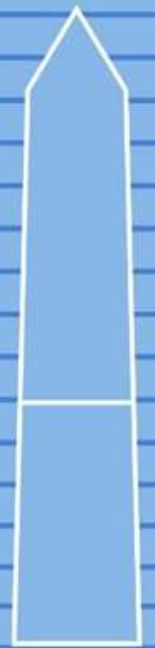


Future ^{OF} Pediatrics

Pediatric Health Network



Supporting Autism Families in the Primary Care Setting Using Collaborative Care Models



Anne P. Inge, PhD

Clinical Director, Center for Autism Spectrum Disorders

Kelly Register-Brown, MD

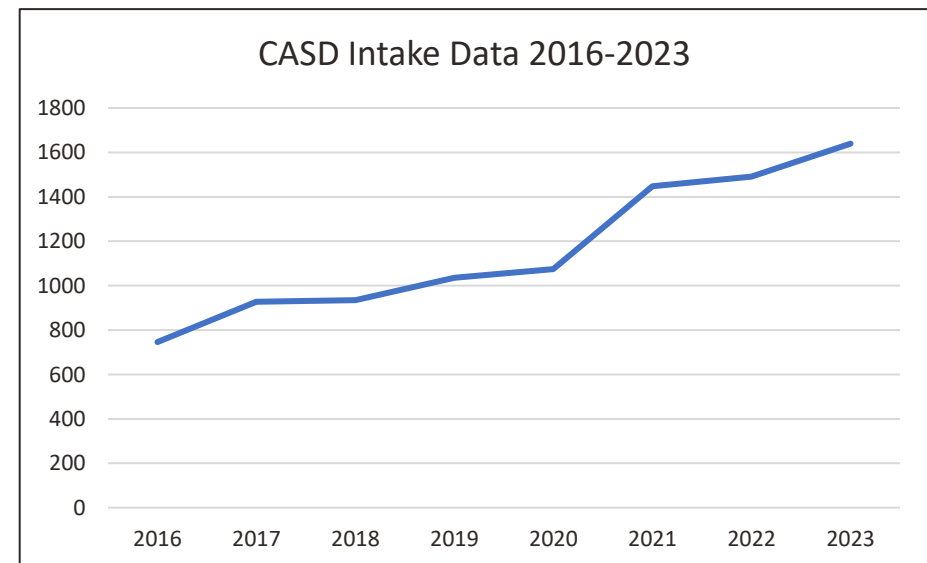
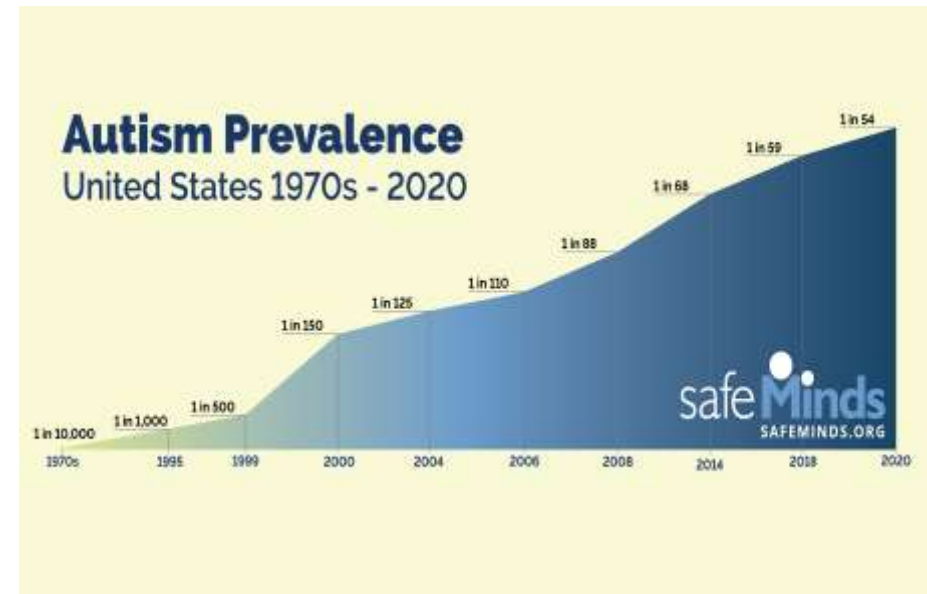
Psychiatrist

Objectives

1. Describe the access crisis in autism care and critical need for innovative practice and shared care models between pediatricians and specialists, highlighting the ECHO Autism program at Children's National
2. Describe a framework to guide PCPs in triage, assessment, and referral to best support autistic children and their families
3. Review provider resources for care of autistic children and their families and opportunities for continued learning

Status of Autism Services

- Increasing autism prevalence, routine referral to specialty clinics from frontline providers, and service disruptions related to Covid-19 have contributed to significant waitlists at autism centers requiring periodic closures to manage demand
- Access crisis has prompted a critical need to innovate autism service delivery in order to grow the workforce that can competently care for autistic children and families to include frontline medical and mental/behavioral health providers



