



SLO Family Meeting: Updates on Neurodevelopmental testing, Autism Spectrum Disorder, IEPs & Accessing School Services June 29, 2019

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Office of the Clinical Director

NIMH



National Institute
of Mental Health

Outline of Talk

- Understand what the Differential Diagnosis of ASD and other disorders is, and methods for making a differential diagnosis
- Learn basics neuropsychological testing and what it gives you
- Understand basics about IEP's and the federal education laws behind them
- Understand basic concepts regarding moving from test scores to recommendations for special education and other services



Autism Spectrum Disorder in DSM-5

A. Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays, and manifest by all of the following **currently, OR BY HISTORY,**

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

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

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

C. Symptoms must be present in early developmental period (but may not become fully manifest until social demands exceed limited capacities)

D. Symptoms clinically impair current functioning

E. Disturbances not better explained by ID, DD



DSM-5: ASD is single spectrum but with significant individual variability

- Severity of ASD Symptoms
- Pattern of Onset and Clinical Course
- Etiologic factors
- Associated conditions
- Individual weaknesses and strengths

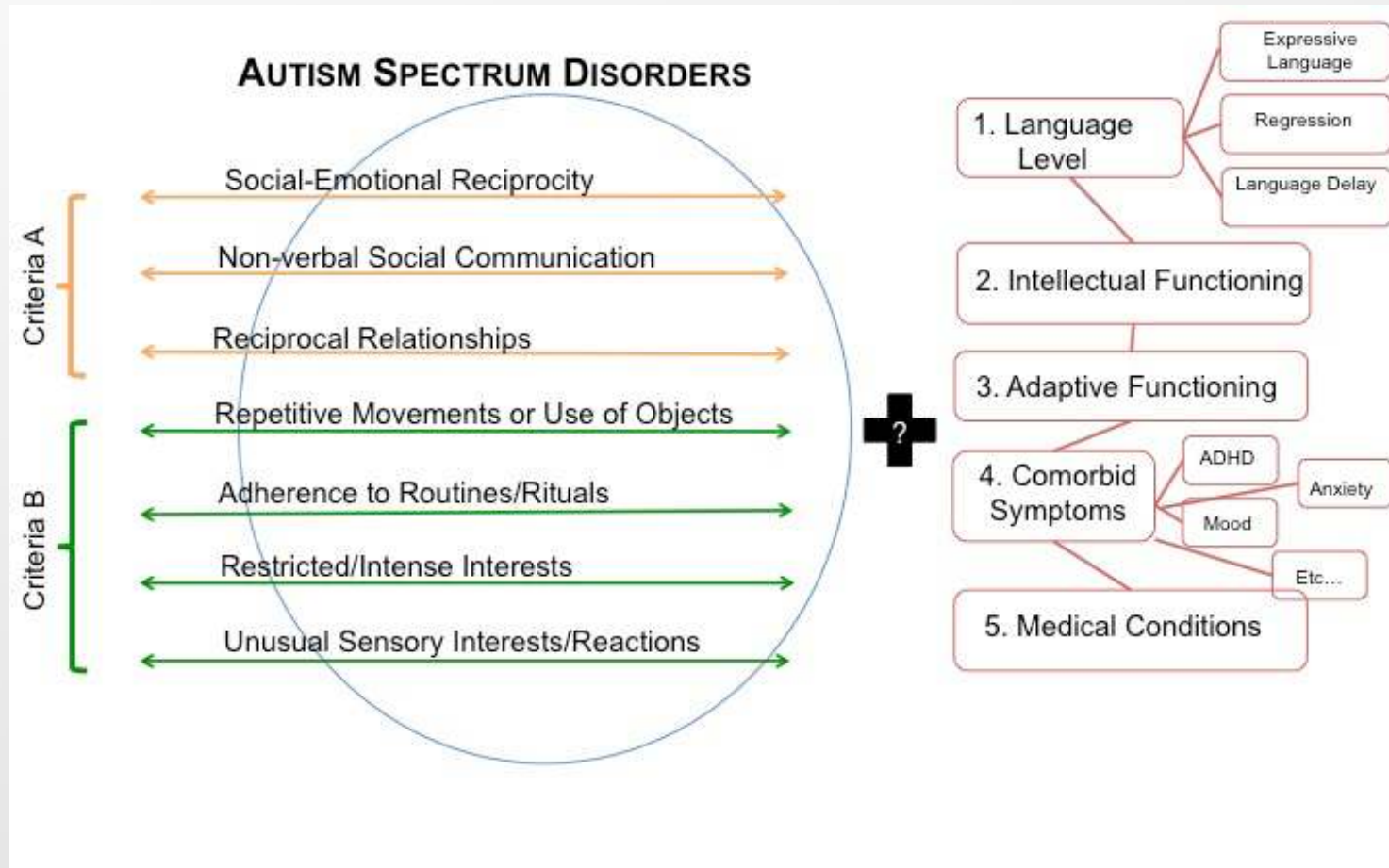
CLINICIANS ARE ENCOURAGED TO DESCRIBE THESE DETAILS WITH DIAGNOSTIC SPECIFIERS



What it really looks like

