joint attention, social communication, and behaviors. Studied as a method for augmenting of therapist-led interventions.	Hanen Research Units in Behavioral Intervention (RUBI) *See above for behavioral interventions with parent training components

More detailed analysis of the evidence base for different approaches can be found at the National Clearinghouse on Autism Evidence and Practice (NCAEP | The National Clearinghouse on Autism Evidence and Practice (unc.edu)) and the National Standards Project (Manual (asatonline.org)). Parent handouts on interventions are included in the Appendix. Of note, the Developmental, Individual Differences, Relationship-Based model (also called "Floor time") and Relationship Development Intervention (RDI) are supported by less evidence than ABA-based models.

Tips for advocating at school

Receiving a medical autism diagnosis does not guarantee access to special education services. The child's autism must impact their ability to access the curriculum. According to the version of IDEA passed in 2004, the "curriculum" includes "nonacademic and extracurricular services and activities." Children with disabilities must be given equal opportunity to participate meaningfully in both the academic *and* the non-academic aspects of school.

Public school systems determine whether a child is eligible for special education services through a formal process. In general, IEPs offer more supports and safeguards than 504 Plans.

Parents must request an IEP in writing; a template letter is in the Appendix. Parents should make sure to have a "paper trail" of when they requested the IEP, because schools must follow a federally mandated process and timeline in responding to the request. Emailing the letter is often sufficient, or parents can print out the form letter from the appendix and ask the school to provide the parent with a signed copy acknowledging receipt. When there are barriers to submitting the letter, with the parent's consent the provider can fill out the form letter and a release of information for the clinic to contact school, and the clinic can fax the parent's letter to the school.

Attending IEP meetings is often stressful for parents. Providing anticipatory guidance about what happens in an IEP meeting can be very helpful. Points to consider:

- Meetings often are very formal and can be driven by process more than content.
- There will be many people at the table. Parents can bring their own supports (including educational advocates and/or lawyers).
- The school district must provide language interpretation if requested.
- Parents should be given a copy of the proposed IEP in advance.
- Placement determination is LAST in the meeting. The many decisions made up to that point about accommodations, etc. justify the placement. So, it is important to advocate at every step throughout the meeting, and not just wait until the end when placement is decided.
- Parents have rights to appeal if they don't agree with what is decided at the meeting.

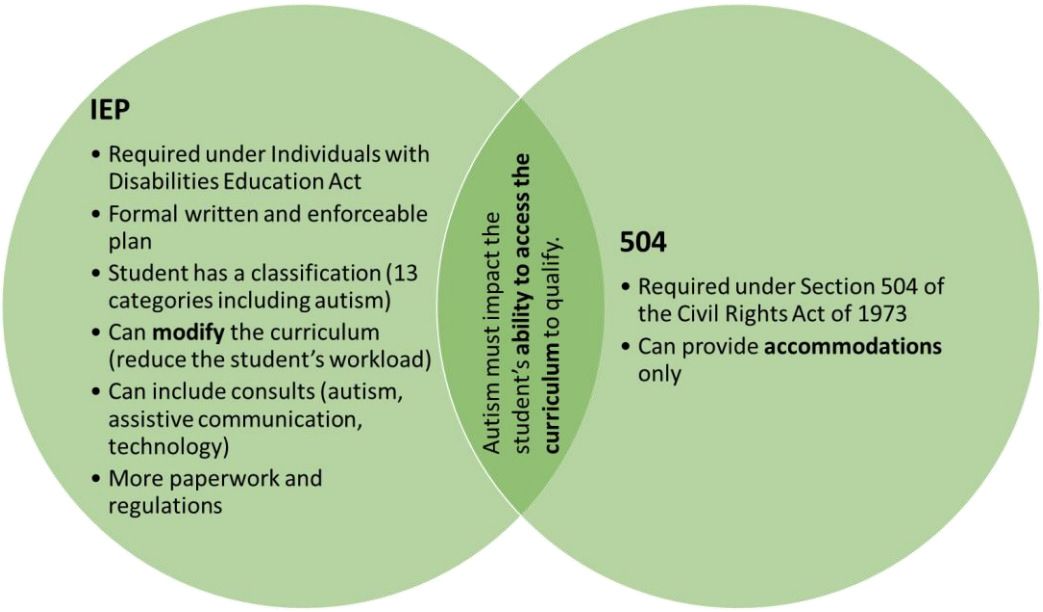
Questions to consider when an autistic child is struggling in school:

• Is there a particular class or time of day that is hard? (Consider learning disorder, executive function weaknesses, sensory overload, stimulant crashes and hunger, teacher/peer relationships).

• Are there IEP changes that could help (additional accommodations, Functional Behavioral Analysis with Behavioral Intervention Plan, more specific goals, visual schedules, lower teacher:student ratio, ABA based curriculum, assistive communication device evaluation, etc.)?

• Is the child being bullied? (If so, talk to school first. If school is unresponsive, consider filling out the district's bullying report form.)

• Parents can request an emergency IEP meeting at any time, for any reason.



A note on informal removals versus suspensions:

Children with disruptive behaviors, including autistic children, are sometimes sent home before the end of the school day without being formally suspended. This reduces paperwork burden, but has

the disadvantage of not creating a "paper trail" that can be used to justify more intensive special education supports despite the child missing out on instructional time. There are limitations on how long a student can be formally suspended before a formal IEP process must be followed,[34] but these rules are circumvented with informal removals. The US Department of Education provided additional guidance in 2022 defining informal removals and specifying that in some circumstances informal removals can be a denial of a Free and Appropriate Public Education under IDEA.[35] The Department of Education recommends that if their child is given an informal removal, parents should:

- *"Document the removal and ask whether the removal is a suspension.*
- *Immediately request an IEP meeting to discuss behavior and potential updates to the Behavior Intervention Plan.*
- *Connect with the Parent Center in your state to access training and individual assistance on your rights related to school discipline."* Parent Center contact information is below:
    - DC: Advocates for Justice and Education https://www.aje-dc.org/
    - MD: Parents' Place of Maryland https://www.ppmd.org/
    - VA: Formed Families Forward https://formedfamiliesforward.org/ and Parent Educational Advocacy Training Center http://www.peatc.org
    - National listing: Find Your Parent Center | Center for Parent Information and Resources (parentcenterhub.org)

Legal resources when parents need additional help advocating include:

- DC: Children's Law Center
- MD: Disability Rights Maryland
- VA: https://www.doe.virginia.gov/special_ed/resolving_disputes/due_process/legal_advocacy_groups.pdf

Ask about what other interventions, including alternative medicine, that families are planning to try.

Autism families very commonly seek alternative medicine treatments, and often do not feel comfortable discussing this with their providers. The Association for Science in Autism Treatment website includes resources for parents including a New Parent Information Packet, explanations of evidence-based treatments, and guides on evaluating sources of information and research studies.[36] The National Center for Complementary and Integrative Health website provides a helpful family-facing guide for evaluating websites (Finding and Evaluating Online Resources | NCCIH (nih.gov)).

[34] See slide 17: OSEP Discipline & Behavior Guidance Webinar (parentcenterhub.org).
[35] Discipline Discussions: Informal Removals Matter | Office of Special Education and Rehabilitative Services Blog.
[36] Autism Treatments | Association for Science in Autism Treatment (asatonline.org)

State-Specific Resources

Washington, D.C.
In 2020 the DC Collaborative for Mental Health in Pediatric Primary Care published Autism Spectrum Disorders Toolkit for Pediatric Primary Care Providers in the District of Columbia Overview and Primer to provide primary care providers with the tools to help families navigate the developmental disabilities landscape in Washington, DC. The toolkit is free online at Autism Spectrum Disorders Toolkit for Pediatric Primary Care Providers in the District of Columbia (dchealthcheck.net).

The DC Autism Collaborative has a collection of resources for providers and families: (https://www.childrensnational.org/in-the-community/child-health-advocacy-institute/community-mental-health/mental-health-initiatives-and-activities/dc-autism-collaborative/dc-autism-collaborative-resources).

Virginia
The Virginia Mental Health Access Program Guide for Promoting Child and Adolescent Behavioral and Mental Health in Primary Care (VMAP Guidebook_6.7.22-1.docx) has a wealth of information and resources, including a chapter on Virginia Resources for Pediatric Mental Health (page 46) and a chapter on autism (page 189).

Maryland
The Maryland Behavioral Health Intervention in Primary Care Practice (BHIPP, Home (mdbhipp.org)) and Pathfinders for Autism (Pathfinders for Autism – Improving the lives of individuals with autism and the people who care for them) websites include professional education and referral information.

CHAPTER 4. ANTICIPATORY GUIDANCE AND MANAGING CHALLENGES.

Building physical and mental health

Like with all patients, pediatric providers for autism families have the opportunity to nudge developmental trajectories through early intervention, preventing "small" issues from becoming "big" issues.

When should parents tell their child they are autistic?
"Findings suggest that telling a child that they are autistic at a younger age empowers them by providing access to support and a foundation for self-understanding that helps them thrive in adulthood."
- Oredipe et al. 2023

Autistic adults with and without intellectual disability are at increased risk of death by suicide and of premature death due to all causes.[37] Most psychiatric diagnoses are 2-10 times more common in autistic individuals.[38] There are a wide variety of factors contributing to this disease burden, including genetic factors, social determinants of health like social isolation and access to care, and adverse experiences including injury and abuse.

Strong support networks that are able to flexibly respond to challenges, and offer access to positive role models can help optimize outcomes for autism families. Consider introducing families to the work of autistic self-advocates (e.g. the Autistic Self Advocacy Network) and other "autism heroes" who speak and write about their experiences and successes.