ECHO AUTISM, hosted by CN's Center for Autism (CASD), creates a virtual learning network that aims to “move knowledge, not patients” using a telementoring format that provides access to a hub of medical experts to support community providers to diagnose, treat and care for autistic children and their families



HOW IT WORKS

- Convenient, **web-based** small-group format
- Learn and share **best practices** for autism care, connecting with community resources, and family/caregiver support
- **Reduce costs** for families and providers by limiting travel, creating **more efficient visits and shorter wait times for care**
- Provides a long-term solution in communities, including underserved areas where access to autism specialists is limited, by **building local capacity** for autism care

BENEFITS:

- **Free CEs** for medical, psychology, social work, speech-language disciplines
- Real-time **case guidance** with multidisciplinary team of autism experts
- Meet a **network of other providers**

WHAT YOU NEED TO START:

- Internet connection



Multidisciplinary Hub Team



Annie Inge, Ph.D.
Clinical Psychologist
Children's National



Kelly Register-Brown, MD
Child Psychiatrist
Children's National



Shalinee Khurana, MD
Developmental
Pediatrician
Pediatric Specialists of
Virginia



Allysa Ware, MSW
Social Worker
Family Voices



Colleen Morgan, MA,
CCC-SLP
Speech-Language
Pathologist
Children's National



Amanda Hastings, PsyD
Clinical Psychologist/
Board Certified Behavior
Analyst
Children's National