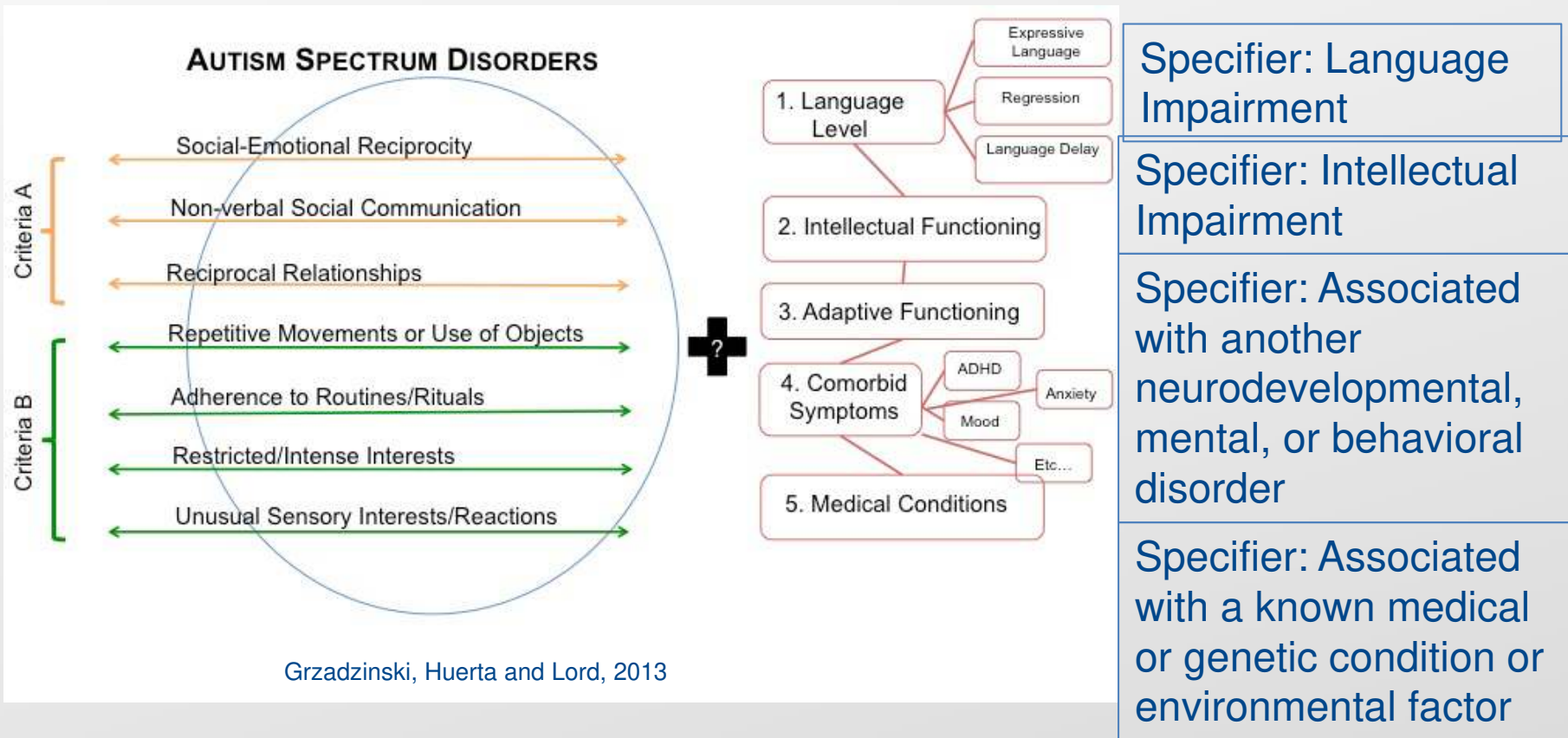


DSM-5's dimensional approach to diagnosing ASD



Grzadzinski, Huerta and Lord, 2013

DSM-5's dimensional approach to diagnosing ASD



Diagnosis of ASD in young children

- Autism still most often first diagnosed in children over age 3
- Recent research indicates diagnoses can be made with good validity/stability in 3rd year of life, with mixed findings in 2nd year of life
- Most frequent referral for autism stems from language delay

Why is diagnosing autism more complicated than diagnosing other neurodevelopmental or psychiatric conditions?

- Based solely on behavior (not physical appearance, underlying genetics, other biomarkers)
- Do not have an informant for self-report (vs. self report being key for most other psychiatric disorders)
- Need to rely on other informants, historical information and good observation

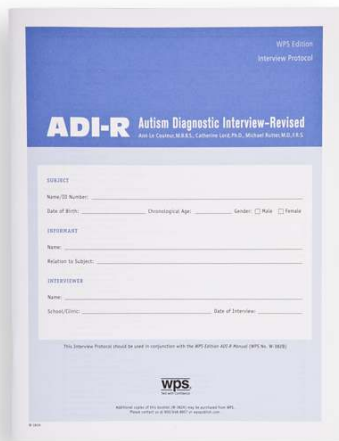


Diagnostic Evaluations for ASD

- Comprehensive Diagnostic Evaluation includes:
 - Cognitive Assessment
 - Adaptive Behavior Measure
 - Parent History
 - Direct Observation
- Parent interview needed for history of early development, report on peer interactions, and report on repetitive behaviors
- Autism Diagnostic Interview (ADI-R)
 - Semi-structured interview to obtain developmental history
 - Reports on pervasiveness of behaviors (in different settings)
 - Coded by trained raters
- Autism Diagnostic Observation Schedule (ADOS)
 - Provides “natural” social environment with examiner
 - Uses hierarchy of “presses” to rate responses
 - Tasks differ according to language level of child



