

Navigating an Autism Diagnosis and Services

April 15, 2026

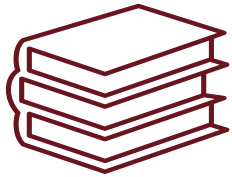
Welcome!

We are Recording

- Please use the chat function or the Q&A button at the bottom of the screen to ask questions.
- A Follow-up email will be sent out with additional resources and a link to the recording of today's presentation.

NDSS Core Programs

NDSS supports and advocates for the Down syndrome community by focusing on four key pillars:



**Resources
& Support**



Research



**Advocacy
& Policy**

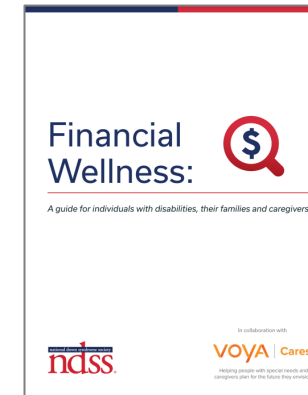
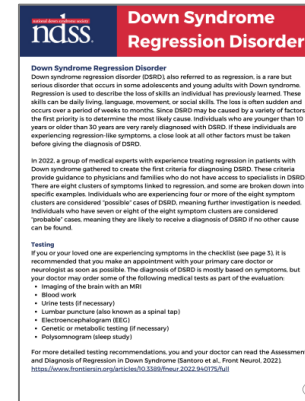


**Community
Engagement**

NDSS Core Programs

Resources & Support

- 1-800 helpline and info email
- Resources and information from birth to end of life
- Education, employment, health and wellness, aging, caregiving, and more



NDSS Talking Points, Cont.

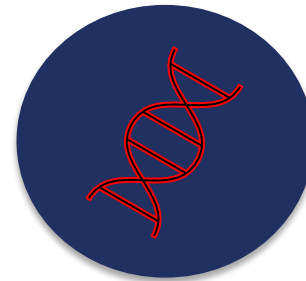
Programs



NDSS Core Programs

Research

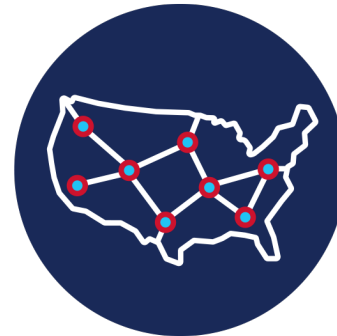
- Bridge between research and our community
- Coordinating research projects
- Preparing scientific industry companies for clinical trials
- Sharing research opportunities with families
- Expanding access to clinical trials, treatments, and diagnostics



NDSS Core Programs

Advocacy & Public Policy

- Federal, state, and local advocacy
- Develop and improve laws to positively impact people with Down syndrome across the country and affirm their human rights
- Legislative agenda spans the life experience of individuals with Down syndrome



NDSS Core Programs

Community Engagement

- Scholarships, grants, and awards
- National Buddy Walk® Program
- Times Square Video Presentation
- Athlete Ambassador Program
- Virtual Racing for 3.21 for World Down Syndrome Day
- Gala, golf, and more!



NDSS Events



Times Square Video and
New York City Buddy Walk®
September 12, 2026



Racing For 3.21
March 2027
Virtual



NDSS Golf Outing
July 20, 2026
Alexandria, VA



Down Syndrome
Advocacy Conference
May 11-13, 2026
Washington D.C.



NDSS Adult Summit
TBD 2027

Family Weekend
Various locations
Fall 2027



Navigating an Autism Diagnosis & Services

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Agenda

An Overview of Autism & Dual Diagnosis

Understanding the Autism Evaluation Process

From Diagnosis to Supports

State-by-State Differences



A Quick Acknowledgment.....