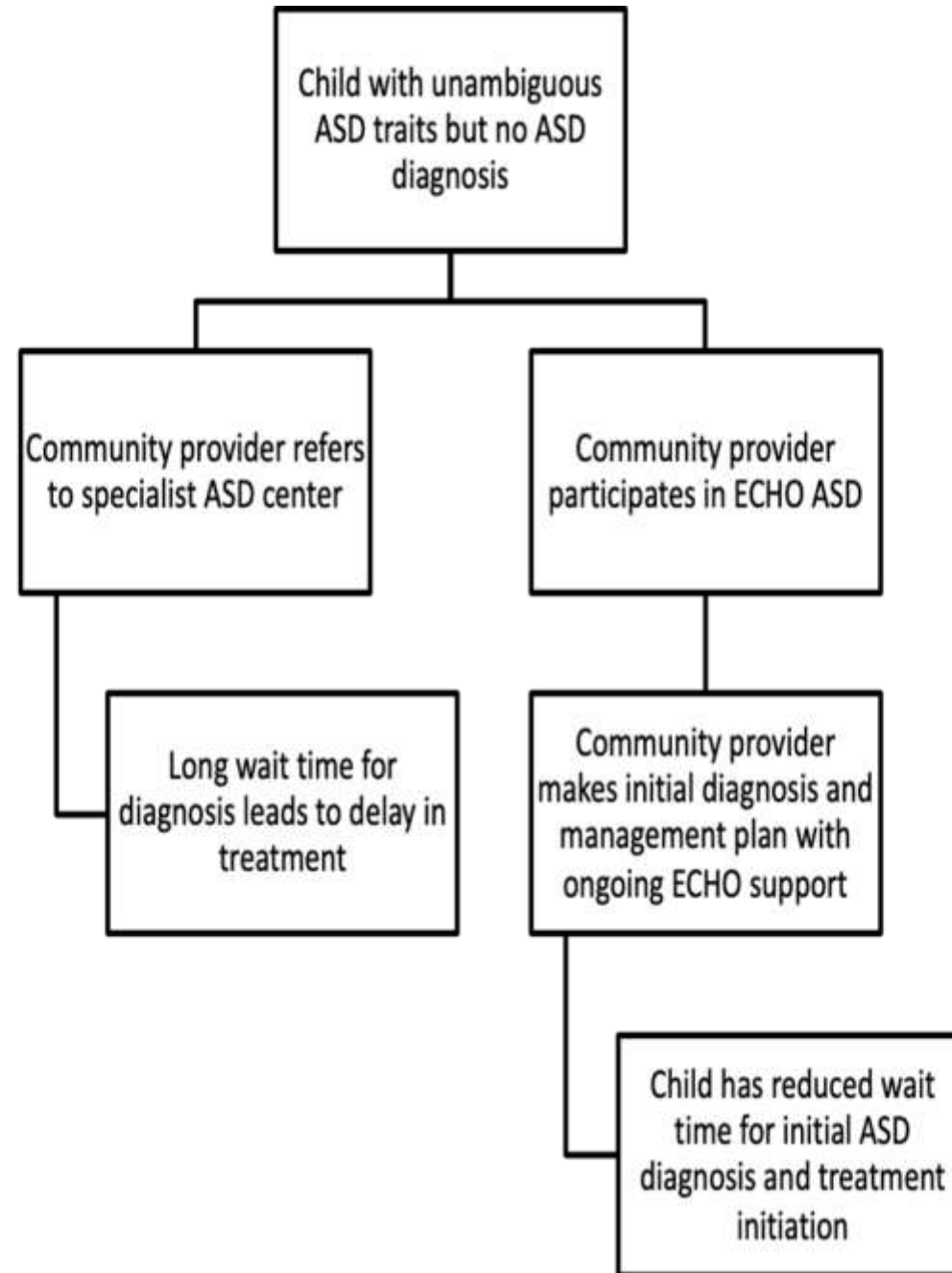


Yetta Myrick
Parent Educator/Advocate
DC Autism Parents

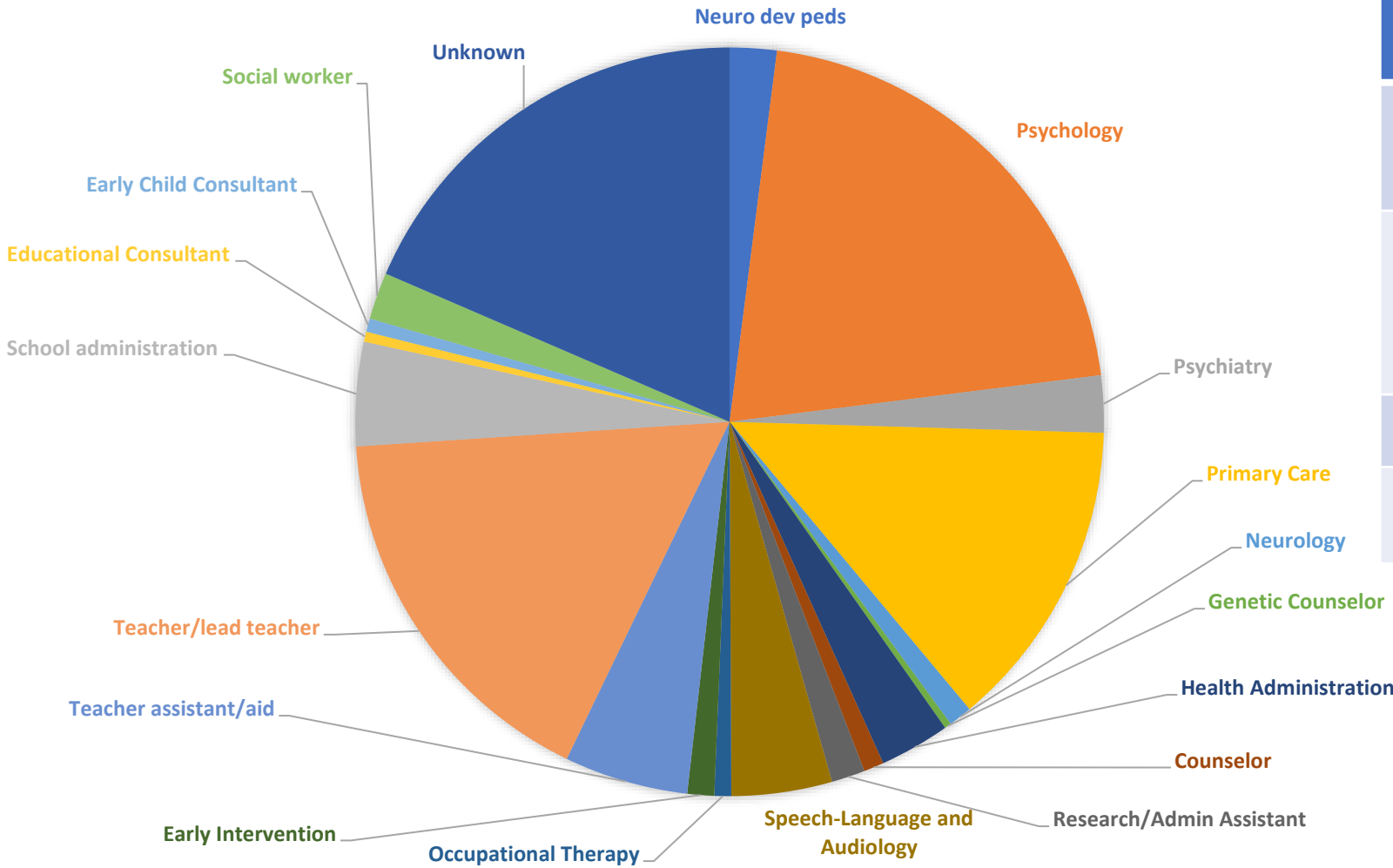


Lori Kraden
Educational Specialist
Fairfax County Public
Schools





ECHO AUTISM ATTENDEES N=691, DISCIPLINE



Quality Improvement Program Evaluation	N	Percent Improved
ASD Knowledge	122	82% (accuracy)
Self-reported efficacy in autism care	135	98%
Feasibility	132	99%
Acceptability	98	100%



Autism Guidebook for Medical Providers

*Kelly Register-Brown, MD and Anne Inge, PhD
with the Children's National ECHO Autism Project Team and the staff
of the Children's National Center for Autism*



A Practical Framework for Conceptualizing Autism Diagnosis and Treatment

CENTER FOR AUTISM GUIDEBOOK FOR MEDICAL PROVIDERS

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.