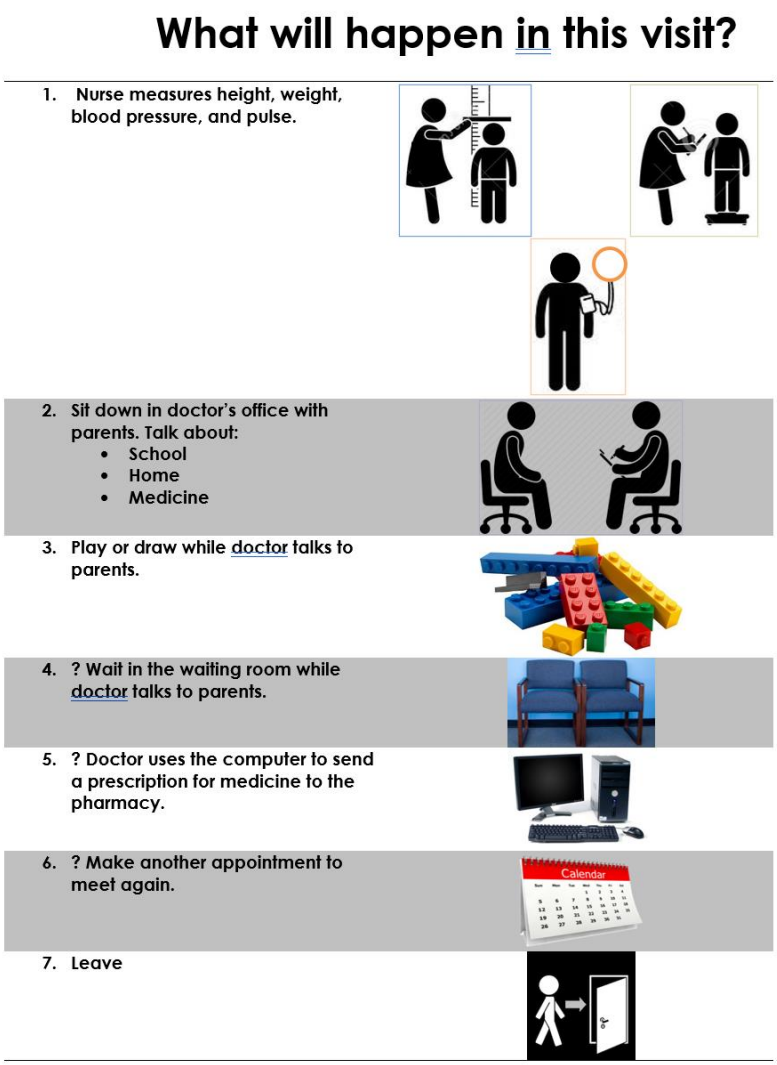
Supporting autistic children during medical visits

At Children's National, the Autism Behavioral Consult (ABC) team offers providers and families consultation and resources to improve safety and access to medical services, and reduce medical trauma for autistic patients.[39] The ABC team has an extensive free online library of resources for visual learners, including visual supports for common medical procedures.

The Massachusetts General Hospital Guide to Medical Care in Patients with Autism Spectrum Disorder provides an overview as well as specialty-specific information. AAP has recently published a spiral-bound book called *Communicating Visually in Pediatrics* with step-by-step color illustrations of

[37] Hirvkovsky et al. Psychological Medicine 2020; Hirvikoski et al. 2016. Oredipe T, Kofner B, Riccio A, Cage E, Vincent J, Kapp SK, Dwyer P, Gillespie-Lynch K. Does learning you are autistic at a younger age lead to better adult outcomes? A participatory exploration of the perspectives of autistic university students. Autism. 2023 Jan;27(1):200-212. doi: 10.1177/13623613221086700. Epub 2022 Apr 11. PMID: 35404 160.
[38] Lai et al., Lancet Psychiatry, 2019. Cooper et al., Eur J Social Psychology, 2017.
[39] Autism Behavioral Consult | Children's National Hospital (childrensnational.org)

common medical procedures.[40] A visual rating scale for assessing difficult feelings in autistic children is provided in the Appendix.



In addition, consider the following tips for communicating with autistic patients:

General considerations:

- **Assume competence.** Make requests directly to the patient.
- Look the patient in the eyes, but don't ask them to look at you.
- Notice and respond to nonverbal communication.
- Don't treat an adult/big kid like a little kid just because they don't use spoken language.
- Look for ways to share delight with the patient and family.

Communication:

- Explain what will happen in advance
- Use visual supports, even if they are sketched during session on scrap paper (see visual schedule example at right and parent handout in Appendix).
- Use the same length of sentence as the person.
- Talk as little as possible and use language concretely, as opposed to figuratively.
- Talk SLOWLY and allow ample time to answer.
- Keep it short, even for people who seem fully verbal.

Sensory:

- Ask permission and/or prepare the person before touching them.
- Silence pager/cell/alarms.
- Cover light switches.
- Have fun distractions (e.g. sensory fidgets) available.

Safety:

- Be aware of potential exit/elopement routes
- A printed out stop sign on a door can sometimes make an eloping child pause for a critical moment

[40] Communicating Visually in Pediatrics [Paperback] | AAP

Anticipatory guidance topics for autism families

Autism families often benefit from anticipatory guidance on common safety and behavioral difficulties. It can be helpful to provide parents with information on the following topics:

Topic	Facts and Resources
ABA: Evidence and controversy	Most of the evidence-based interventions for autism use the principles of ABA.[41] The CDC parent-facing website states, "ABA encourages desired behaviors and discourages undesired behaviors to improve a variety of skills. Progress is tracked and measured."[42] Many families will read negative information about ABA online. Common criticisms are that historically ABA has included punishment, overfocused on compliance at the expense of self-advocacy, and has had the goal of minimizing behaviors rather than improving functioning. Like any therapy, ABA as practiced by an individual provider with an individual child can be a poor fit. Parents should be empowered to research treatment options for their child, and to search for a different provider if they do not feel that their child is benefiting from a therapy. Some resources for parents on ABA and other evidence-based treatments: The Controversy Around ABA – Child Mind Institute Autism Treatments | Association for Science in Autism Treatment (asatonline.org) A parent handout on this topic is included in the Appendix.
Emergencies: agitation, wandering, and unintentional injury including drowning	Individuals with autism are 3x as likely to die of unintentional injury, with wandering leading to drowning a leading cause of death.[43] Tips and resources include: • Always say "autism" when calling 911 because many areas have specially trained responders. Call the local mental health crisis line rather than 911 when possible for children exhibiting agitation. • Safety information from AAP for parents of autistic children: Keep Kids with Autism Safe from Wandering: Tips from the AAP - HealthyChildren.org • Safety toolkit for autism families: NAA's Big Red Safety Box® - National Autism Association • Consider MedicAlert/GPS device/door alarms, and make a wandering Emergency Plan: FWEP.pdf (nationalautismassociation.org) • Information on water safety from Autism Speaks: Swim and Water Safety | Autism Speaks

[41] Hyman SL, Levy SE, Myers SM; COUNCIL ON CHILDREN WITH DISABILITIES, SECTION ON DEVELOPMENTAL AND BEHAVIORAL PEDIATRICS. Identification, Evaluation, and Management of Children With Autism Spectrum Disorder. Pediatrics. 2020 Jan;145(1):e20193447. doi: 10.1542/peds.2019-3447. Epub 2019 Dec 16. PMID: 31843864.

[42] Treatment and Intervention Services for Autism Spectrum Disorder | NCBDDD | CDC

[43] Guan J, Li G. Injury Mortality in Individuals With Autism. Am J Public Health. 2017 May;107(5):791-793. doi: 10.2105/AJPH.2017.303696. Epub 2017 Mar 21. PMID: 28323463; PMCID: PMC5388960.

Topic	Facts and Resources
Toileting	Toileting can be a behavioral goal for ABA therapy, and can be a goal in IEPs. AAP has published a toolkit on toilet training for autistic children: Toilet Training—Autism Toolkit | Pediatric Patient Education | American Academy of Pediatrics (aap.org) Vanderbilt's TRIAD center has many resources including a family handout on toilet training: toilettrainasd.pdf (vumc.org)
Feeding and eating problems	The AAP Autism Toolkit has a chapter on Nutrition and Eating problems: Nutrition and Eating Problems—Autism Toolkit | Pediatric Patient Education | American Academy of Pediatrics (aap.org) Autism Speaks has a toolkit for families on feeding behavior: ATN/AIR-P Guide to Exploring Feeding Behavior in Autism | Autism Speaks Some children benefit from referral to a feeding disorder specialist.
Advocating in the school system	Parent Training and Information Centers (PTI) are parent-led, federally-funded organizations that provide education and advocacy support to parents of children with disabilities. They are a useful free referral for families who need support navigating the school system. There is at least one PTI in each state: *DC:* Advocates for Justice and Education Home - Advocates for Justice and Education (aje-dc.org) *MD:* Parents' Place of Maryland Parents' Place of Maryland - Maryland's Special Education and Health Information Center (ppmd.org) *VA:* Formed Families Forward FFF – Formed Families Forward and Parent Educational Advocacy Training Center Homepage - PEATC *National listing:* Find Your Parent Center | Center for Parent Information and Resources (parentcenterhub.org)
Building parent and sibling resilience	Parenting an autistic child can be extra complicated when there are other children in the house. A helpful resource for families is: https://researchautism.org/families/sibling-support/ The Parent Centers listed above can help refer families to parent support groups in their area.
Puberty, sexuality, and safe relationships	Autistic individuals, particularly those with intellectual disability, are at increased risk of being mistreated and abused.[44] Free autism-focused materials on sexual development and consent include: Organization for Autism Research Sex Ed for Self Advocates: https://researchautism.org/self-advocates/sex-ed-for-self-advocates/ *Charting the Course*, a pdf document developed with autism self-advocates that includes visual supports on puberty topics and a worksheet on different types of

[44] Ohlsson Gotby V, Lichtenstein P, Långström N, Pettersson E. Childhood neurodevelopmental disorders and risk of coercive sexual victimization in childhood and adolescence - a population-based prospective twin study. J Child Psychol Psychiatry. 2018 Sep;59(9):957-965. doi: 10.1111/jcpp.12884. Epub 2018 Mar 23.

Topic	Facts and Resources
	relationships and levels of intimacy (page 115): https://edge.sitecorecloud.io/cnh-e6162ccc/media/cnhs-site/files/departments/casd/charting-the-course.pdf
LGBTQ+ identities	Growing evidence suggests that LGBTQ+ identities are quite common among autistic people. In particular, transgender and gender-diverse identities are especially common among autistic individuals. For more information on the common co-occurrence of transgender identity and autism, please see the Gender and Autism Program website: https://www.childrensnational.org/get-care/departments/gender-and-autism-program.
Suicidality	Autistic children and adults are at substantially increased risk of suicidality and self-harm behavior.[45] Screening for suicidality is essential in autistic youth with and without intellectual disability. The American Association for Suicidology has information for providers and for the community on suicidality in autistic individuals: Autism Resources - American Association of Suicidology HealthyChildren.org has an article for parents on mental health in autistic teens: https://www.healthychildren.org/English/health-issues/conditions/Autism/Pages/autism-and-mental-health-how-to-support-your-teen.aspx.
Transition to adulthood	Half of autistic adults have poor occupational/social/independent living outcomes.[46] Autism-specific supports including an emphasis on adaptive functioning (regardless of cognitive and verbal abilities) improves outcomes. Healthychildren.org has an introductory article for parents: Helping Teens With Autism Transition to Adulthood: Tips for Parents & Caregivers - HealthyChildren.org. The Organization for Autism Research has a free 124 page guidebook: A Guide for Transition to Adulthood | Organization for Autism Research (researchautism.org). The Autistic Self Advocacy Network has free books including a *Roadmap to Transition* and *Navigating College*: Books - Autistic Self Advocacy Network (autisticadvocacy.org).
Supported decision making (including guardianship)	There is a range of options for supporting the decision-making of adults with disabilities. Guardianship is the most restrictive option. Less restrictive options like power of attorney, healthcare advanced directives, supported decision-making arrangements, Social Security Income representative payees, and special needs trusts may be more appropriate in some cases. More information is available at: https://supporteddecisionmaking.org/.