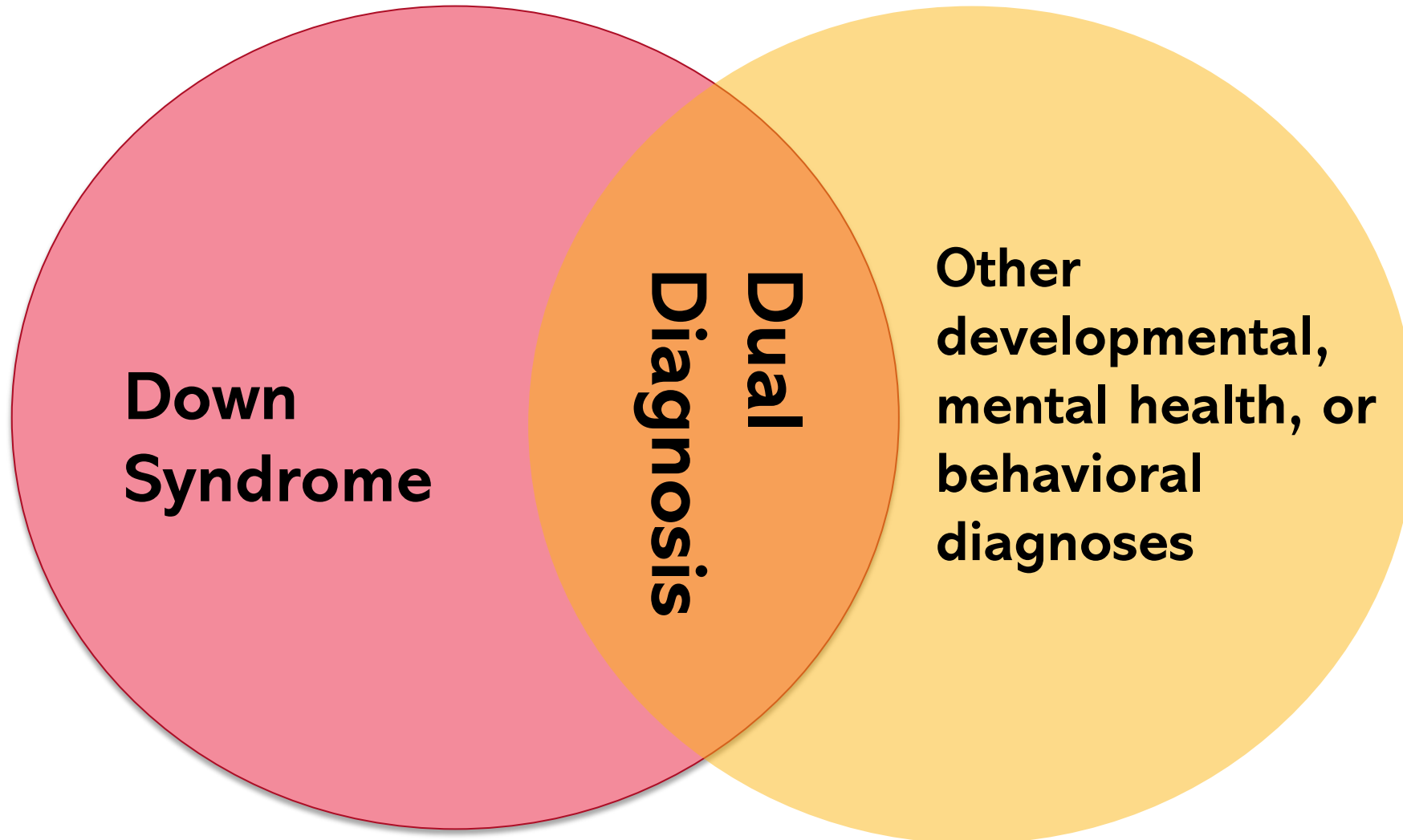
This process is challenging. We engage in this work every day, and still find the process confusing sometimes. For families of individuals with Down syndrome seeking further neurodevelopmental assessment, evidence suggests even more barriers than may typically be in place can delay or prevent access to assessment and intervention services. Please reach out to us or to advocacy networks for support!



An Overview of Autism & Dual Diagnosis



Defining Dual Diagnosis





What is Autism?