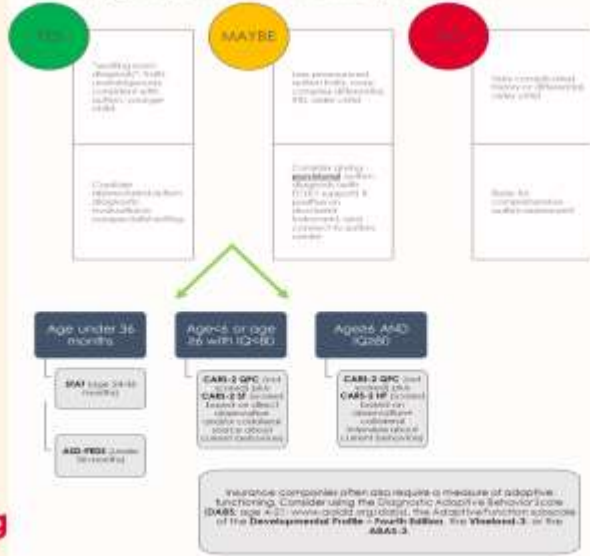
Development and Dissemination of a Feasible Clinical Toolkit for Supporting Autism Families in Nonspecialist Settings

Kelly Register-Brown, M.D., Annie Inge, Ph.D., Anna Chelsea Armour, M.A., Kelly Miller, Allysa Ware, Ph.D., Yetta Myrick, Amanda Hastings, Psy.D., Angela Bollich, Ph.D., Elise Horne, Colleen Morgan, MA, CCC-SLP, Shalinee Khurana, M.D., Lori Kraden, Lauren Kenworthy, Ph.D.



Step 1: Triage diagnosis

Is a community autism diagnosis appropriate for this patient?



Step 2: Quantify autism traits and adaptive functioning

Document autism developmental history and quantify autism traits

Medical
Take history and quantify both in your non-specialist setting, or refer to autism center, depending on scope assessment (see step 1).

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

Speech-language evaluation

Medical
Refer to outpatient SL therapy for testing. Consider when there is remaining AAC and/or pragmatic language testing is indicated.

School
IEP services include SL testing and therapy involving AAC evaluation and services. IEP services involving language services are required.

Cognitive testing and adaptive functioning evaluation

Medical
Refer to psychology/therapist/psychologist 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.

Universal Referrals

Medical
• Genetics
• Hearing screening

State and Federal Supports
• All ages: Parents should submit ASD and Health care waiver applications for their state.
• Age 1+; Parents should apply to the Division of Vocational Rehabilitation in their state.

Step 3: Facilitate evaluation in all systems of care

ECHO Model



Systems of Care Model



Universal Referring 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 as they can access insurance-funded services like ABA. This typically involves a medical provider using a structured instrument to quantify autism traits (ADOS-2, CARS-2, or other instrument) and that document both another system of care) estimate adaptive functioning (e.g., ABAS-3), and providing the parent with support.
 - Have they had an IEP evaluation of school that targets autism-specific learning and behavioral needs that just for general learning or behavioral concerns? If there are barriers, consider referral to the PFI or their state:
 - DC: Advocates for Autism and Education: www.aae-dc.org
 - MD: Parents' Place of Maryland: www.ppmj.org
 - VA: Formed Family Forward: www.formedfamilyforward.org and Parent Education and Advocacy Training Center: www.peratc.org
 - National Center for Parent and Family Involvement: www.nationalcenterforparentandfamilyinvolvement.org
 - Have parents submitted Administration on Intellectual and Developmental Disabilities (AIDD) Medical Waiver: (msd) (page 14) (Division of Vocational Rehabilitation application) 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 not 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 (in either referral or diagnostic) (documenting using CARS-2 QPC, CARS-2 SF, and spcCARS-2F)
 - Adaptive functioning measurement (e.g. Vineland-3, ABAS-3)
 - Cognitive (IQ) testing
 - Speech/language testing including pragmatic language testing
 - Hearing testing
- Have parents been offered a referral to genetics?

What intensity of support does this family need now?



Step 4: Triage support needs

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 REIMAX Foundation.

Talking about, screening for, and sometimes performing an abbreviated **MEDICAL** evaluation for autism

CENTER FOR AUTISM GUIDEBOOK FOR MEDICAL PROVIDERS

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 specialist¹⁰ **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:

Language matters.

"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)."