Does Lack of Sensitivity of our measures end with screeners? No! It extends to diagnostic measures



These measures were not developed for:

- 1) non-walkers
- 2) Children with mental ages below 18 months
- 3) Children with very significant other behavioral problems



SRS Items

1. Seems much more fidgety in social situations than when alone.
2. Expressions on his or her face don't match what he or she is saying.
3. Seems self-confident when interacting with others.
4. When under stress, he or she shows rigid or inflexible patterns of behavior that seem odd.
5. Doesn't recognize when others are trying to take advantage of him or her.
6. Would rather be alone than with others.
7. Is aware of what others are thinking or feeling.
8. Behaves in ways that seem strange or bizarre.
9. Clings to adults, seems too dependent on them.
10. Takes things too literally and doesn't get the real meaning of a conversation.
11. Has good self-confidence.
12. Is able to communicate his or her feelings to others.
13. Is awkward in turn-taking interactions with peers (e.g., doesn't seem to understand the give-and-take of conversations).
14. Is not well coordinated.
15. Is able to understand the meaning of other people's tone of voice and facial expressions.
16. Avoids eye contact or has unusual eye contact.
17. Recognizes when something is unfair.
18. Has difficulty making friends, even when trying his or her best.
19. Gets frustrated trying to get ideas across in conversations.
20. Shows unusual sensory interests (e.g., mouthing or spinning objects) or strange ways of playing with toys. .

Intellectual Disability (Intellectual Developmental Disorder) in DSM-5

- **A. Deficits in intellectual functions, such as reasoning, problem solving, planning, abstract thinking, judgment, and academic learning and learning from experience, confirmed by both clinical assessment and individualized, standardized intelligence testing.**
- **B. Deficits in adaptive functioning that result in failure to meet developmental and sociocultural standards for personal independence and social responsibility. Without ongoing support, the adaptive deficits limit functioning in one or more activities of daily life, such as communication, social participation, and independent living, and across multiple environments, such as home, school, work, and recreation.**
- **C. Onset of intellectual and adaptive deficits during the developmental period.**
 - **Additional diagnosis of global developmental delay for individuals under age 5 and unspecified intellectual disability for uncertainty over age 5**



Intellectual Disability – what it really means

MILD ID: IQ 50 to 70; Slower than typical in all developmental areas; No unusual physical characteristics; Able to learn practical life skills; Attains reading and math skills up to grade levels 3 to 6; Able to blend in socially; Functions in daily life

MODERATE ID IQ 35 to 49; Noticeable developmental delays (i.e. speech, motor skills); May have physical signs of impairment; Can communicate in basic, simple ways; Able to learn basic health and safety skills; Can complete self-care activities; Can travel alone to nearby, familiar places

SEVERE ID IQ 20 to 34; Considerable delays in development; Understands speech, but little ability to communicate; Able to learn daily routines; May learn very simple self-care; Needs direct supervision in social situations

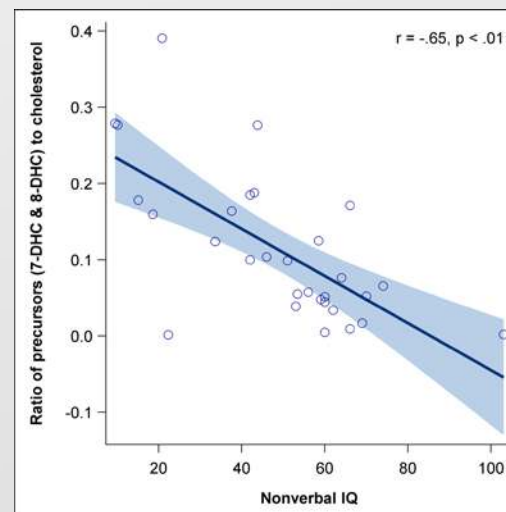
PROFOUND ID IQ less than 20; Significant developmental delays in all areas; Obvious physical and congenital abnormalities; Requires close supervision; Requires attendant to help in self-care activities; May respond to physical and social activities; Not capable of independent living

Example of Biomarker-Behavioral Correlations: Cholesterol precursors in Smith-Lemli-Opitz Syndrome

Thurm et al., 2016

NIH + KKI Sample	
n	33
Male, n (%)	19 (58 %)
Age, years (M ± SD)	8.98 ± 4.78
Nonverbal IQ (M ± SD)	46.68 ± 21.96
ASD diagnosis	18 (55 %)

Higher concentrations of cholesterol precursors 7-DHC and 8-DHC moderately-to-strongly associated with both IQ and Vineland scores



The Importance of Early Diagnosis

- Early Intervention
 - Early Intervention
 - Early Intervention
-
- BUT IT IS TRICKY!!!!