American Psychiatric Association. (2022). *Diagnostic and statistical manual of mental disorders* (5th ed., text rev.). https://doi.org/10.1176/a_ppi.books.9780890425787

Symptom Criteria	Traits
Deficits in social communication & social interaction across multiple contexts	Deficits in social-emotional reciprocity; Deficits in nonverbal communication behaviors (e.g., gestures) used for social interaction; Deficits in the development, maintenance, and comprehension of relationships
Restricted, repetitive patterns of behavior, interests or activities	Stereotyped movements, speech, and use of objects; Inflexibility to change of routines or ritualized patterns; Restricted interests with strong, abnormal attachments; Hypo- or hypersensitivity to environmental factors
Symptoms must be present in early developmental period	Symptoms may not manifest until social demands exceed limited capacities
Combination of symptoms significantly impair daily functioning	Level 3 - Requiring very substantial support Level 2 - Requiring substantial support Level 1 – Requiring support



Dual Diagnosis and Down Syndrome

In general, children with Down syndrome and other developmental/mental health diagnoses:

- Are twice as likely to be male (especially for ASD)
- Tend to experience greater medical complexity
 - Feeding disorders, GERD, constipation
 - Epilepsy
- Have higher rates of repetitive behaviors and interfering behaviors



Research has found that individuals with ASD & Down syndrome have a distinct profile that differs from others with a single diagnosis of ASD or Down syndrome.

Additional areas to consider

Compared to youth with autism alone, children with Down syndrome + autism are more likely to present with:

More significant cognitive challenges

Cognitive demands of both conditions compound. Assessments should account for the overlap and not attribute all difficulties solely to one diagnosis.

Slower processing speed

Processing differences may be misread as stubbornness or noncompliance. Allowing extra response time is essential in educational and clinical settings.

HOW DS + AUTISM COMPARES

Area	vs. autism only	vs. Down syndrome only
Social interest	More social interest	Less social initiation
Repetitive behaviors	Less severe	More frequent / intense
Cognitive load	Greater challenges	Additive effect

Key Indicators Warranting Further Assessment for Autism



Loss of previously acquired social or communication skills

Minimal social engagement relative to developmental level

Limited or absent joint attention

Repetitive behaviors that interfere with daily life

Significant sensory distress

Plateau in progress despite appropriate Down syndrome supports



Understanding the Autism Evaluation Process



Importance of Multi-Method, Multi- Informant Assessment Approach

Multiple methods of assessment

- Observations
- Interviews
- Standardized scales

Multiple informants a part of assessment

- Child
- Teachers
- Parents

Importance of Multidisciplinary Approach



Audiology

Speech-Language Pathology

Internal Medicine

Endocrinology

Sleep Specialist

Psychology

Gastroenterologist

Ear, Nose, Throat

Neurologist

Teachers

The diagnostic approach should ***rule-out*** other possible contributing factors to presenting symptoms



Types of Evaluations

	School	Clinical	Medical
Evaluation Professional	School Psychologist	Licensed Psychologist	Developmental Behavioral Pediatrician, Psychiatrist, Neurologist
Timeline	60 days	30-90 days (after intake)	Dependent on services provided
Outcome	School Verification	Clinical (DSM/ICD) diagnosis	May screen and then refer for further testing



The Clinical Evaluation Process



Medical Model	Social Model
<ul style="list-style-type: none">• Aim: <i>treat or eliminate the condition</i>• Deficit-based (typically)• Sometimes neglects environmental/social influences on mental and behavioral health	<ul style="list-style-type: none">• Aim: <i>include and accommodate individuals with a condition</i>• Strengths-based (typically)• Contends that conditions arise due to the environment not accommodating individuals appropriately• Neurodiversity

Whelpely et al. (2023)

**move
towards**



Biopsychosocial Model

- **Aim: *understand how condition impacts a person as an individual and the supports they need to thrive***
- Components of medical model (biological domain)
- Components of social model (social domain)
- Individual's beliefs and attitudes about condition and how it impacts them in their daily lives (psychological domain)

The Clinical Evaluation Process at MMI



1

Referral: school, caregiver, medical provider

2

Initial intake: developmental, medical, and family history, current functioning; rating scales provided to caregivers and teachers

3

Testing session: standardized clinical measures, may include cognitive assessment and autism assessment

4

Feedback session: review of evaluation results, recommendations

Consultation with medical providers, school, other therapists

Preparing Families for an Evaluation



- The first appointment includes a lot of information gathering!
 - Background information: early medical, developmental, educational, and social history
- Child needs to be present, but caregiver will be heavily involved

Tips!