[45] Blanchard A, Chihuri S, DiGuiseppi CG, Li G. Risk of Self-harm in Children and Adults With Autism Spectrum Disorder: A Systematic Review and Meta-analysis. JAMA Netw Open. 2021 Oct 1;4(10):e2130272. doi: 10.1001/jamanetworkopen.2021.30272.

[46] Mason D, Capp SJ, Stewart GR, Kempton MJ, Glaser K, Howlin P, Happé F. A Meta-analysis of Outcome Studies of Autistic Adults: Quantifying Effect Size, Quality, and Meta-regression. J Autism Dev Disord. 2021 Sep;51(9):3165-3179. doi: 10.1007/s10803-020-04763-2. Epub 2020 Nov 17.

Medical Comorbidity

In their AAP Clinical Report on autism, Hyman et al. (2020) include a review of common medical conditions in autistic children. Key points in this article include:

Topic	Facts and Resources
Seizures	Autistic children have an increased risk of seizures (7-23% in community samples), and children with epilepsy have an increased risk of autism (about 6%, or higher in children with ID). Risk factors include intellectual disability, specific genetic disorders (e.g. tuberous sclerosis), female sex, and prematurity. Onset is bimodal with peaks in early childhood and adolescence, but 20% of first seizures occurring in autistic adults. Screening EEG is not recommended for asymptomatic autistic children.
GI symptoms	Common symptoms include abdominal pain, constipation, diarrhea, GERD, and feeding problems, and these may present as behavioral difficulties (e.g. agitation, food refusal, sleep disruption) due to problems with communication and interoception. Workup and treatment is dependent on symptoms.
Obesity	Autistic youth are at increased risk of overweight and obesity, particularly if they are prescribed atypical antipsychotics. Metformin has evidence to prevent antipsychotic-associated weight gain in pediatric patients (see below).
Dental health	Routine toothbrushing and complying with dentist examinations can be very challenging for autistic children. Dental pain should be included in the differential of any behavioral changes.
Pica	Autistic youth, particularly those with ID, are more likely to put nonfood items into their mouth, and are at increased risk of sequelae of ingestions. Primary care monitoring of blood lead level and iron deficiency, as well as counseling on behavioral strategies, increasing supervision, and environmental safety are recommended for children with pica.
Sleep	Sleep problems occur in up to 80% of autistic children. The most common cause of delayed sleep onset and night wakings in autistic children is learned behavior, and there is evidence supporting parent education and behavioral interventions. Workup should include evaluation for medical comorbidity. Iron panel including ferritin should be tested if there is restless sleep and night wakings. There is no FDA indicated medication for sleep in autistic children. Melatonin (in immediate release and extended release formulations) starting at low doses (0.5-1mg) up to 6mg qhs can be helpful. The American Academy of Neurology has a useful parent handout summarizing their practice guideline on sleep in autistic children and adolescents: https://www.aan.com/Guidelines/Home/GetGuidelineContent/998.
Regression	Loss of language and social interest skills is most frequently recognized between 18 and 24 months of age in children who are later diagnosed with autism. Regression in later childhood requires more thorough investigation.

Irritability and problem behaviors

The AAP Practice Pathway for managing irritability and problem behaviors in autistic children in primary care settings[47] provides detailed guidance on assessing and responding to problem behaviors. To summarize, there are 5 common reasons for changes in behavior: medical problems like pain, communication frustration, psychosocial factors like educational factors or bullying, maladaptive reinforcement patterns, and psychiatric comorbidity. Adults should try to identify the cause of a behavioral change as precisely as possible so that treatment can target the underlying cause.

Psychotropic medications are important tools, but they carry significant risks and should not be used if a non-medication intervention would be effective and accessible. For example, non-speaking autistic children often have difficulty tolerating tooth brushing and dental exams, so they are at risk of being put on risperidone to "treat" headbanging behavior that is actually due to dental pain.

Clinical Pearls for Prescribing Psychotropic Medication to Autistic Children

- *Diagnose carefully and treat precisely.*
- *Try non-medication interventions first when possible.*
- *Use the medication with the most favorable risk/benefit profile; this may involve discussing the pros/cons of prescribing off label with families.*
- *If you use a medication, start low (e.g. half the usual starting dose or half of the smallest pill) and titrate slowly (e.g. twice as long between dose increases).*
- *Autistic individuals and their families are the experts. Listen carefully.*
- *Autistic children are often more likely to have side effects (e.g. activation from SSRIs, irritablility from stimulants, hypotension from alpha agonists).*
- *Weird side effects happen. Just because we don't have an explanation for a symptom doesn't mean it's not important.*
- *Be on alert for trauma and suicidality.*
- ***Key Question:** What is* really *happening, why it is it happening now, and what is the safest and most effective way for me to intervene?*

Risperidone and aripiprazole

Risperidone (age 5-16)[48] and aripiprazole (age 6-17)[49] have FDA indications for the irritability associated with autism. Side effects include metabolic syndrome (weight gain, hyperlipidemia, hyperglycemia requiring regular blood monitoring) and movement and muscle problems which may be temporary or permanent (extrapyramidal symptoms including dystonia and tremor; tardive

[47] McGuire K, Fung LK, Hagopian L, Vasa RA, Mahajan R, Bernal P, Silberman AE, Wolfe A, Coury DL, Hardan AY, Veenstra-VanderWeele J, Whitaker AH. Irritability and Problem Behavior in Autism Spectrum Disorder: A Practice Pathway for Pediatric Primary Care. Pediatrics. 2016 Feb;137 Suppl 2:S136-48.
[48] Risperdal (risperidone) tablets label (fda.gov)
[49] label (fda.gov)

dyskinesia). Sedation, GI symptoms, and headaches are also common. Risperidone can cause hyperprolactinemia (leading to gynecomastia and/or galactorrhea). Aripiprazole can sometimes be more likely than risperidone to cause akathisia during initial titration.

Risperidone and aripiprazole can cause a significant increase in appetite, that at times can lead to behavioral changes including aggression. Weight gain tends to be most prominent in the first 15 weeks and plateau after about a year, although it can continue long-term.[50] Metformin reduces antipsychotic-associated weight gain in children and adolescents, with effect starting 1-2 months after starting metformin.[51] Clinically, both risperidone and aripiprazole are about equally likely to cause weight gain.[52]

ADHD, Anxiety, and Autism

About half of autistic children also meet criteria for ADHD. Although ADHD rating scales like the Vanderbilt ADHD Rating Scale are not validated in autism, they are widely used and provide helpful clinical information. Especially when there is clear hyperactivity, non-autism specialists should feel confident diagnosing and treating ADHD in autistic (or possibly autistic) children if that is part of their usual practice for non-autistic children. The differential of ADHD symptoms includes overload (e.g. caused by language, sensory, or social demands) mimicking inattention, and escape behaviors mimicking hyperactivity. Methylphenidate is the first line treatment for ADHD in autistic youth. Amphetamine derivatives have less supporting data, and clinically may be more likely to cause irritability, although they are still used. Atomoxetine and alpha agonists are also useful as second-line or adjunctive agents.[53]

Similarly, about half of autistic individuals meet criteria for an anxiety disorder. In youth who have difficulty verbalizing their emotions, anxiety may be manifested behaviorally, for example as aggression or self-injurious behavior in response to demands or unexpected events. There have been some studies of anxiety scales, including the freely available Spence Children's Anxiety Scale (https://www.scaswebsite.com/) and the SCARED (Clinical Tools | Child and Adolescent Bipolar Spectrum Services (pitt.edu)), in autistic youth, but parent-child agreement is low and reliability is limited by the patient's ability to verbalize their emotional experience (due to language,

[50] CL van der Esch et al. Risk factors and pattern of weight gain in youths using antipsychotic drugs. Eur Child Adolesc Psychiatry. 2021 Aug;30(8):1263-1271.
[51] BL Handen. A Randomized, Placebo-Controlled Trial of Metformin for the Treatment of Overweight Induced by Antipsychotic Medication in Young People With Autism Spectrum Disorder: Open-Label Extension. J Am Acad Child Adolesc Psychiatry. 2017 Oct;56(10):849-856.e6.
[52] Siafis S et al. Pharmacological and dietary-supplement treatments for autism spectrum disorder: a systematic review and network meta-analysis. Mol Autism. 2022 Mar 4;13(1):10.
[53] Hyman et al. 2020. Barbaresi WJ, Campbell L, Diekroger EA, Froehlich TE, Liu YH, O'Malley E, Pelham WE Jr, Power TJ, Zinner SH, Chan E. Society for Developmental and Behavioral Pediatrics Clinical Practice Guideline for the Assessment and Treatment of Children and Adolescents with Complex Attention-Deficit/Hyperactivity Disorder. J Dev Behav Pediatr. 2020 Feb/Mar;41 Suppl 2S:S35-S57.

interoception, and/or alexithymia issues).[54] Cognitive behavioral therapy interventions for anxiety in autistic youth, such as the Facing Your Fears program, have good evidence.[55] As in youth without autism, SSRI medications can be useful tools for moderate to severe anxiety; however, autistic youth are at increased risk of adverse effects including the activation syndrome, so the medication should be started at a low dose and titrated more slowly with careful follow-up.

[54] Magiati I, Lerh JW, Hollocks MJ, Uljarevic M, Rodgers J, McConachie H, Ozsivadjian A, South M, Van Hecke A, Hardan A, Libove R, Leekam S, Simonoff E. The measurement properties of the spence children's anxiety scale-parent version in a large international pooled sample of young people with autism spectrum disorder. Autism Res. 2017 Oct;10(10):1629-1652.

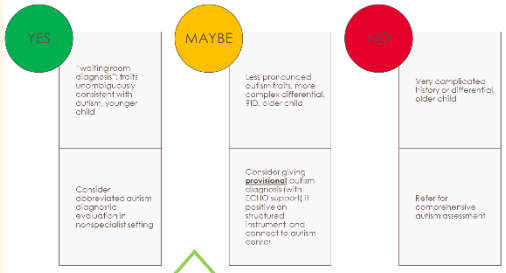
[55] Reaven J, Pickard K, Meyer AT, Hayutin L, Middleton C, Reyes NM, Tanda T, Stahmer A, Blakeley-Smith A, Boles RE. Implementing school-based cognitive behavior therapy for anxiety in students with autism or suspected autism via a train-the-trainer approach: Results from a clustered randomized trial. Autism. 2024 Feb;28(2):484-497.

APPENDIX A: PROVIDER REFERENCE SHEETS

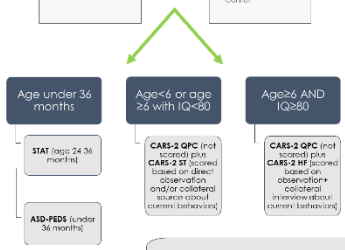
Summary Graphic: Supporting Autism Families

Step 1: Triage diagnosis

Is a community autism diagnosis appropriate for this patient?