Treatments for Young Children: the whole package

Behavior
therapies



Educational
services

medications



Other
therapies

behavioral testing, neurodevelopmental assessment, neuropsychological testing: what does this give me?



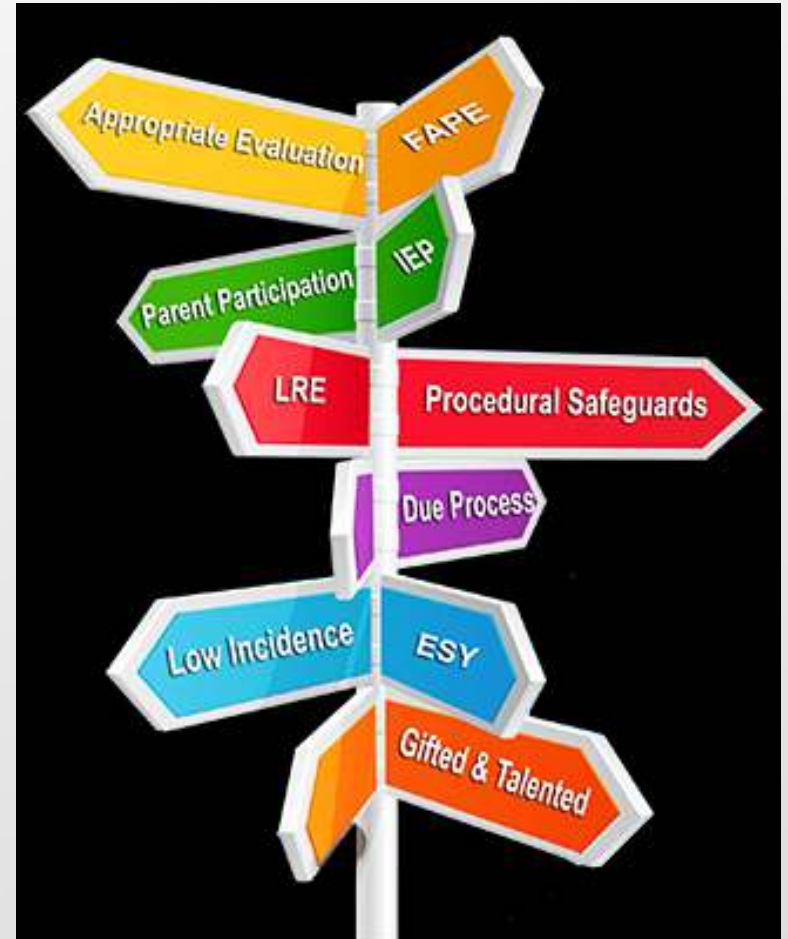
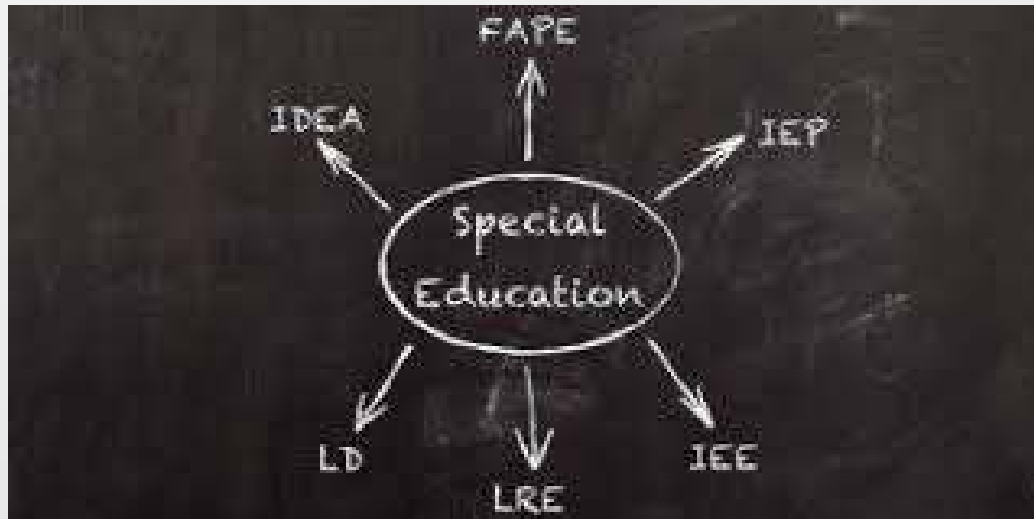
Reports typically include:

- 1) Background
- 2) Behavioral observations
- 3) Test results – IQ scores and other scores
- 4) Summary – should contain diagnoses
- 5) Recommendations – which can translate into IEP goals



Typical Cognitive-behavioral battery

- Assessment of cognitive functioning (IQ test or developmental test for younger children if appropriate) – includes nonverbal and verbal
- Assessment of adaptive behavior (what the child is actually DOING in natural environment)
- Assessment of behavioral problems
- Assessment of specific disorders at heightened risk given knowledge of disorder (e.g. autism, ADHD etc..)