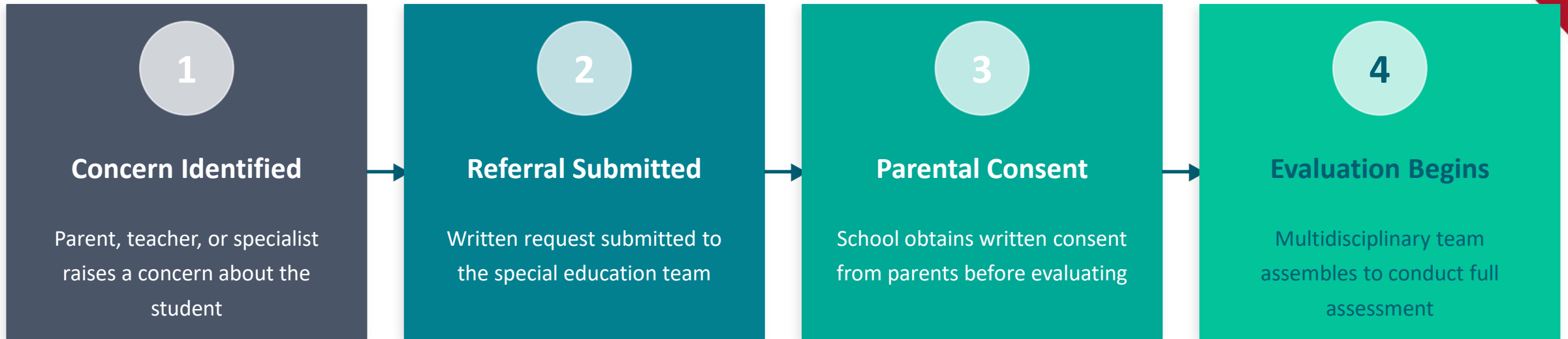
- Take and bring notes and examples of behavioral concerns to first appointment
- Bring school and medical records


Reminder for caregivers: There are no blood tests or x-rays that will pinpoint mental health diagnosis like there is for many physical/medical conditions. It may take time to understand symptoms and behaviors, and diagnoses can change over time.



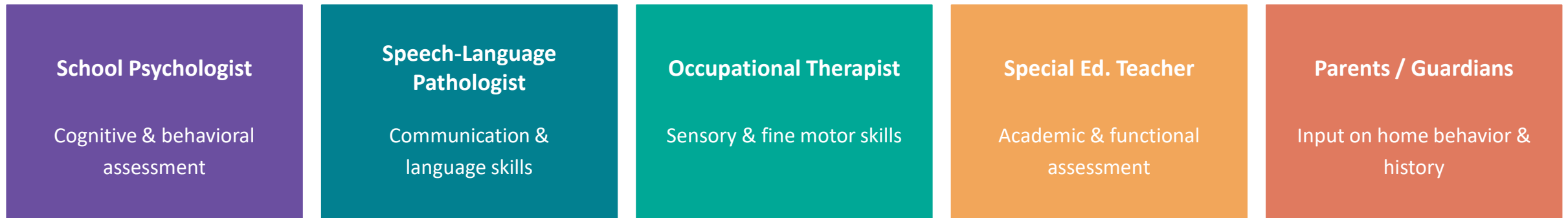
The School Evaluation Process

The School Evaluation Process - Phase 1: Initiating the Evaluation



 Timeline: Schools must complete the evaluation within 60 days of receiving parental consent (timelines vary by state)