Step 2: Quantify autism traits and adaptive functioning



Insurance companies often also require a measure of adaptive functioning. Consider using the Diagnostic Adaptive Behavior Scale (**DABS**: age 4-21; www.aaidd.org/dabs), the Adaptive Function subscale of the **Developmental Profile – Fourth Edition**, the **Vineland-3**, or the **ABAS-3**.

Step 3: Facilitate evaluation in all systems of care

Document autism developmental history and quantify autism traits

Medical
Take history and quantify traits in your nonspecialist setting, or refer to autism center, depending on triage assessment (see step 1).

School
Have parent request (in writing) IEP evaluation for autism educational classification with educational supports. Letter templates are available online.

Cognitive testing and adaptive functioning evaluation

Medical
Refer to psychology/neuropsychology if child has not already had this testing at school.

School
IEP evaluation often involves cognitive and adaptive functioning assessment; this usually does not need to be repeated by a medical provider.

Speech-language evaluation

Medical
Refer to outpatient SL therapy for testing. Consider specifically recommending AAC and/or pragmatic language testing as indicated.

School
IEP plans can include SL testing and therapy, including AAC evaluation and services. IEPs consider pragmatic language concerns less frequently.

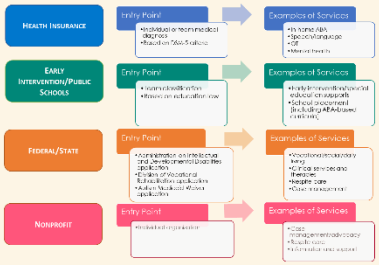
Universal Referrals

Medical
- Genetics
- Hearing screening

State and Federal Supports
- All ages: Parents should submit AIDD and Medicaid Waiver applications for their state.
- Age 14+: Parents should apply to the Division of Vocational Rehabilitation in their state.

ECHO Model

Systems of Care Model

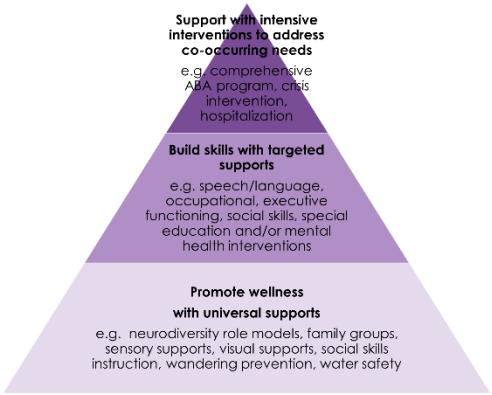


Universal Referral Checklist for Autistic Pediatric Patients

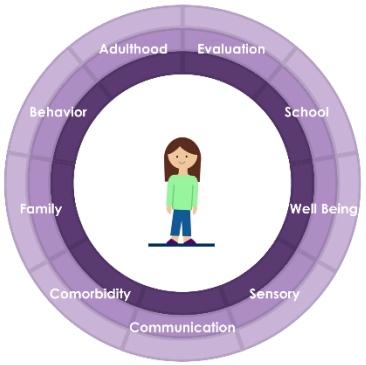
- **Has the child gone through the entry point ("front door" initial application process) for at least the medical, educational, and federal/state systems of care?**
  - Do they have a medical diagnosis of autism so they can access insurance-funded services like ABA? *This typically involves a medical provider using a structured instruments to quantify autism traits (ADOS-2, CARS-2, or other instrument) and (if not documented in another system of care) estimate adaptive functioning (e.g., ABAS-3), and providing the parent with a report.*
  - Have they had an IEP evaluation at school that targets autism specific learning and behavioral needs (not just for general learning or behavioral concerns)? *If there are barriers, consider referral to the EI in their state:*
    - DC: Advocates for Justice and Education, www.aje-dc.org
    - MD: Parents' Place of Maryland, www.ppmd.org
    - VA: Formed Families Forward, www.formedfamiliesforward.org, and Parent Educational Advocacy Training Center, www.peatc.org
    - National listing: www.parentcenterhub.org
  - Have parents submitted Administration on Intellectual and Developmental Disabilities (AIDD), Medicaid Waiver, and (if age 14+) Division of Vocational Rehabilitation applications for their state?
- **Has the child been referred for all of the elements of the gold standard diagnostic evaluation for autism?** *These evaluations do not all need to be done in the same system of care. For example, often autism is first diagnosed by a medical provider, and the school system then does speech/language and cognitive testing as part of the IEP evaluation.*
  - Autism developmental history and behavioral observation (consider referral or diagnosing/documenting using Comer dot phrases =psCARS2ST and =psCARS2HF)
  - Adaptive functioning measurement (e.g. Vineland, ABAS-2)
  - Cognitive (IQ) testing
  - Speech/language testing including pragmatic language testing
  - Hearing testing
- **Have parents been offered a referral to genetics?**

Step 4: Triage support needs

What intensity of support does this family need now?



In which domains does this family need additional support?



Step 5: Build support system to address needs

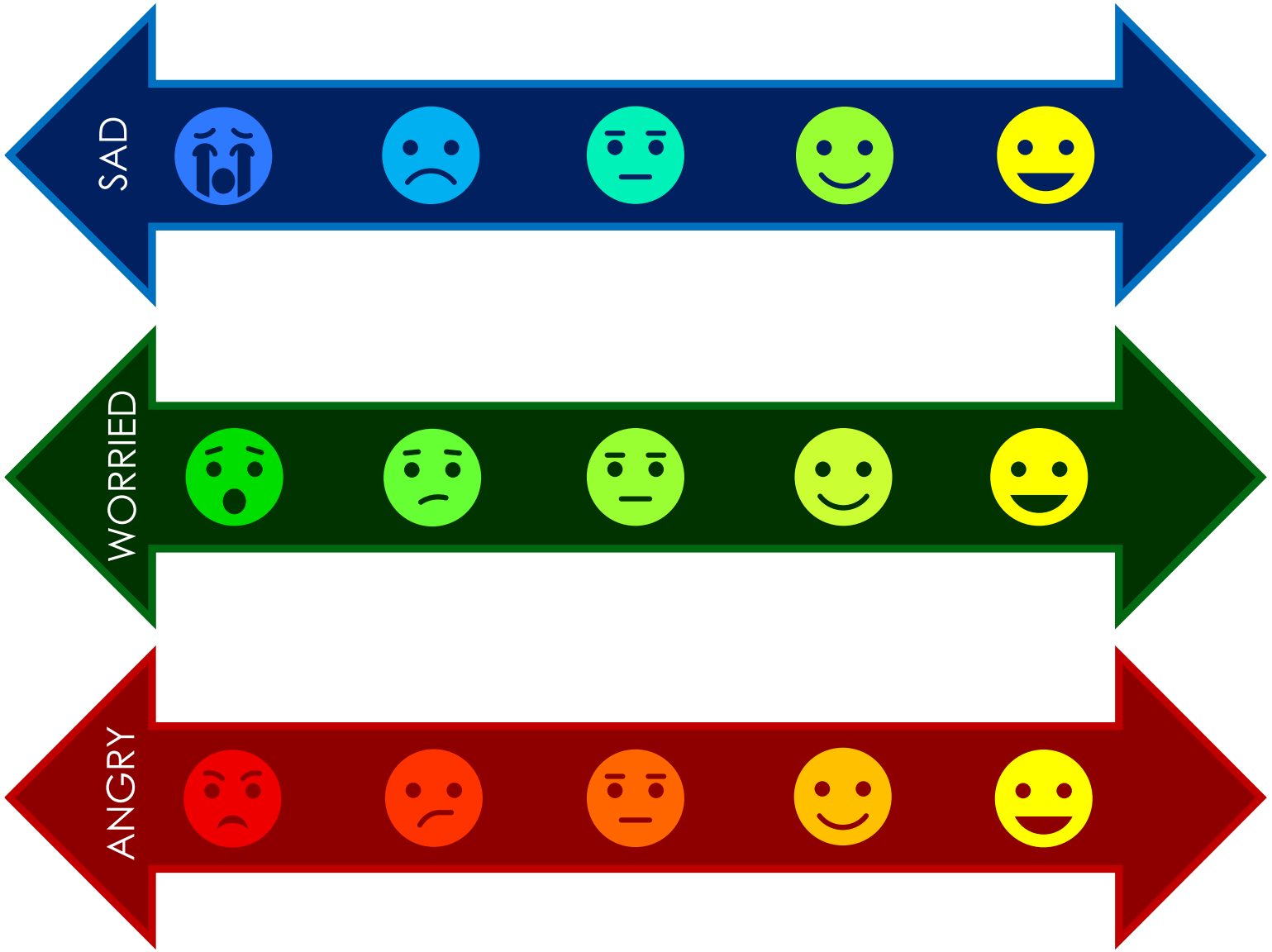
Funding for CN CASD ECHO Autism was provided by the A. James & Alice B. Clark Foundation, the Alexander and Margaret Stewart Trust, and the RE/MAX Foundation.