Individuals with Disabilities Education Act (IDEA)

- The Individuals with Disabilities Education Act (IDEA) ensures that all children with disabilities are entitled to a *free appropriate public education to meet their unique needs and prepare them for further education, employment and independent living.*
 - Prior to IDEA, over 4 million children with disabilities denied appropriate access to public education.



Part C of IDEA



- Part C of IDEA recognizes the need for identifying reaching very young children with disabilities.
- Every family is entitled to appropriate, timely, and multidisciplinary identification and intervention
- Families receive an Individualized Family Service Plan (IFSP)
- Families have a right to participate in the creation of the IFSP
- Parents are entitled to timely resolution of all conflicts or complaints regarding the evaluation or services provided to their child.

Individual Family Service Plan (IFSP)

- An Individual Family Service Plan (IFSP) is a plan for special services for young children with developmental delays.
- An IFSP applies to children from birth to three years of age.
- This program was created by US Public Law 99-457.1.
 - Large role for family involvement



Early Intervention

- Early Intervention is a federally mandated program of coordinated services, through IDEA Part C, that provides support and education to children with developmental delays and their families.
- Children ages 0-3 exhibiting delays in physical, cognitive, communication, and social/emotional development may be eligible for services.
- The goal of EI is to help children with developmental delays as soon as possible so they can reach their fullest potential.



What to Target in Early Intervention?

- In young children, targets are often:
 - Language (speech)
 - Imitation
 - Social engagement
 - Joint attention
 - Play skills (functional and pretend)



Models of Early Intervention

- **ABA (Applied Behavioral Analysis)**
- **PRT (Pivotal Response Training)**: a behavioral treatment intervention based on the principles of applied behavior analysis (ABA). Focus on 2 pivotal behaviors that affect a wide range of behaviors in children with autism: motivation and responsivity to multiple cues.
- **Early Start Denver Model (ESDM)** is a behavioral therapy for children with autism between the ages of 12-48 months. Based on applied behavior analysis (ABA) and uses play to build relationships and skills.
- **TEACCH** (Treatment and Education of Autistic and other related Communication handicapped Children): builds on autism-specific strengths and characteristics (e.g. visual spatial skills, need for predictable routines, environmental structure)
- **DIR/Floortime**: **D**evelopmental, **I**ndividual-Difference, **R**elationship-Based model, or "DIR®/Floortime". Floortime is based on the theory that autism symptoms are caused by problems with brain processing that affect a child's relationships and senses, among other things.
- **RDI: Relationship Development Intervention (RDI®)** is a parent-based clinical treatment that seeks to correct the core social problems of autism, such as friendship skills, empathy and the desire to share personal experiences with others

Myths about ABA

The screenshot shows a web browser window with the URL <https://www.kennedykrieger.org/stories/myths-facts-about-applied-behavior-analysis>. The website header includes navigation links: APPOINTMENTS & REFERRALS (888-554-2080), CAREERS, EVENTS, FACULTY AND STAFF, GIVE, LOCATIONS, MYCHART, and I WANT TO. The main navigation bar lists: Kennedy Krieger Institute, Patient Care, Research, Training, Education, Community, and a Search icon.

Myths & Facts About Applied Behavior Analysis

Home — Stories — Myths & Facts About Applied Behavior Analysis

Myth: ABA is a specialized therapy just for people with autism and is not useful for people with other diagnoses.

Fact: ABA therapies have been shown to improve behavior for students with ASD; however, they have also been used **to help decrease problem behavior for students with a variety of backgrounds** (Simonsen, Fairbanks, Briesch, Myers, & Sugai, 2008).

This includes classroom management (e.g. group contingencies) and direct intervention strategies for typically-developing students (Simonsen et al., 2008), students with intellectual disabilities (Horner et al., 2005), and students with emotional and/or behavioral disabilities (Wehby et al., 2003).

Many believe this particular inaccurate view of ABA was perpetuated by the findings of Ivar Lovaas, a pioneer who worked to help improve the lives of children with autism