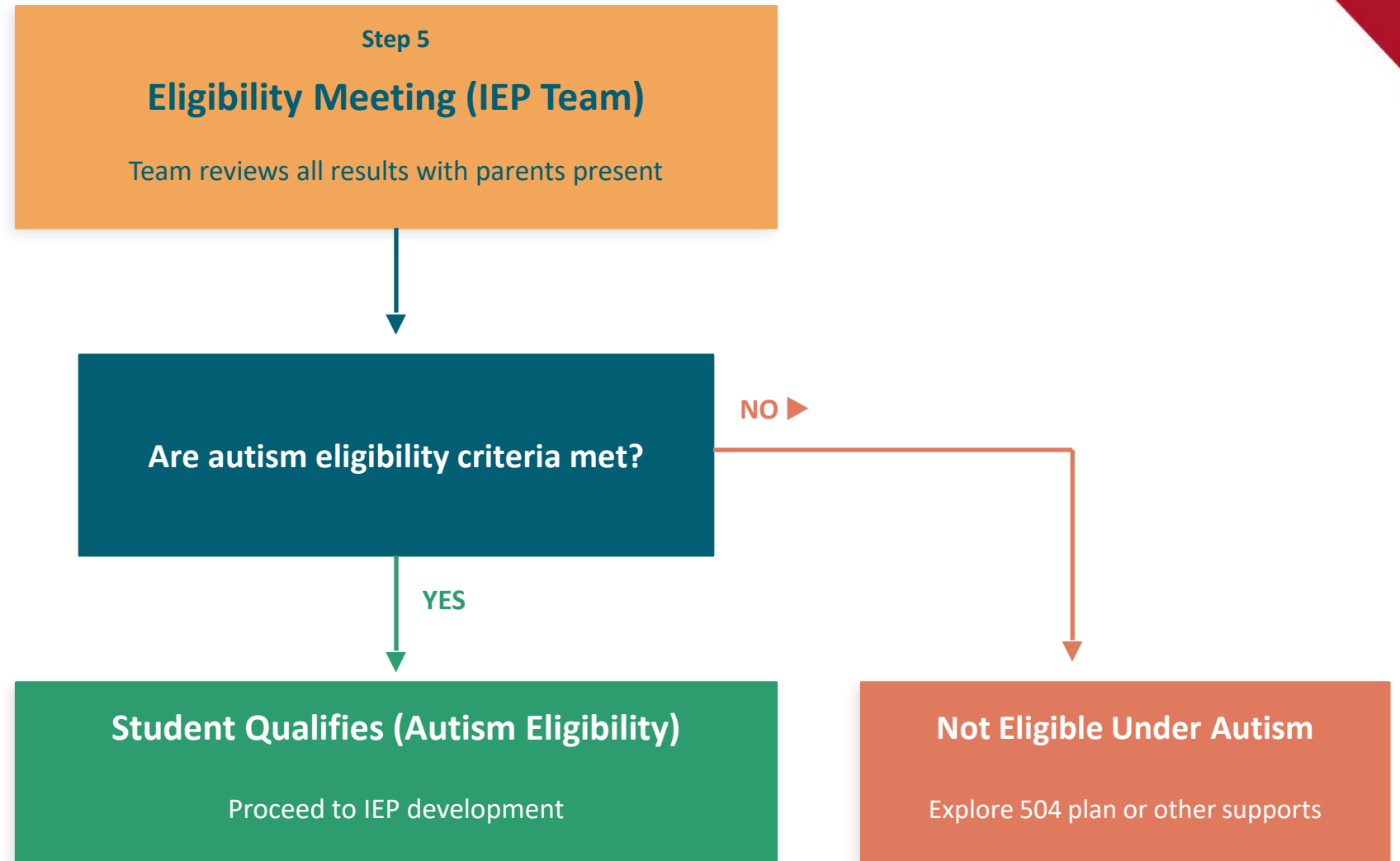
The Multidisciplinary Evaluation Team



The School Evaluation Process - Phase 2: Eligibility Determination

Parent Rights

- Must be present at all meetings
- Receive written notice of decisions
- Can request independent evaluation
- Can dispute decisions (mediation / due process)