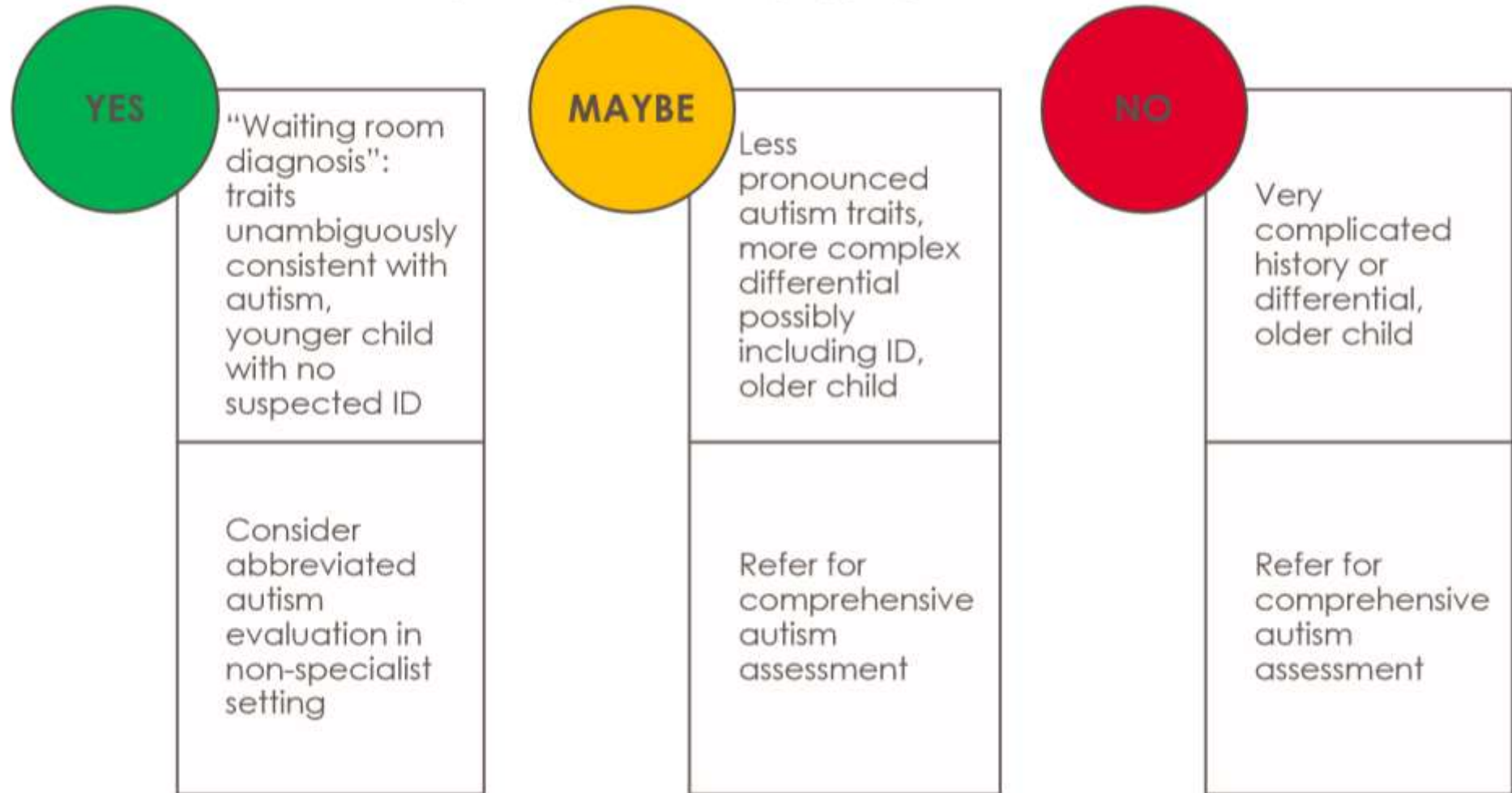
-DSM 5

"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

<https://awnnetwork.org/resource-library/>

Next Steps After Positive Screen: Is a non-specialist ASD diagnostic evaluation appropriate for this patient?



For Green Cases Only: Quantify Autism Traits & Adaptive Functioning

Age under 36 months

STAT (age 24-36 months)

ASD-PEDS (under 36 months)

Age < 6 or age ≥ 6 with IQ < 80

CARS-2 QPC (not scored) plus **CARS-2 ST** (scored based on direct observation and/or collateral source about current behaviors)

Age ≥ 6 AND IQ ≥ 80

CARS-2 QPC (not scored) plus **CARS-2 HF** (scored based on observation+ collateral interview about current behaviors)

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





Autism Behavioral Interview Protocol: Emerging Language to Phrase Speech



I. Child-led free play with social presses (10 minutes)

- 1) **Free Play:**
Examiner observes child's interests, play level, language. Examiner begins to establish themselves as a social partner
- 2) **Response to name**
- 3) **Response to joint attention**



II. Interactive examiner-led activities (15-20 minutes)

- 4) **Communicative temptations**
 - 5) **Imitation prompts with 2-3 objects**
 - 6) **Fine motor activity**
 - 7) **Make-believe play and joining in play**
- For children with consistent use of 2-3 word phrases (or more):*
- 8) **Social Insight**
 - 9) **Conversational bids/Social language use**

Embedded Demands:

- Ability to transition between activities
- Object attachments/strong interests
- Emotion regulation including anxiety
- Social relating (e.g., shared enjoyment)
- Sensory regulation (e.g., aversions and interests)
- Maintenance of eye contact
- Motor coordination and body use
- Activity level

Medical OR
Educational System

Adaptive
functioning testing

IQ testing

Speech/language
testing

Hearing testing

Medical AND
Educational Systems

Developmental history and behavioral observation
(autism diagnosis/classification)