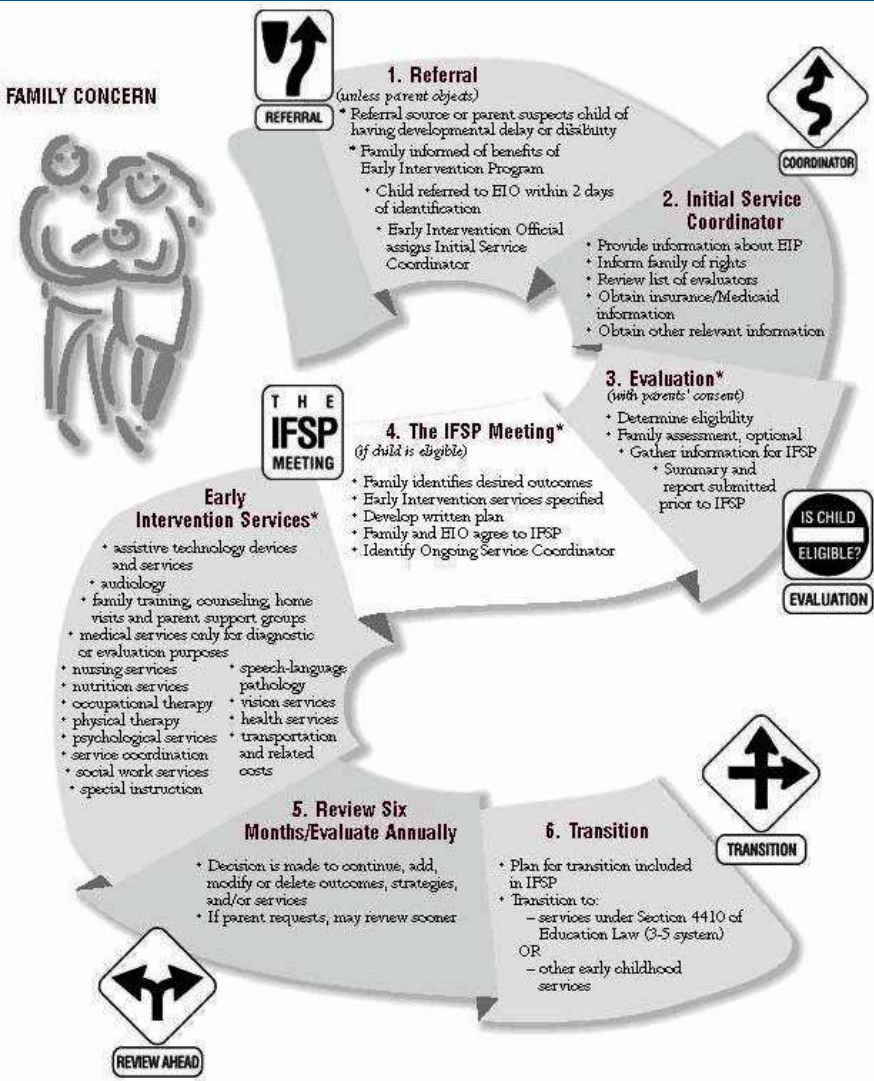
Report Recommendations: Preparing for School

- Increasing exposure to table top activities
 - Increasing tolerance over time, gradually extending “work” time
- Increasing tolerance for non-preferred activities
 - Interspersing non-preferred activities with desirable ones
 - Movement and music breaks



TODAY, _____
will... DATE: _____

INITIALS: _____



Transition from IFSP to IEP

- Moving from Part C → Part B of IDEA
- 6 months prior to third birthday transition planning begins
- Moving from a family focus to child focus

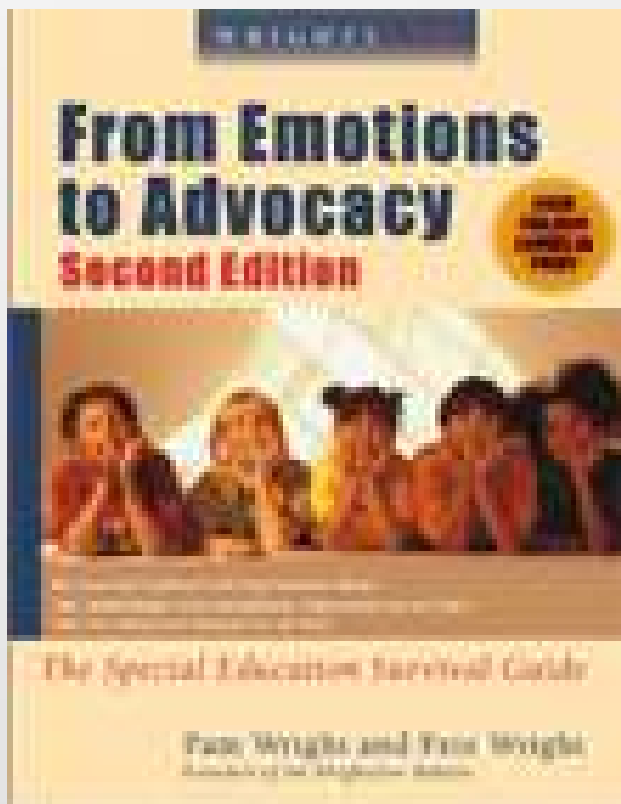


IFSP	IEP
Birth through age 3	Age 3-21
Is inclusive of the family's needs	Focuses on the child's needs
Services provided in natural environments	Services provided at school
Families are assigned a service coordinator	No service coordinator
Generally reviewed every 6 months	Generally reviewed 1x per year
IFSP Team makes decisions	IEP Team makes decisions
Governed under Part C of IDEA	Governed under Part B of IDEA

Purpose of an IEP

The IEP has two primary purposes:

- 1) to set reasonable learning goals for a child
- 2) to state the services that the school district will provide for the child.



Has chapters on

- Preparing for meetings
- Creating paper trails
- Due process

Things to Know about IEPs



- IEPs are a part of public education.
 - Private schools don't offer IEPs.
- Unlike an IFSP which is renewed every six months, in many states an IEP is renewed or updated each year.
 - Triennial review every 3 years
- An IEP can be renewed sooner at the request of the parent or an IEP team member. Parents can call an IEP at any time!

IEP Categories – look for this!

13 categories of special education as defined by the Individuals with Disabilities Education Act (IDEA).