Universal Referral Checklist for Autistic Pediatric Patients

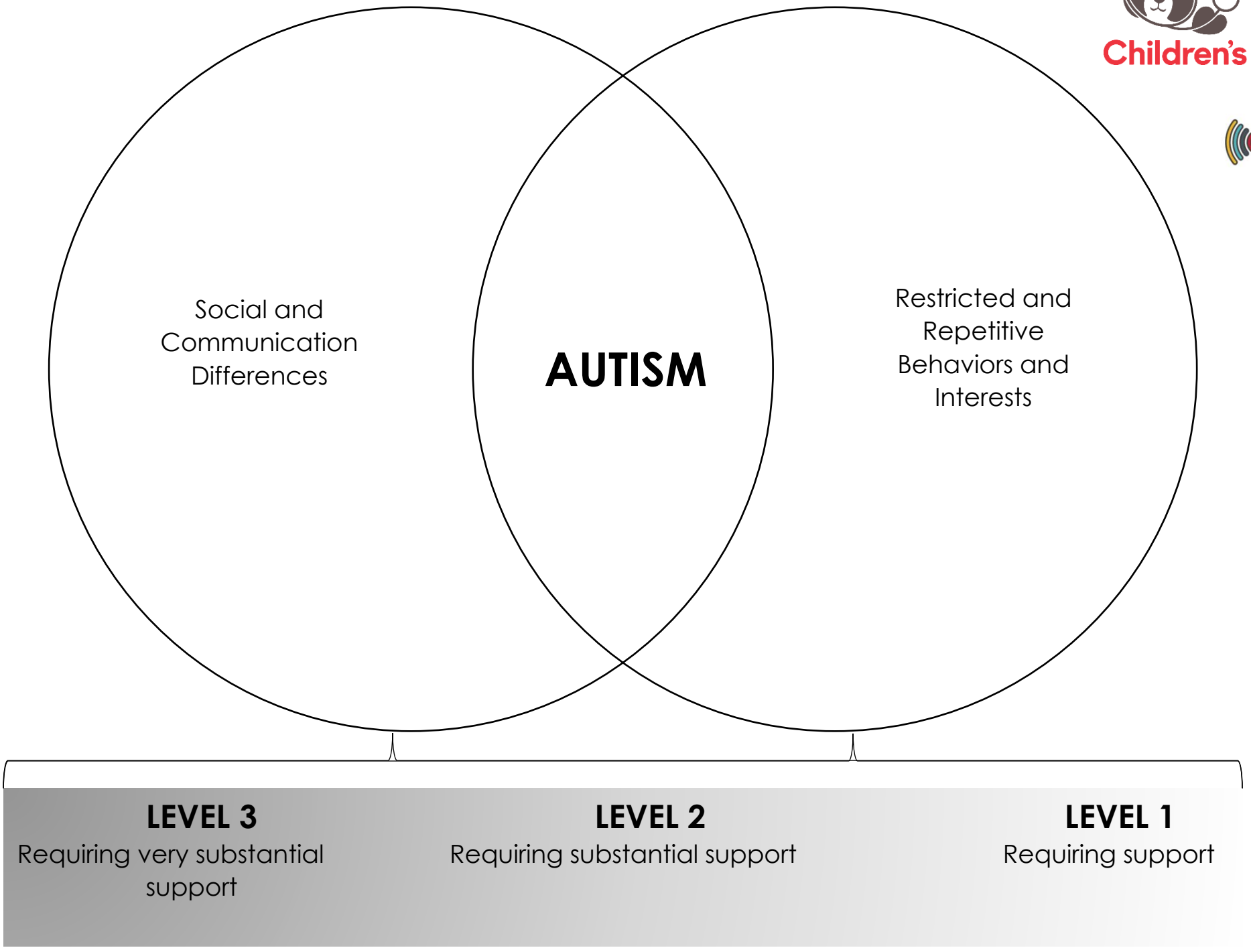
- **Has the child gone through the entry point ("front door" initial application process) for at least the medical, educational, and federal/state systems of care?**
  - Do they have a medical diagnosis of autism so they can access insurance-funded services like ABA? *This typically involves a medical or mental health provider using a structured instruments to quantify autism traits (ADOS-2, CARS-2, or other instrument) and (if not documented in another system of care) estimate adaptive functioning (e.g., ABAS-3), and providing the parent with a report.*
  - Have they had an IEP evaluation at school that targets autism-specific learning and behavioral needs (not just for general learning or behavioral concerns)? *If there are barriers, consider referral to the PTI in their state:*
    - *DC: Advocates for Justice and Education https://www.aje-dc.org/*
    - *MD: Parents' Place of Maryland https://www.ppmd.org/*
    - *VA: Formed Families Forward https://formedfamiliesforward.org/ and Parent Educational Advocacy Training Center http://www.peatc.org*
    - *National listing: https://www.parentcenterhub.org/find-your-center/*
  - Have parents submitted Administration on Intellectual and Developmental Disabilities (AIDD), Medicaid Waiver, and (if age 14+) Division of Vocational Rehabilitation applications for their state?
- **Has the child been referred for all of the elements of the comprehensive diagnostic evaluation for autism?** *These evaluations do not all need to be done in the same system of care or simultaneously. For example, often autism is first diagnosed by a medical provider, and the school system then does speech/language and cognitive testing as part of the IEP evaluation.*
  - Autism developmental history and behavioral observation (consider referral or diagnosing/documenting using Cerner dot phrases =psCARS2ST and =psCARS2HF)
  - Adaptive functioning measurement (e.g. VABS-3, ABAS-3)
  - Cognitive (IQ) testing
  - Speech/language testing including pragmatic language testing
  - Hearing testing
- **Have parents been offered a referral to Genetics?**

Children's National

Feelings Rating Scales



Children's National

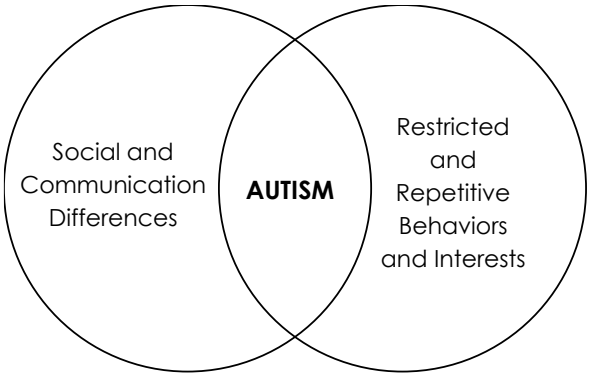

Social and Communication Differences
AUTISM
Restricted and Repetitive Behaviors and Interests
LEVEL 3
Requiring very substantial support
LEVEL 2
Requiring substantial support
LEVEL 1
Requiring support

APPENDIX B: HANDOUTS FOR FAMILIES

Autism

What is autism?

Autism is a name for a pattern of brain-based differences in how a person experiences and interacts with their environment. Autistic people have differences in how they socialize and communicate ("social and communication differences") AND in the way they react to changes and deal with sensory experiences like loud noises and bright lights ("restricted and repetitive behaviors and interests").



What does autism look like?

Like all people, autistic people are individuals. Some autistic people are happy to spend more time alone, and some people are very sociable and outgoing. Some autistic people speak to communicate, and some use signs, or a device, or behavior to communicate. Some autistic people have passionate interests that become their life's work. Some move differently and find joy or relaxation in movements like flapping their hands or walking on their tiptoes. All autistic people experience love, joy, loneliness, sadness, pain, and every other emotion, but they may have a unique way of showing how they are feeling. There is not one way to be autistic, like there is not one way to be human.

What does an autism diagnosis mean for my child?

Your child is still the same amazing and unique person no matter what labels they are given. Being diagnosed with autism does not put any limitations on what they can do. An autism diagnosis means that a professional thinks that certain therapies, teaching strategies, and parenting techniques may help your child reach their full potential. Without an autism diagnosis from a medical or mental health provider and an autism classification at school, your child may not get access to all of the services that would benefit them.

Where can I find out more?

- Centers for Disease Control and Prevention Autism Spectrum Disorder (ASD) | Autism | NCBDDD | CDC
- Children's National Center for Autism Resources for Families - Autism Spectrum Disorders | Children's National Hospital (childrensnational.org)
- Vanderbilt TRIAD Families First Families First Program - Vanderbilt TRIAD Free Autism Services in Tennessee (vumc.org)
- the Autistic Self Advocacy Network: https://autisticadvocacy.org/about-asan/about-autism/
- Neurodivergent Narwhals: https://neurodiversitylibrary.files.wordpress.com/2017/01/the-signs-of-autism.pdf

Prepared by: Kelly Register-Brown, MD and Anne Inge, PhD
Children's National Center for Autism, 5/7/24

Autism Therapies

Children's National

Autism Therapies: What Works?

There are many kinds of autism therapy. Some therapies are based on high quality scientific data, so they are more likely to help children learn. Here are some examples:

Type of Therapy	Description	Example Programs
Applied Behavior Analysis (ABA)	Understanding what happens just before and just after a child's behavior helps adults know how to respond. For example, if a child gets a reward every time they do something, they are more likely to repeat it.	General ABA programs Pivotal Response Training* Discrete Trial Teaching Early Start Denver Model*
Naturalistic Developmental Behavioral Approaches	Intervention focusing on techniques to increase motivation and performance (child-preferred activities in the natural environment, incidental teaching, consideration of developmental prerequisites). Informed by ABA methods.	Early Start Denver Model* Pivotal Response Training* Early Achievements Program Joint Attention Symbolic Play Engagement and Regulation (JASPER)* Project ImPACT*
Developmental Approaches	Focus on improving certain skills, like motor, communication, or daily living skills, in a way that is appropriate for the child's age and level of development.	Speech/language therapy Occupational therapy Physical therapy
Educational Approaches	Deliberate modifications to the classroom environment, materials, demands, and instruction to accommodate needs of autistic students with weaknesses in social learning and promote new skill/content acquisition	Treatment and Education of Autistic and Related Communication-Handicapped Children (TEACCH)
Social Approaches	Teaching children what to expect in social situations can help improve relationships and reduce stress.	Social Stories Social Thinking Social skills groups like PEERS
Cognitive Behavioral Therapy Informed Interventions	Thoughts, feelings, and behaviors are all related. Helping a child see a new way of thinking about a situation can help them feel and act differently.	Facing Your Fears (for anxiety) Unstuck and On Target (for cognitive inflexibility)
Parent-Mediated Intervention	Parent training and coaching to provide consistent intervention for joint attention, social communication, and behaviors. Studied as a method for augmenting therapist-led interventions.	Hanen Research Units in Behavioral Intervention (RUBI) *See above for behavioral interventions with parent training components

Prepared by: Kelly Register-Brown, MD and Anne Inge, PhD
Children's National Center for Autism, 5/7/24

Autism Therapies

Other therapies have not been studied in as much detail, so less is known about how well they work. Examples of these include the Developmental, Individual Differences, Relationship-Based model (also called "Floor time") and Relationship Development Intervention (RDI). Finally, there are many therapies that do not work, and might even be harmful. There is no medication to target the core traits of autism.

Where to find out more:

Centers for Disease Control and Prevention: https://www.cdc.gov/ncbddd/autism/treatment.html
National Clearinghouse on Autism Evidence and Practice: https://ncaep.fpg.unc.edu/
National Standards Project:
https://asatonline.org/wp-content/uploads/asatdocuments/National-Standards-Project-Phase-2.pdf

Prepared by: Kelly Register-Brown, MD and Anne Inge, PhD
Children's National Center for Autism, 5/7/24

Autism: ABA Therapy

What is Applied Behavior Analysis (ABA) Therapy?

Applied Behavior Analysis (ABA) is a type of therapy based on learning and behavior science. The fundamental principle of ABA is that what happens right before and right after a behavior teaches someone whether they should repeat that behavior again in the future. For example, if a child gets praised and gets what she wants every time she says "please," she is more likely to say "please" next time she wants something. Or, if a child gets to have more screen time every time they tantrum when an adult tries to take the screen away, they realize that tantrums are an effective strategy for getting what they want. ABA therapy changes what happens right before and after a behavior to teach a child to behave differently.

ABA was first developed in the 1960s, and has changed dramatically since then. Many different types of therapies based on ABA have been developed, but they are often all included under the umbrella term "ABA." Some examples are:

	Examples	Comments
Applied Behavior Analysis (ABA)	Understanding what happens just before and just after a child's behavior helps adults know how to respond. For example, if a child gets a reward every time they do something, they are more likely to repeat it.	General ABA programs Pivotal Response Training* Discrete Trial Teaching Early Start Denver Model*
Naturalistic Developmental Behavioral Approaches	Intervention focusing on techniques to increase motivation and performance (child-preferred activities in the natural environment, incidental teaching, consideration of developmental prerequisites). Informed by ABA methods.	Early Start Denver Model* Pivotal Response Training* Early Achievements Program Joint Attention Symbolic Play Engagement and Regulation (JASPER)* Project ImPACT*
Parent-Mediated Intervention	Parent training and coaching to provide consistent intervention for joint attention, social communication, and behaviors. Studied as a method for augmenting therapist-led interventions.	Research Units in Behavioral Intervention (RUBI) *See above for behavioral interventions with parent training components

What are some commonly expressed concerns about ABA?