Building an Autism Treatment Plan

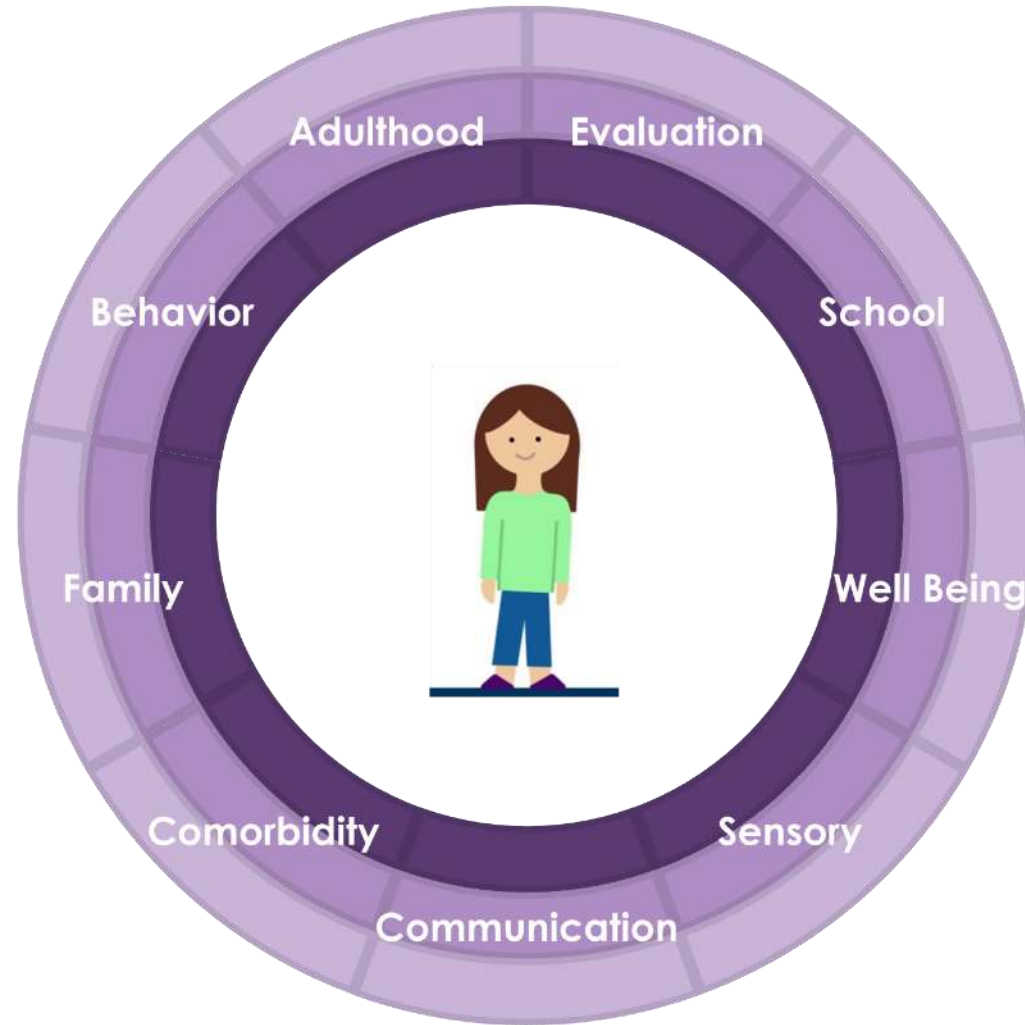
CENTER FOR AUTISM GUIDEBOOK FOR MEDICAL PROVIDERS

CHAPTER 3: BUILDING AN AUTISM TREATMENT PLAN.