In order to qualify for special education, the IEP team must determine that a child has one of the following:

- [Autism](#)
 - Blindness
 - Deafness
 - Emotional Disturbance
 - Hearing Impairment
 - Intellectual Disability
 - Multiple Disabilities
 - Orthopedic Impairment
 - Other Health Impaired
 - Specific Learning Disability
 - [Speech or](#) Language Impairment
 - Traumatic Brain Injury
 - Visual Impairment
- Note: these may differ from medical diagnoses!



FAPE

- Free Appropriate Public Education (FAPE) is an educational right of all children in the United States that is guaranteed by the Rehabilitation Act of 1973 and the Individuals with Disabilities Education Act (IDEA).
- Under Section 504, FAPE is defined as, "...the provision of regular or special education and related aids and services that are designed to meet individual needs of handicapped persons as adequately as the needs of nonhandicapped persons are met"
- FAPE is defined as an educational program that is individualized to a specific child, that meets that child's unique needs, provides access to the general curriculum, meets the grade-level standards established by the state, and from which the child receives educational benefit.
- To provide FAPE to a child with a disability, schools must provide students with an education, including specialized instruction and related services, that prepares the child for further education, employment, and independent living.

Least Restrictive Environment (LRE)

- The least restrictive environment clause states that students with disabilities should be educated with students without disabilities to the maximum ***appropriate*** extent.
 - Designed to provide access to typical peers
 - Emphasis on “appropriate.”

Defining LRE – Input from the Court



- *Daniel R.R. v. State Board of Education (1989)*: Not an all-or-nothing educational system
- *Sacramento City Unified School District v. Rachel H., 14 F.3d 1398 (1994)*, four factors to consider when determining if a student's LRE is appropriate.
 1. the educational benefits of integrated settings versus segregated settings,
 2. Non-academic benefits (primarily social interaction with non-disabled peers)
 3. Effect the student with a disability can have on the teacher and their peers
 4. Cost of supplementary services that will be required for that student to stay in the integrated setting

Educational Settings

- **General education classroom with support.** The child spends the entire day in a general education class. Receives supports and services like a tutor or aide, assistive technology, accommodations etc.
- **Partial mainstream/inclusion classroom.** The child spends part of the day in a general education class. Receives some individual or small-group instruction in a special education class, or is pulled out of class for resource supports.
- **Special education class.** This is a program with specialized instruction for children with similar learning needs.
- **Specialized program outside of your school district.** This can include private schools or residential programs.

Educational Settings

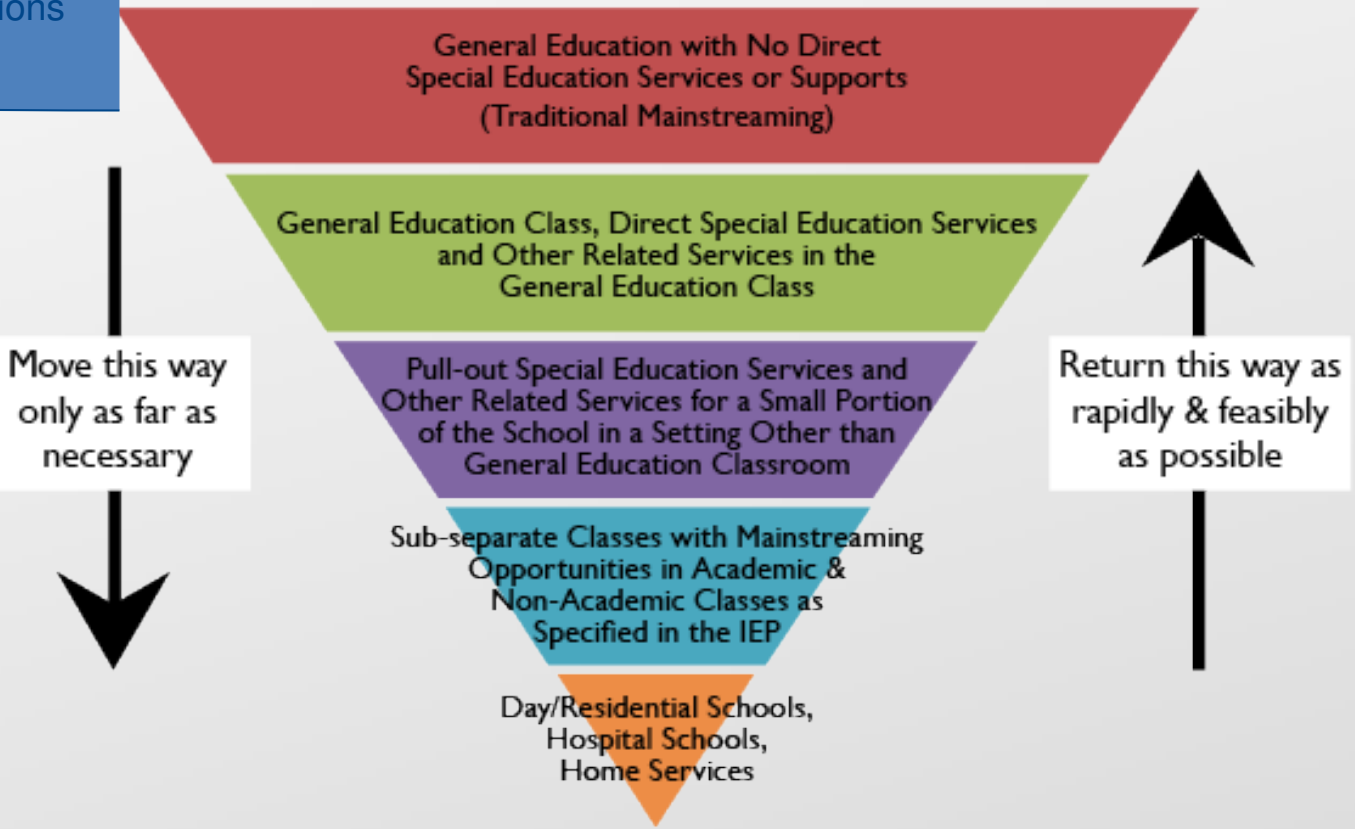
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- **Special education class.** This is a program for children with similar learning needs.
- **Specialized program outside of your school.** These programs include private schools or residential programs.