The School Evaluation Process - Phase 3: IEP Development & Ongoing Support

Step 6: IEP Developed

Goals, services, accommodations, and supports defined with parent input



Step 7: Services Begin

Special education services implemented promptly in the school setting

Common IEP Services for Students with Autism

Speech-Language Therapy

Communication & social skills

Occupational Therapy

Sensory & daily living skills

Applied Behavior Analysis

Behavioral support strategies

Social Skills Groups

Peer interaction practice

Classroom Support

Para educator or aide assistance

Assistive Technology

AAC devices & visual supports

Step 8: Annual Review & Triennial Re-evaluation | IEP updated every year · Full re-evaluation every 3 years



Do we need a clinical evaluation or a school evaluation?

It depends.....



From Diagnosis to Services

Common Services for Individuals with Autism



Early Intensive Behavioral Intervention/Applied Behavior Analysis

Social Skills Intervention

School Supports & Interventions

Self-Advocacy

Occupational Therapy

Speech Therapy



Why do children with ASD need different teaching methods?

Children without ASD learn throughout the day through exploration, creative play, modeling, and conversation



Children with ASD

Have deficits in communication skills

May have less motivation to explore

Demonstrate delays in play skills



Early Intensive Behavioral Intervention (EIBI)

- Typically for children under age 5
- High-frequency and high-intensity, of 20-40 hours a week
- Conducted in home or clinic
- Utilizes ABA strategies
- Addresses communication, social, self-care, and academic readiness skills; reducing challenging behavior



Applied Behavior Analysis

Communication

Social Skills

Repetitive or sensory-seeking behaviors

Challenging or maladaptive behaviors

Adaptive skills





A Meta-Analysis of Single-Case Research on Applied Behavior Analytic Interventions for People With Down Syndrome

Nicole Neil, Ashley Amicarelli, Brianna M. Anderson, and Kailee Liesemer

- Suggested ABA is efficacious for increasing communication skills and decreasing challenging behavior
- Common procedures include prompting and reinforcement; decreasing trends of intrusive strategies over time



Social Skills Intervention

- Research suggests mixed results
- Good social skills intervention
 - Is developmentally appropriate
 - Has specific goals
 - Includes peer models
 - Includes role-play & modeling activities
 - Includes reinforcement strategies
 - Plans for generalization of skills



Self-Advocacy

Teaching individuals about...

- Their diagnoses
- Their areas of strength and need
- Strategies to request what they need
- Support or accommodation strategies that work for them
- Safety and independence
- Sensory needs and strategies



How do we access these services?
































- State-funded waivers
- Medicaid
- Private insurance
- Family grants



State-by-State Differences

AUTISM DIAGNOSIS & SERVICE ACCESS: STATE COMPARISON

NEBRASKA | PENNSYLVANIA | ARKANSAS

	 Nebraska	 Pennsylvania	 Arkansas
 Initial Step	 Consult with PCP or specialist	 Consult with PCP or school	 See Medicaid PCP first
 Who Can Diagnose?	 Multidisciplinary Centers (e.g. UNMC)	 Multidisciplinary Teams	 2 of 3 Clinicians (MD, Psych, SLP)
 Evaluation Process	 Two-Part Assessment	 Comprehensive Standards	 Dual Clinician Review
 Oversight	 DHHS Developmental Disabilities	 ODP & Bureau of Autism Services	 DDS Autism Services
 Medicaid / Waivers	 HCBS DD & AD Waivers	 ASERT & County Programs	 Arkansas Autism Waiver (AAP)
 Unique Requirements	 Early Intervention Focus	 Act 62 Diagnostic Guidelines	 Two Clinician Verification
 Notable Features	 Family-Centered Evaluations	 Statewide Assessment Standards	 Intensive ABA Program

Difference #1 & #2: How Families Get Started & Who Can Diagnose

HOW FAMILIES GET STARTED

PCP referral required

Some states (e.g. Medicaid-heavy systems) require families to first see a primary care physician, who must refer them before any evaluation can begin. Skipping this step can delay access significantly.