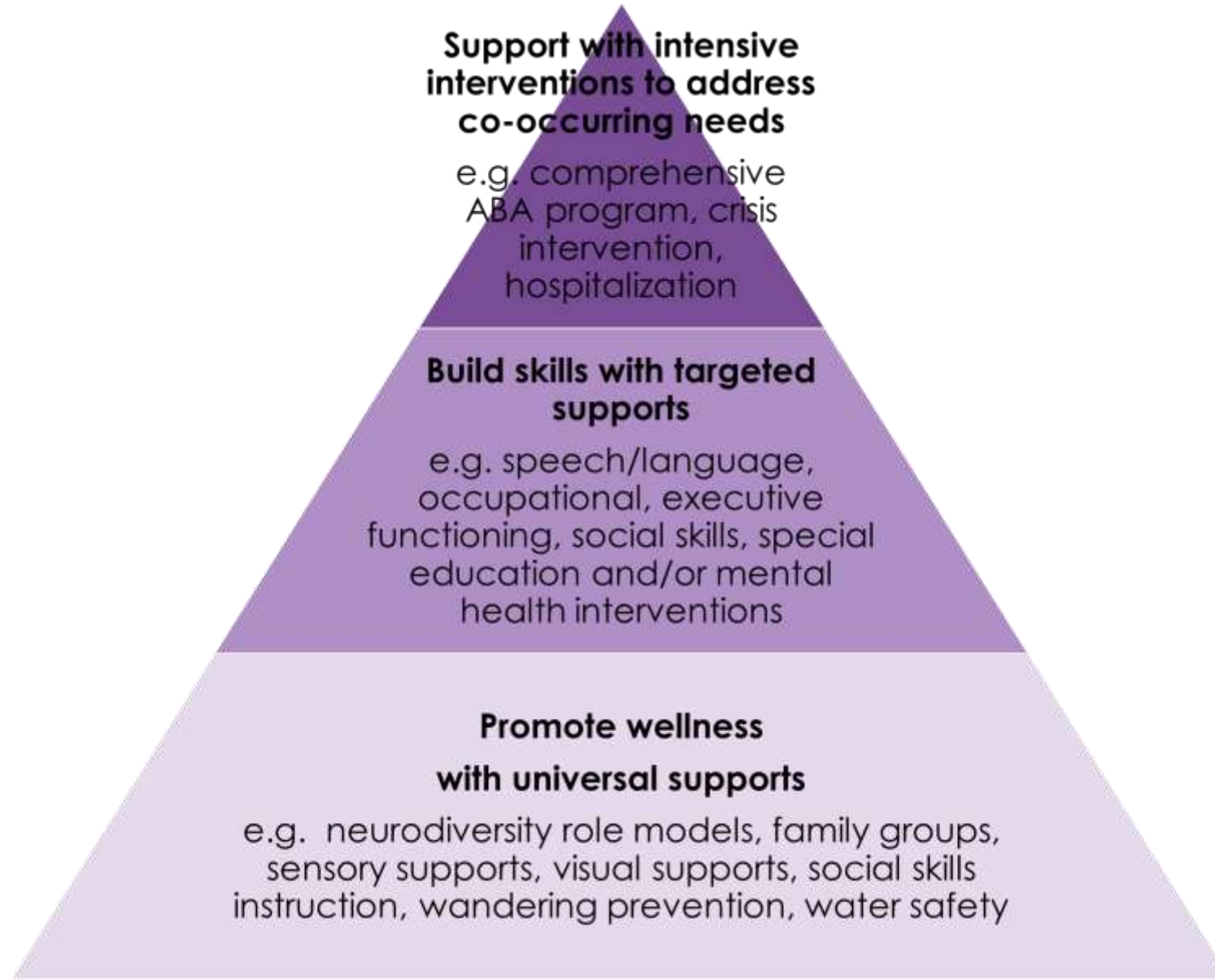
Assess for missing elements of the autism diagnostic evaluation, and refer as needed.

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:

Key Domains Requiring Support



What intensity of support does this family need now?



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

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.ppmmd.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?**

Getting the Right Supports for Your Autistic Child



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-4efrakatie-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:

Anticipatory Guidance and Managing Challenges

CENTER FOR AUTISM GUIDEBOOK FOR MEDICAL PROVIDERS

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.