Some adult autistic self-advocates and other stakeholders have expressed strong concerns about ABA therapy. Some examples of these opinions include:

Prepared by: Kelly Register-Brown, MD, Deborah Potvin, PhD, and Anne Inge, PhD
Children's National Center for Autism, 5/7/24

Autism: ABA Therapy

- Concerns that ABA teaches children to comply with adults rather than advocate for themselves or respond naturally to their own discomfort, which is psychologically damaging and potentially increases the risk of abuse.
- Concern that ABA prioritizes blending in with non-autistic ("neurotypical") people over building useful skills for improving quality of life
- Concern that ABA therapy assumes that autistic behaviors are wrong and autistic people cannot be accepted unless they change who they are
- Concerns that ABA therapy is rooted in an ableist perspective (that being autistic is not the "right" way of being in the world)
- Concerns that ABA therapy aims to suppress child's expression of distress (e.g. meltdowns) rather than provide accommodations (e.g. reduced sensory demands)
- Concerns about the history of aversive methods being used in ABA therapy

However, other autism stakeholders point out that ABA is a huge, generic category of interventions that has evolved since it was first developed about 60 years ago. Some of the criticisms may apply to the way ABA therapy was implemented in the past, but less so now. Ideally, modern ABA-based therapy uses more flexible, child-led techniques in the natural environment (home or school) to work on goals for lessening disability and improving quality of life. This evolution is due in part to the vigorous and successful advocacy efforts of autistic adults who had negative or even traumatic childhood experiences with older ABA methods.

How can parents choose a therapy that best supports their autistic child's learning and emotional health?

Choose a type of therapy backed by scientific evidence. There are many types of autism therapies. Some are helpful, some are ineffective, and some are harmful. Every family has a limit to the resources (money, time, energy) they can devote to autism therapy, so ideally every therapy session will help a child move closer to their goals. Therapy is most likely to be effective if it is backed by objective scientific studies.

Trust your instincts. Parents are the experts on their children, and are often the first to notice if something is not going well. If a parent is concerned that a therapy is not helpful or is harmful for their child, they should talk to their support system including the child's doctors and teachers.

Not every therapist is right for every child. Sometimes a therapist is not a good "fit" for a family, but a different therapist or type of therapy might be very helpful for them. This does not mean the first

Prepared by: Kelly Register-Brown, MD, Deborah Potvin, PhD, and Anne Inge, PhD
Children's National Center for Autism, 5/7/24

Autism: ABA Therapy

Children's National

therapist is unskilled or "bad." (When we try on a pair of shoes that doesn't fit, we don't assume that all shoes are wrong for us, just that we need to try on another pair.)

Ask your child's therapist lots of questions. High quality therapy should have explicit, individualized, measurable goals that the family and therapist agree on together. This means that the therapist and family will talk about what the goals are, how to work on goals, and how to measure progress periodically so that everyone can make adjustments as needed.

Where can I find out more?

The Autism Navigator website from Florida State University has video examples of different types of therapies. https://autismnavigator.com/asd-video-glossary/

The Autistic Self Advocacy Network has a policy statement page explaining their position on ABA. https://autisticadvocacy.org/about-asan/what-we-believe/

The Autism Science Foundation also has a position statement on ABA. https://autismsciencefoundation.org/statement-on-use-of-applied-behavior-analysis-aba-for-autism/

This article for doctors from the American Academy of Pediatrics has more technical information on autism interventions. Identification, Evaluation, and Management of Children With Autism Spectrum Disorder | Pediatrics | American Academy of Pediatrics (aap.org)

Prepared by: Kelly Register-Brown, MD, Deborah Potvin, PhD, and Anne Inge, PhD
Children's National Center for Autism, 5/7/24

What is Social Cognition?

Social cognition refers to the many things that our brains do that help us understand social and emotional information about others and ourselves. It includes components such as being able to:

- Interpret facial expressions and nonverbal cues
- Understand and express emotion with: voice intonation, facial expression, body language, gesture, verbal nuance
- Recognize one's own emotional state (e.g. know when you are feeling anxious)
- Label emotions in self and others
- Describe other people meaningfully (e.g. she is a shy person, he is funny)
- Discern social rules (e.g. know that you shouldn't pick your nose in public)
- Understand human relationships (e.g. what is a friend)
- Understand the meaning of different social contexts (e.g. acceptable behavior in a party is different from acceptable behavior in church)
- Engage in imaginative play (e.g. act out unique stories with characters and spontaneously respond to the play of others)
- Have a *theory of mind* (understanding that others have different ideas and experiences that drive their behaviors).

Social cognition drives many pragmatic language or conversational skills, such as being able to:

- Initiate, maintain, and end topics (e.g. sticking with a topic in conversation)
- Know when and how to shift topics (e.g. recognizing when someone is bored with a topic)
- Recognize misunderstandings and know how to correct them (e.g. recognizing that you have hurt someone's feelings)
- Take the perspective of others in conversation (e.g. partner doesn't know as much about a topic as you do and needs some background)
- Show sensitivity to conversational partner (e.g. recognizing that your conversational partner is bored)

We socialize differently.
Some of us might not understand or follow social rules that non-autistic people made up. We might be more direct than other people. Eye contact might make us uncomfortable. We might have a hard time controlling our body language or facial expressions, which can confuse non-autistic people or make it hard to socialize. Some of us might not be able to guess how people feel. This doesn't mean we don't care how people feel! We just need people to tell us how they feel so we don't have to guess. Some autistic people are extra sensitive to other people's feelings.

- Autistic Self Advocacy Network

About Autism - Autistic Self Advocacy Network (autisticadvocacy.org)

What are Executive Functions?

Executive Functions are a group of abilities, including impulse control, organization, flexibility, planning, and working memory (or on-line processing), which play a major role in the functional impacts that can be associated with autism. Because of their executive dysfunction, autistic children have difficulty:

- Organizing, or integrating their world into a meaningful whole (think of a person who stands too close to a mosaic and sees only individual pieces of the design, not the big picture). They have good attention to detail, but miss the forest for the trees, unless people work with their detail analysis strengths to help them build a big picture, piece by piece.
- Flexibly shifting gears from one thing to another. This means that they can get stuck on irrelevant details and have problems generating new ideas. Often inflexible thinking patterns drive "stubborn" behaviors. Repetitive behaviors and over focused interests are also related to inflexibility.
- Keeping track of multiple step tasks.
- Keeping track of, and using directions and information spoken to them by others.

These executive problems interfere with social interaction skills, daily living skills, and academic skills (especially written expression, reading for meaning, making inferences, long-term projects, note-taking, and studying for tests). These executive problems pose greatest risk in situations that are

- New or unfamiliar (e.g. the first day of school)
- Unexpected or unpredictable (substitute teacher)
- Unstructured or chaotic (lunch room, bus, field trip)
- Group activities that involve more than a few people
- Demanding of listening skills (new procedure is explained orally)
- Social.

Where to find out more:

Free videos and tip sheets on research-tested strategies for supporting executive functioning at home:
Support Videos | Unstuck and On Target

Advice from Experienced Autism Parents

Parent Advisory Committee, Center for Autism (CASD), Children's National Hospital

We are a volunteer group of parents of autistic children and adolescents who act as community liaisons for CASD. We have all been through the experience of having a professional diagnose one or more of our children with autism.

On first hearing the autism diagnosis, many of us felt sad, angry, lonely, or even utterly devastated. Some of us were also relieved that we had finally found a professional who understood our child, and who might hold a key to interventions that would help. We all reacted differently, and sometimes our reactions were very different than those of our partner.

For some of us, the fact that our child suddenly had a diagnostic "label" was highly significant: It validated our sense that our children are extraordinary in complicated ways, and that our parenting struggles were not due to inadequacies on our part. On the other hand, some of us were not terribly interested in whether or not our child had a label, as long as s/he could get necessary services: After all, we adore our endlessly fascinating, wonderful children just as much with or without their labels. Following is some advice we compiled based on our experiences parenting autistic kids.

> "Parents need as much love and professional help as their autistic child needs, maybe more. Most people get through parenting by the seat of their pants; parents of autistic children aren't even provided pants. If the autistic child has siblings, provide proactive professional help to them as early as possible."

You and your other children need as much love, support, and professional help as your child with autism needs – maybe more. If you don't take good care of yourself, you won't be able to take the best care of your children.

- Ask for help often, from many people.
- Find someone (partner, friend, family, spiritual leader, doctor) to talk to about your feelings. Surround yourself with people who reflect the positive aspects of a situation back to you.
- Don't neglect your close relationships. Often partners have different emotional reactions to their child's diagnosis, have difficulty sharing their feelings, disagree on how to proceed with evaluations and interventions, and experience stressful financial and time constraints. Communicate, protect your time together, and try not to judge each other.

Connect with other parents of children with autism, for example by joining a support group. Parenting a child with autism can be extremely isolating. Our children look beautiful; people can

Advice from Experienced Autism Parents

think they act out because they're just "brats" or we're bad parents. Other parents of kids with ASDs will "speak the same language" as you. They'll understand why your child had a meltdown in the grocery store, or why you're so frustrated with your child's school. When you're going through tough times with your child and you're looking at everything up close, you'll need another parent who has been through the same thing to help you regain perspective.

Focus on the positive, be very selective in what you choose to be upset about, and keep your sense of humor. Sometimes things get too intense, and we just need to doggie paddle to the side of the pool and regroup. If we worried about every little thing, we'd be overwhelmed – in fact, we'd be gelatinous blobs on the floor. It can be very freeing to focus only on things that are really important.

"A professional told me my son is transition age, and asked about my expectations for him. I said he loves the computer. The professional looked at his record, and I know saw my son's IQ score. He told me and my husband that my son needed to do things like stuff envelopes. Well guess what…I asked at my son's last IEP meeting that he begin to do some typing. We had a parent conference recently and the teacher told me my son typed sentences that he thought up himself, and that he typed really fast. When I see the professional for a follow-up appointment, I will tell him the 'paper tasks' my son should do ARE on the computer!! Yes!!"

Helping your child will probably involve addressing your own or your loved ones' challenges. Autistic-like traits, including social differences, language difficulties, and rigidity, tend to cluster in families. For many of us, our child's diagnosis led us to understand ourselves and our families in new and empowering ways. This increased our tolerance and strengthened some of our relationships, but it also sometimes led us to be more frustrated and irritated with our own and our partners' autistic-like traits. Don't feel guilty if you feel your child has inherited your or your partner's weaknesses. Your child is amazing, just like you are!