School as an entry point

Many states allow families to request a school-based evaluation directly, without a medical referral. Under IDEA, schools must evaluate within 60 days of written parental consent.

Direct specialist access

Other states allow families to go directly to a developmental pediatrician, neurologist, or autism specialist. This route is often faster but may involve longer waitlists at specialty clinics.

WHO CAN MAKE THE DIAGNOSIS

Multidisciplinary team required

Many states require a team evaluation including a psychologist, speech-language pathologist, and/or developmental specialist. This is generally considered the gold standard.

Single licensed clinician accepted

Some states allow a diagnosis from a single licensed provider — often a developmental pediatrician or psychologist — which can speed up access but may vary in comprehensiveness.

Multi-clinician agreement rules

A few states require independent agreement from 2 or more separate clinician types before a diagnosis is official. This adds a verification step but may reduce diagnostic inconsistency.


Difference #3 & #4: Medicaid Waivers & Age Eligibility Windows

Medicaid waivers are the primary funding mechanism for autism services in most states — but eligibility rules, age windows, service hours, and waitlist lengths vary enormously. Families who move between states often face a complete restart of the application process.

Early childhood waivers

Ages 18 months – 5 or 8 years


Some states offer intensive early-intervention waivers specifically for very young children. These typically fund 20–30 hours/week of in-home ABA. Enrollment deadlines are strict — families must often apply before the child's 3rd or 5th birthday.

 **Missing the enrollment deadline means losing eligibility entirely**

Lifespan waivers

Birth through adulthood

Other states use a single waiver system that covers individuals with autism across the lifespan. These tend to be more flexible but often have long waitlists — in some states, years long — because they serve a much larger population.

 **Waitlists can span 3–10+ years in high-demand states**

Adult-only waivers

Age 21 and older

Several states have developed separate adult autism waivers for individuals who age out of school-based services at 21. Access, service types, and funding caps differ significantly and the "services cliff" at age 21 is a critical transition point for families.

 **The "services cliff" at age 21 is a major challenge nationally**

OTHER KEY WAIVER DIFFERENCES ACROSS STATES

Service Hours

Ranges from 10 to 40+ hrs/week

ABA Coverage

Not universally covered; varies by plan

Waitlist Length

Weeks to 10+ years depending on state

Income Limits

Some states have strict income thresholds

Provider Availability

Rural areas face significant shortages


Difference #5 & #6: School vs. Clinical Services + Moving Between States

School-Based (IDEA / IEP)

- › Free evaluation — no insurance needed
- › Legal right to request under IDEA
- › Governed by federal law (consistent baseline)
- › Services tied to educational goals only
- › Does not require a clinical ASD diagnosis
- › Varies in intensity by district & state funding

Clinical / Medicaid (Community-Based)

- › Requires Medicaid enrollment or insurance
- › Services extend beyond school hours
- › More intensive intervention possible (ABA)
- › Tied to clinical diagnosis and waiver rules
- › Waitlists common; access varies by state
- › May cover in-home, community, clinic settings

 Families can and should pursue BOTH pathways simultaneously — school services and clinical/Medicaid services are not mutually exclusive.

Moving Between States

What families must know

-  Waivers do NOT transfer across state lines — you restart the application process entirely
-  Waitlists in the new state begin at day one — prior wait time does not carry over
-  IEPs are not automatically honored — new district has 30 days to hold an IEP meeting
-  Diagnosis may need to be re-confirmed if the new state has different clinician requirements
-  Contact the new state's Medicaid office and school district BEFORE you move if possible
-  Bring all records: diagnosis reports, IEP, therapy logs, waiver documentation

Start by calling your state's Medicaid office, Parent Training & Information Center (PTI), or the Autism Society affiliate in your area — they can map your local options.



How to Get Started



Share your concerns with

Pediatrician/Primary Care Provider
Case Manager
School Psychologist



If you are still not sure

State Department of Education
State Department of Health and Human
Services



Questions or Comments?



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