Autistic adults with and without intellectual disability are at increased risk

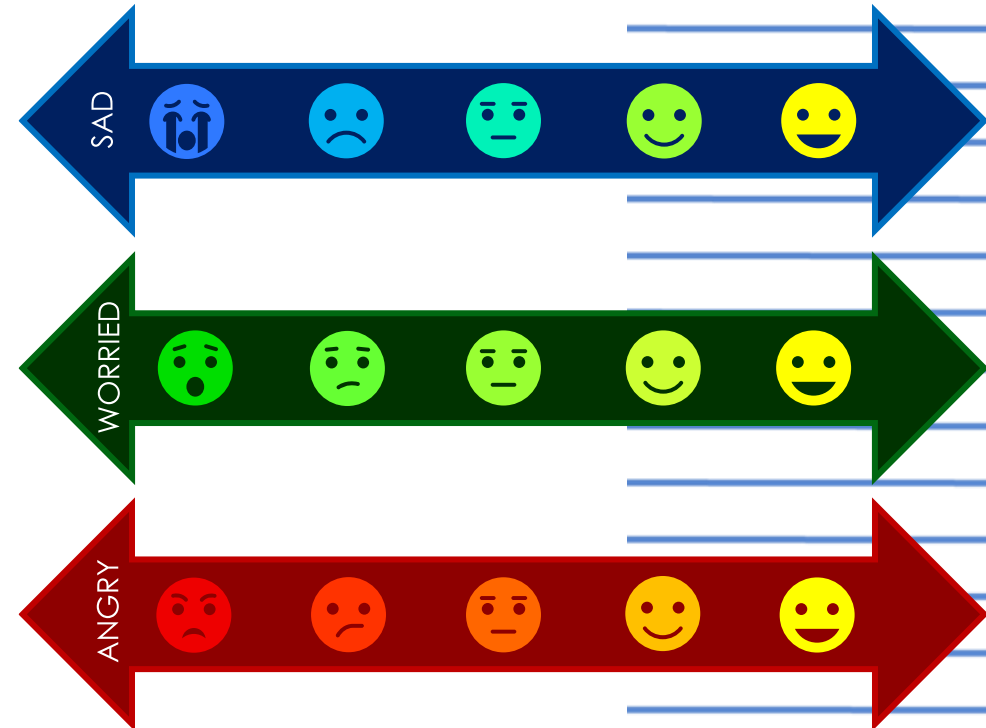
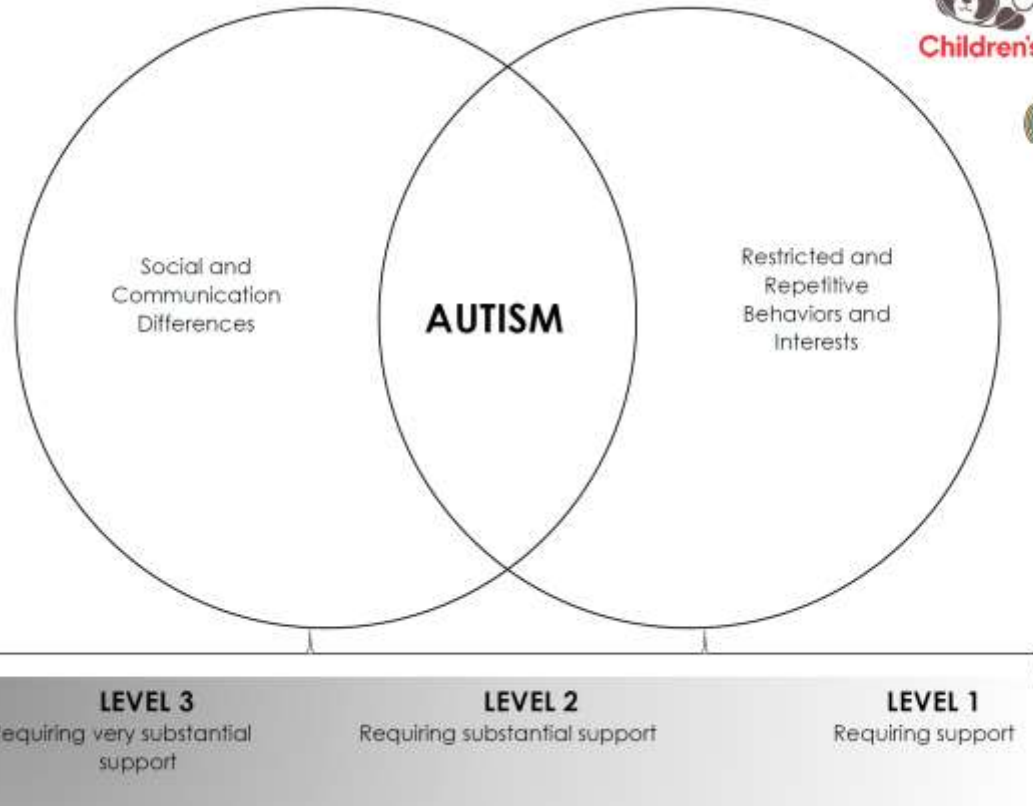
When should parents tell their child they are autistic?

“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

Topic	Facts and Resources
Toileting	<p>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)</p> <p>Vanderbilt's TRIAD center has many resources including a family handout on toilet training: toilettrainasd.pdf (vumc.org)</p>
Feeding and eating problems	<p>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)</p> <p>Autism Speaks has a toolkit for families on feeding behavior: ATN/AIR-P Guide to Exploring Feeding Behavior in Autism Autism Speaks</p> <p>Some children benefit from referral to a feeding disorder specialist.</p>
Advocating in the school system	<p>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:</p>

Provider Reference Sheets

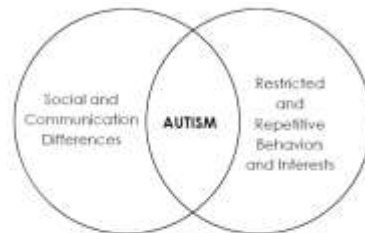


Handouts for Families



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 | NCBDDB | 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://neurodiveritylibrary.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



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:

Questions?



Save the Date!

ECHO Autism Diagnostic Tools for the Primary Care Provider

12:00-1:00 PM EST
First and Third Fridays
January 5, 2024 – June 21, 2024



TOPICS COVERED:

1/5, Supporting Autistic Children in Outpatient and Medical Visits	4/5, CARS-2 ST, Administration and Scoring Practice Session
1/19, Triage Clinical Concerns for ASD/Forming a Clinical Impression	4/19, CARS-2 HF, Administration and Scoring Practice Session
2/2, Screening Tool for Autism in Toddlers (STAT)	5/3, Autism Mental Status Exam (AMSE)
2/16, ASD-PEDS, Overview and Kit	5/17, Troubleshooting, Biases, and Pitfalls: Difficult Areas in Assessments
3/1, ASD-PEDS, Administration and Scoring Practice Session	6/7, Considerations When Talking to Families about Autism
3/15, CARS-2, Overview and Kit	6/21, Treatment Planning for Autistic Children

<https://www.childrensnational.org/get-care/departments/center-for-autism-spectrum-disorders/provider-resources>