The professionals may be experts on autism, but you're the expert on your child. You can understand and communicate with your child in a way that professionals simply can't. Professionals can be wrong; evaluate their recommendations with a critical eye. Sometimes relying on professionals won't work, so you'll need to use your own instincts to get things moving the right direction again.

Read and ask questions until you fully understand your child's evaluations, IEPs, and other documents. Professionals have a responsibility to explain jargon to you, and to include you in your child's interventions and education. If you understand what is going on at school or in therapy,

Advice from Experienced Autism Parents

you will be more able to reinforce those interventions at home. For example, if a report recommends your child has a visual schedule at school, ask the professional how you can make a visual schedule to use at home also.

Get organized early. Keep every report, evaluation, and IEP-related document in one place. Save examples of your child's schoolwork so you have hard evidence of positive or negative trends in their work. If your school has an online portal for tracking assignments, take dated screenshots throughout the term to show trends in grades and missing assignments.

You are your child's best advocate – no one else is going to fight as hard for your child as you will. Emotions will make you forget what you wanted to ask in a meeting or appointment, so be sure to go into a meeting prepared. Write down your questions in advance, and don't be afraid to ask them. It can help to give a list of your questions or a copy of your agenda to professionals in advance, or at the beginning of the meeting/appointment.

Don't ever let a professional tell you what your child can't do. There are many examples of kids whose abilities were underestimated because of their disabilities. Your job is to get professionals to focus and build on what your child *can* do.

When to Seek Help

Parents often find that seeking out mental health support for themselves helps them to care more effectively for their children. You should talk to your doctor or a licensed mental health provider if:

- You find yourself taking out your feelings on your child or loved ones
- You feel trapped, like there's nowhere to turn
- You worry excessively and can't concentrate
- The way you feel affects your sleep, eating habits, job, relationships, or everyday life
- You feel unsafe, like having scary thoughts of harming yourself or someone else even if you would never actually act on these thoughts.

Additional Information

The Organization for Autism Research has guidebooks for families on safety, siblings, transition to adulthood, and many other helpful topics: Family Guidebooks | Organization for Autism Research (researchautism.org).

Creating Visual Supports for Autistic Kids at Home

Children's National

What are Visual Supports?

Understanding information presented visually is often a strength for autistic people. Visual information can be particularly helpful for children who have language disorders and/or difficulty processing auditory information. Special educators and clinicians created visual support tools to support autistic people at home and at school. This handout describes how to build some of these tools at home.

Finding Pictures to Use in Visual Supports

Color photographs of the actual items (e.g. the child's toothbrush) are easiest to understand. Adults sometimes take digital photographs of the child's environment and include these in the support. Some children can understand line drawings like free clip art, or the "picture symbols" used by speech and language pathologists. Some picture symbols are available for free online by searching for "picture exchange communication system" or "pecs." Hand-drawn pictures are the hardest for children to understand because they are different every time (and because not all adults are natural artists). Words can be helpful for children who have advanced reading skills, but words are less helpful for emerging readers.

Using Pictures to Make Visual Supports

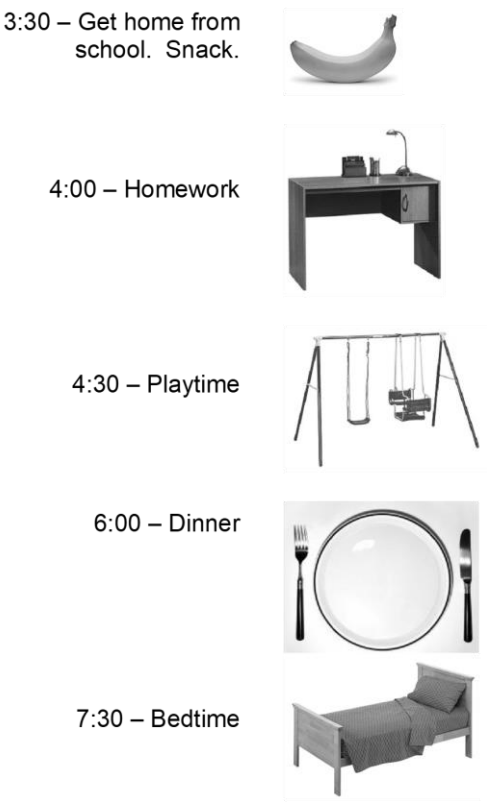
In general, the goal is to have easy access to the visual support when a demand is being placed on a child and the child is still fairly calm. Laminated printouts are a common format for visual supports. If parents do not have access to a computer and printer, often schools or the public library can help print visual supports for use at home. Also some parents use apps on their smartphone rather than printouts.

For laminating, options include self-adhesive laminating sheets, clear Contact Paper, a home laminating machine, and asking school if they will laminate the page. Families can write on laminated pages with markers (e.g. washable or dry erase markers).

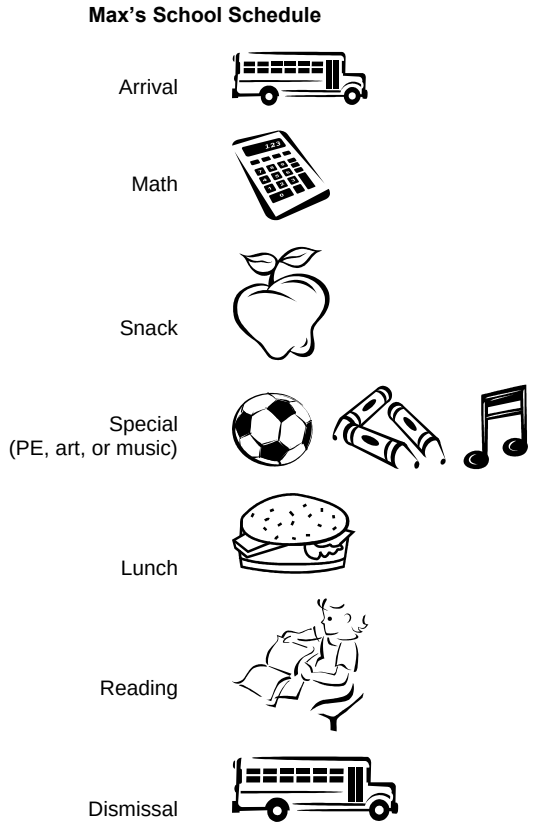
Visual Schedules

Autistic children and adolescents typically do best when they have a regular, predictable routine that they understand. A visual schedule is a written or picture representation of a

Max's Afternoon Schedule



Creating Visual Supports for Autistic Kids at Home



schedule that a child can refer to throughout the day. Parents and teachers can make visual schedules for a particular routine (e.g. brushing teeth), part of the day (e.g. the morning routine), the whole day, or the week, depending on the child's needs. Posting the schedule in the child's environment, and including a laminated copy in the child's backpack, at his/her desk, or in a frequently used notebook can help ensure the child has easy access to the schedule.

Parents and teachers should think carefully about including times on the schedule, as some autistic children are careful timekeepers who are upset by minor changes. Depending on the child, the schedule could include disclaimers like "about" or "approximately," or omit times entirely and just list events in order. If there will be a change in the schedule, tell the child well in advance if possible. Emphasize the things that will remain the same in the schedule (for example, "There's no school on Monday, but you'll still have PE on Tuesday and art on Wednesday"). If part of the schedule will vary from day to day or has not yet been decided, include a "?" or a generic term in the schedule. For example, a weekend schedule might begin "get dressed, eat breakfast, ?, come home for lunch," etc., with the "?" representing an outing that will change from week to week.

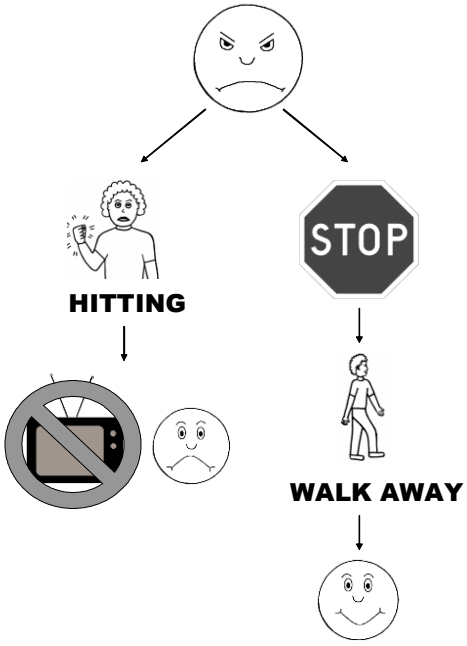
Some parents and teachers use the laminated, Velcro-backed picture technique described below to create a simplified visual schedule board. The schedule board contains three squares where pictures for past ("Finished"), current ("Now"), and future ("Next") activities are attached. When it is time to transition to a new activity, children help move the "Next" picture to "Now," add a new "Next" picture, etc. This type of visual schedule is useful for children who have difficulty with transitions, and whose language skills are still emerging.

Flowcharts

Flowcharts can be a powerful tool for helping autistic children and adolescents visualize the potential consequences of their choices. Flowcharts can be made with words or pictures, depending on the skills of the child. Some parents and teachers find it helpful to keep a white board or pad of paper handy so they can quickly sketch out a child's options as needed

Creating Visual Supports for Autistic Kids at Home

throughout the day. Others create laminated flowcharts incorporating a child's interests to reinforce important concepts.



Choice Boards

A choice board is a visual representation of a child's options for a particular choice, like what to have for snack or what to do during free play time. Parents and teachers can laminate photographs or picture symbols, and put Velcro on the back of each picture. They can then create a "choice board" by putting squares of Velcro on a piece of poster board. The child can show his/her choice by attaching a picture to the choice board. For example, parents can provide pictures of foods so a child can show what s/he wants for snack. Many examples are available online (search the internet for "choice boards").

Tables

Autistic children often have trouble understanding other people's perspectives. This can make others' behavior seem confusing to the child, and can lead to frustration and behavioral problems. Drawing a table illustrating two conflicting perspectives and possible compromises can help defuse a situation and coach perspective taking skills.