In reverse mainstreaming, regular education students are brought into special education classrooms.

THE CONTINUUM OF SERVICES

504=
accommodations

IEP=
special
education



Writing IEP Goals

IEP goals should:

- consider the student's **present levels of performance**
- **be realistic** for the student to achieve
- explain **how** the student will accomplish the goal
- include a brief description of **how progress will be measured**
- document **what constitutes successful completion** of each goal.



SMART IEP Goals

S	specific	The goal should be specific in naming the skill or subject area and the targeted result.
M	measurable	You should be able to measure the goal using standardized tests, curriculum-based measurements or screening, work samples, or even teacher-charted data.
A	attainable	The goal needs to contain skills that are attainable for the student
R	results-oriented	The goal should clearly spell out the expected result.
T	time-bound	The goal should state specifically by what date the student is expected to accomplish it.

IEP Recommendations in Reports



Due Process

- Due process is a formal way to resolve disputes with a school about a child's education.
- Parents can file a due process complaint only for special education disputes, not for general education issues.



2) Due Process Hearing



General Education Interventions

- Talk with your child's teacher about support and [accomodations](#) that can be provided in the classroom
- Meet with [General Education Intervention Team](#) (SIT, SAT, CARE) to develop an intervention plan.

Section 504 Plans

- If your child needs additional accomodations and modifications and he/she has a documented disability, then he/she may need a [504 plan](#).
- Talk with your school about evaluating him/her for 504 services and develop a 504 plan.

IEP

- If your child 's needs cannot be met through genral education or 504 services , then a [special education evaluation](#) should be conducted.
- If the results of the evaluation indicate that your child is eligible for special education services, then an [IEP](#) will be developed.

IEP versus 504 Plan

IEP	504 Plan
The Individualized Educational Plan (IEP)	Named for Section 504 of the Rehabilitation Act
Plan or program developed to ensure that a child who has a disability identified under the law and is attending an elementary or secondary educational institution receives specialized instruction and related services .	Plan developed to ensure that a child who has a disability identified under the law and is attending an elementary or secondary educational institution receives accommodations that will ensure their academic success and access to the learning environment.
For students with disabilities <u>who do require</u> specialized instruction	For students with disabilities who <u>do not require</u> specialized instruction
IDEA controls the procedural requirements and an IEP is developed	504 plan assures students will receive equal access to public education and services by outlining their specific accessibility requirements.
Updated annually	Updated annually

Children with disabilities *and* behavior problems: Response in the IEP



- If the behavior of a child impedes the child's learning or the learning of other children, the IEP Team must consider the use of positive behavioral supports, supports, and other strategies to address that behavior. (20 U.S.C. § 1414(d)(3)(B)(i), 34 C.F.R. § 300.324(a)(2)(i))
- If the child's behavior that impedes learning is not addressed in the IEP, the IEP Team must **review and revise the IEP** to ensure that the child receives appropriate positive behavioral interventions and supports and other strategies. (34 C.F.R. § 300.324(a)(2)(i) and 34 C.F.R. § 300.324(a)(3)(i)).
- School districts must ensure that scientifically based research drives their professional development activities and services. (34 C.F.R. § 300.226(b)(1))

Additional Terms and Concepts

- Functional Behavioral Assessment
- Positive Behavioral Supports
- Extended School Year (ESY)
- Diploma-bound versus certificate
- Transition services

High School Diploma	High School Certificate	
What it means	A student has met all the requirements for graduation.	A student has completed high school, but didn't meet all the requirements for graduation.
What are the graduation requirements	To earn a diploma, a student typically must pass grade-level English, math, social studies, science and other classes. The number and type of class credits required vary by state. Some states also require a student to pass a high school exit exam to get a diploma.	It depends on the state and school. Unlike a diploma, the requirements are often flexible and can be tied to a student's IEP goals .
Accommodations allowed	Yes	Yes
Curriculum modification allowed	Maybe. By changing what she learns, modifications can hurt a student's ability to earn a high school diploma.	Yes
Accepted by the military	Yes	No
Accepted by colleges	Yes	Maybe. It depends on the college.



Questions ?