Dad wants/feels…	I want/feel…	Possible compromises…
for me to clean my room	to watch tv	• clean my room first, then watch an extra 10 minutes of tv • watch my favorite show now, then clean my room quickly. If I don't clean up quickly I can't watch any tv tomorrow

Thermometers and Rating Scales

Autistic children often have trouble gauging and communicating the intensity of their own emotional and physical experiences, making it difficult for them to respond appropriately. Thermometers and ratings scales are intended to give children tools for gaining insight into how

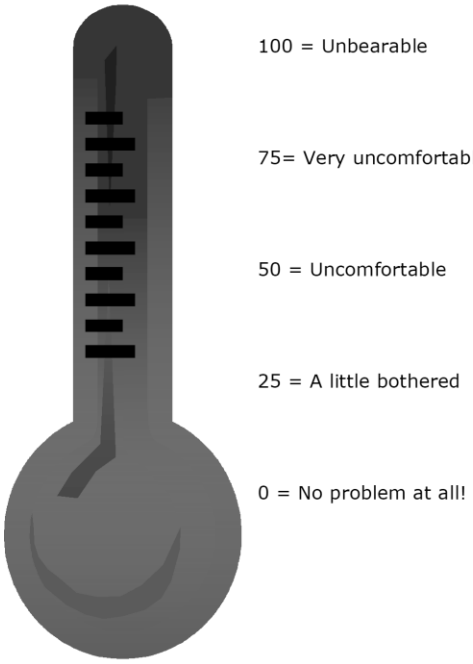
Creating Visual Supports for Autistic Kids at Home

they are currently feeling. Ideally, immediately after using these self-assessment tools, children are helped to cope with the feelings they have identified. For example, after recognizing that she is angry, a child should be reminded of her "cooling off" strategy so she does not escalate further.

More Information

- The University of Florida Center for Autism and Related Disorders has videos and instructions. Visual Supports » Center for Autism and Related Disabilities » College of Medicine » University of Florida (ufl.edu)
- The website dotolearn.com has many free resources including picture symbols and schedule templates.

Recognizing Your Uncomfortable Feelings Using a Feelings Thermometer



Getting the Right Supports for Your Autistic Child

Children's National

Autistic children need many different kinds of services. Services are paid for by health insurance, schools, the state and federal government, and nonprofit agencies. To get all of the services they need, most autistic children have to be diagnosed with autism by a medical provider (like a doctor, psychologist, or nurse practitioner) AND be given an autism classification by their school. Here are some tips on getting autism services:

Who pays for this service?	How does my child become eligible?	What are some examples of this service?	Where can I find out more?
Health insurance	Medical provider tests for autism	ABA Speech therapy Occupational therapy	Ask your pediatrician or your child's insurance company for referrals to a provider who can diagnose autism.
School	School system tests for autism	IEP services like special education, speech therapy at school, and special school placement.	If your child has started school, ask your local public school. If your child has not started school, here are websites with more information: DC: Early Childhood | specialeducation (dc.gov) Maryland: Infants and Toddlers Child Find Contact List (marylandpublicschools.org) Virginia: EI Overview — Infant & Toddler Connection of Virginia (itcva.online)
State and local government	Apply	Vocational (work) programs, respite care, case management	DC: 1) Get Katie Beckett waiver and HSCSN health insurance: https://dhcf.dc.gov/service/tax-equity-and-fiscal-responsibility-act-tefrakatie-beckett 2) Apply for DDA services: https://dds.dc.gov/service/how-apply-services 3) Age 14+: Apply for RSA services: RSA Eligibility and Intake Process | dds (dc.gov) Maryland: 1) Apply for DDA services: https://health.maryland.gov/dda/Pages/apply.aspx 2) Get on the Autism Waiver wait list:

Getting the Right Supports for Your Autistic Child

Who pays for this service?	How does my child become eligible?	What are some examples of this service?	Where can I find out more?
			https://www.marylandpublicschools.org/programs/Pages/Special-Education/autismfactsheet.aspx 3) Age 14+: Apply for DORS services: DORS Home (maryland.gov) Virginia: 1) Contact your local Community Service Board https://dbhds.virginia.gov/community-services-boards-csbs/ 2) Age 14+: Apply for DARS services: Virginia Department for Aging and Rehabilitative Services
Nonprofits	Apply	Respite care, afterschool programs, parent groups, advocacy	DC: Advocates for Justice and Education https://www.aje-dc.org/ MD: Parents' Place of Maryland https://www.ppmd.org/ VA: Formed Families Forward https://formedfamiliesforward.org/ and Parent Educational Advocacy Training Center http://www.peatc.org

Mental Health Support Resources for Families

Children's National

In the case of mental health emergency, call 911 or go to the nearest emergency room.

Maryland Residents

- Ask your child's primary care provider if they are able to call **BHIPP** for mental health case management services and psychiatry consultation.
- **Call the Emergency Mobile Crisis Response Line:** 211 or county-specific number
    - *PG County: 301-429-2183 | Montgomery County: 240-777-4000 | Howard County: 410-531-6677 | Anne Arundel County: 410-768-5522 | Baltimore City: 410-433-5175*

Virginia Residents

- Ask your child's primary care provider if they are able to call **VMAP** for mental health case management services and psychiatry consultation.
- Call **CR2** (Children's Regional Crisis Response): 844-627-4747
    - *CR2 Provides 24-hour rapid response to all youth (17 and younger) facing a mental health and/or substance use crisis. Serving Arlington, Fairfax, Loudoun and Prince William Counties and the Cities of Alexandria, Fairfax, Falls Church, Manassas and Manassas Park.*

Washington, D.C. Residents

- Ask your child's primary care provider if they are able to call **DCMAP** for mental health case management services and psychiatry consultation.
- **Call ChAMPS Hotline:** (202) 481-1440
    - *ChAMPS is a 24/7 emergency response service for DC-based children, teenagers and adolescent adults (ages 6 to 17) who are having a mental health or behavioral health crisis. ChAMPS also serves children ages 18 to 21 if they are in the care and custody of DC Child and Family Services Agency. This service is provided at no cost to District residents and DC foster children in foster placement in Maryland.*

National Resources

These resources provide 24/7 free and confidential support for people in crisis as well as resources and best practices to health professionals managing those in crisis.

- **988 Suicide and Crisis Lifeline (formerly the National Suicide Prevention Lifeline)**: 988
- **Online Lifeline Crisis Chat text line:** Text HOME to 741741 to reach a crisis counselor
- **The Trevor Project for LGBTQI Young People:** Connect to a crisis counselor 24/7, 365 days a year, from anywhere in the U.S. It is 100% confidential, and 100% free.
  Call: 1-866-488-7386 ● **Text:** 678678 ● **Chat:** https://www.thetrevorproject.org/get-help/

Psychiatric Medications Used in Children and Teenagers

Treating emotional and behavioral problems in children and teenagers often includes a combination of approaches. There are many research-based, effective treatments for children and teenagers with different mental health problems. Both talk therapy (psychotherapy) and medications have scientific evidence for improving mental health problems.

Talk to your child's doctor if you have concerns about:

- **Physical aggression or threats of self-harm:** You are afraid that your child's behavior could present a danger to self or others. ***(Call 911, go to the nearest emergency room, or call your local mental health crisis line for any safety concerns or emergencies.)***
- **Severe tantrums or other problem behaviors:** Your child's verbal outbursts frequently escalate to uncontrollable screaming and/or physical aggression.
- **Severe worry or anxiety:** In children, worries often appear as physical symptoms (stomachaches or headaches) or behaviors (reluctance to go to school or take part in normal activities, trouble eating and sleeping, irritability, etc.).
- **Mood problems:** These can include irritability, sadness, elation, or severe mood swings.
- **Academic difficulty:** This can include falling grades or trouble keeping up at school.
- **Attention and/or hyperactivity issues:** Your child has fidgeting or trouble paying attention beyond what is normal for their age, and this is interfering with functioning.
- **Sleeping or eating difficulty:** You are concerned because your child gets too little, too much, or disrupted sleep; has nightmares; or has had a significant increase or decrease in appetite or weight, or is a very picky eater.
- **Substance use:** Your child is using alcohol or other drugs.
- **Unusual movements:** Your child has unintentional, sudden, repetitive movements like facial grimaces, eye blinking, head jerking, sniffing, or throat clearing.
- **Other adults' concerns:** Other trusted adults in the child's life, like teachers and grandparents, have noticed a significant worsening of your child's functioning.
- **Overall functioning:** Everyday life is a huge struggle, or you are worried about your child.

Depending on your child's needs, their provider may recommend therapy and/or medication. Here are some of the psychiatric medications most often prescribed to children and adolescents:

Type of Medication	Common Uses	Examples
Attention deficit hyperactivity	Attention problems, distractibility, hyperactivity	Methylphenidate Amphetamines Clonidine

Psychiatric Medications Used in Children and Teenagers

Type of Medication	Common Uses	Examples
disorder medications		Guanfacine Strattera (atomoxetine) Qelbree (viloxazine)
Antidepressants	Depression, irritability, anxiety, obsessive-compulsive disorder	Prozac (fluoxetine) Zoloft (sertraline) Lexapro (escitalopram)
Neuroleptics (also called antipsychotics)	Irritability, tantrums, aggression, and unstable mood. Also used to treat tics (involuntary movements or verbal outbursts), disorganized thinking, hallucinations, and delusions.	Risperdal (risperidone) Abilify (aripiprazole)
Mood stabilizers	Unstable mood, seizures (epilepsy), migraine headaches	Depakote (valproate) Lamictal (lamotrigine) Lithium
Sedatives	Severe sleep problems (used for limited periods of time in addition to behavioral interventions)	Melatonin Vistaril (hydroxyzine) Desyrel (trazodone)

Questions to ask if your child is prescribed a psychiatric medication (*source: AACAP**):

- What information is available about the risks and benefits of this medication for my child?
- If the medication works well, what behavior changes will we see, and when?
- What side effects and drug interactions might occur, and how should we manage them?
- When and how should we take the medication? What should we do if we miss a dose?
- What information should we bring to our next appointment so we can evaluate whether the medication is working?
- Who will monitor my child's progress and adjust dosing? How often will we be seen for follow-up appointments?
- How long will my child be on this medication? How will we decide when to discontinue the medication?

Additional Resources:

American Academy of Child and Adolescent Psychiatry Parents' Medication Guides. Parents' Medication Guides (aacap.org)

*AACAP Facts for Families. Psychiatric Medication For Children And Adolescents Part III - Questions To Ask (aacap.org)

Letter Requesting and Consenting for IEP Evaluation

_____
PARENT/CAREGIVER ADDRESS

_____
CITY, STATE, ZIP CODE

_____
DATE

_____
NAME OF SCHOOL

_____
ADDRESS OF SCHOOL

_____
CITY, STATE, ZIP CODE

Dear Principal:

I am the parent/guardian of _____ (_____) who is a
NAME OF STUDENT DATE OF BIRTH
_____ grader at your school. I am writing to ask for a special education evaluation for my child.
GRADE

My child is not doing well in school, and I believe this may be due to a disability. I believe my child may need special services at school in order to learn. This letter serves as my request and my consent for my child to be evaluated.

Please contact me at _____ to schedule an Individualized Education Program (IEP)
PHONE NUMBER
meeting. The best time to reach me is _____.
TIME OF DAY

Sincerely,

_____
PARENT/CAREGIVER SIGNATURE

_____
PARENT/CAREGIVER PRINTED NAME

RECEIVED BY:

_____ _____ _____
SCHOOL OFFICIAL NAME SCHOOL OFFICIAL SIGNATURE DATE

School official, please provide a copy of this letter to the parent/caregiver.