

What Makes Developmental Medicine Developmental *MEDICINE*?

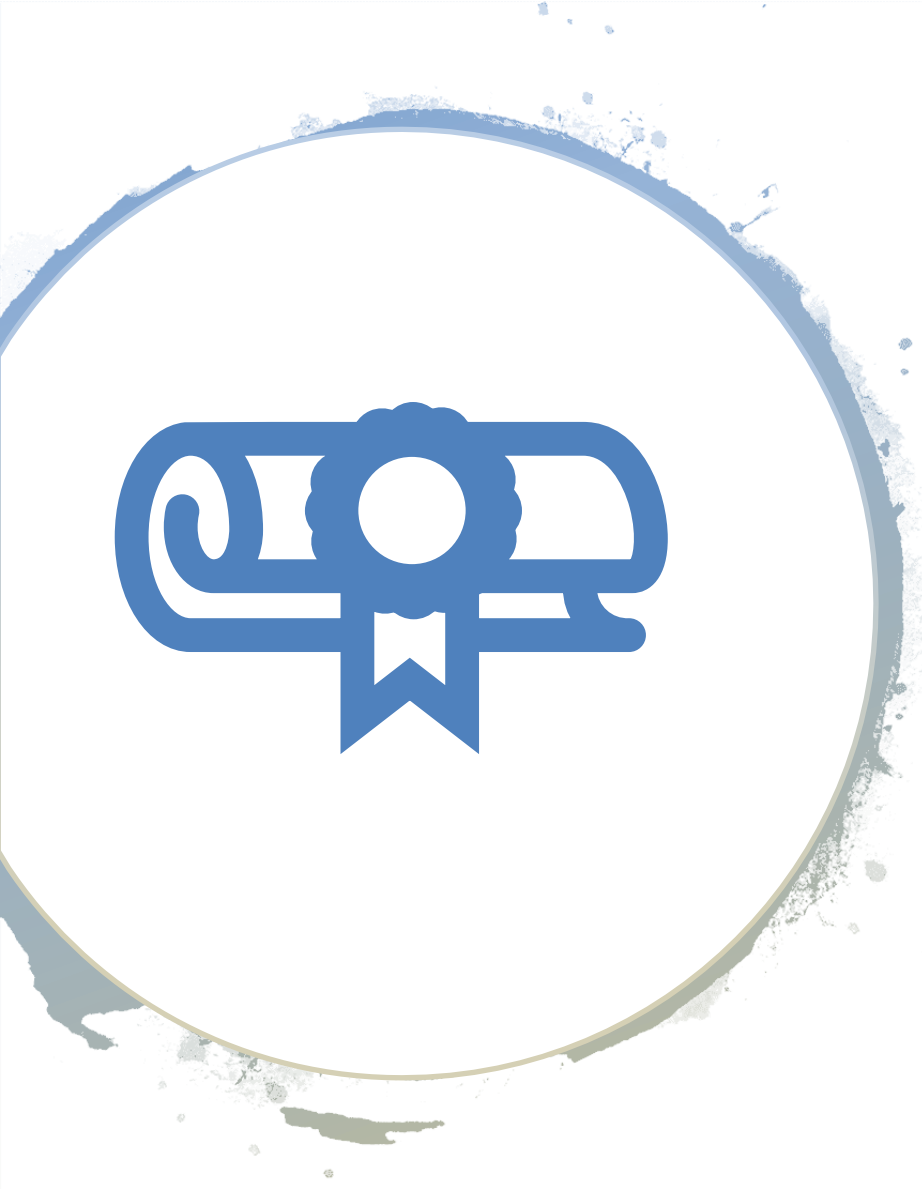
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Faculty Disclosure Information

- I have the following financial relationships with the manufacturer of any commercial product and/or provider of commercial services:
 - Developmental-Behavioral Pediatrics Editor for “Up to Date”
- I do not intend to discuss an unapproved/investigative use of a commercial product/device in my presentation

Objectives

- Describe how child development is the basic science of pediatric medicine
- Compare developmental screening to medical developmental evaluation
- Define the processes that underlie problems in development: delay, dissociation, and deviation.
- Describe the spectrum and continuum of developmental-behavioral diagnoses

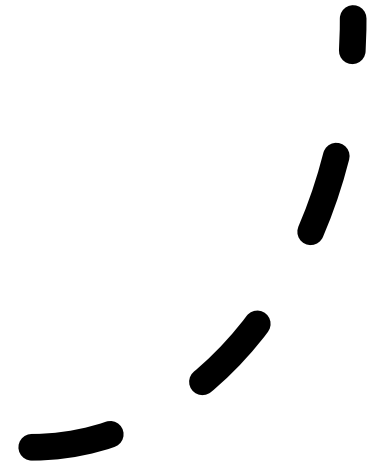
Child Development: The Basic Science of Pediatrics*

- The longitudinal process of child development distinguishes pediatric medicine from all other medical specialties
- Child development and behavior have an impact on every pediatric healthcare encounter

Julius Richmond, MD (1916–2008)
1st National Director of Head Start &
the 12th Surgeon General of the
United States (1977-1981).

The Basic Science of Pediatrics

- **Developmental-behavioral problems are by far the most prevalent chronic medical conditions in children**



Prevalence of Developmental-Behavioral Disorders and Other Chronic Medical Conditions in Children ≤18 yrs*

Condition

Global LD (IQ 70-89)

Asthma

Specific LD

AD/HD

Other developmental delay/Intellectual Disabilities

Autism Spectrum Disorder

Epilepsy

Congenital Heart Disease

Cerebral Palsy

Inflammatory Bowel Disease

Juvenile rheumatic diseases

Diabetes

Cancer

Cystic Fibrosis

Chronic renal disease

Prevalence (%)

23%

8.4%

7.7%

6.7%

4.4%

2.3%

1%

1%

0.4%

0.4%

0.4%

0.2%

0.02%

0.04%

0.008%

**Need
75,375
DBPs**

**3015
Pediatric
Cardiologists**

The Basic Science of Pediatrics

- Contemporary focus on screening – AAP recommends referring those who fail screening for further evaluation with a subspecialist to make a diagnosis*
- Who ya gonna call?

NATIONAL STATS

Population of US $\leq$ 19 yrs of age

77 million

Children in US $\leq$ 19 yrs of age with development/learning disorders

19 million

of board-certified DBPs

709*

new DBP fellows Matched in December 2021/2022

**2021: 26 (54% of open positions)
2022: 31 (61% of open positions)**

of DBPs 61+ years of age

216 (30%)*

*ABP Workforce Data. <https://www.abp.org/dashboards/pediatric-subspecialists-ever-certified>. Accessed June 1, 2023

Louisiana Stats

% of Population < 18 years	1,074,116
# of Children in Louisiana with disorders of development or learning	268,529
# Children in Louisiana with autism	24,705
# of Boh Center new patient visits 2022	1794

The Basic Science of Pediatrics

- Given high prevalence and lack of access to subspecialty consultation:
 - ⦿ Vast majority of children with developmental-behavioral disorders **need clinical developmental evaluations within their primary care medical homes**

AAP Definition of Developmental Screening*

- Administration of a brief standardized tool that aids the identification of children at risk of a developmental disorder at specified ages
 - Completed by parents in waiting room
 - Scored by non-physician office staff
 - Refer those who fail screen to subspecialist (who?)
 - ??But child development is the **BASIC SCIENCE of Pediatrics** – why remove the pediatrician from the equation??
-

Myth #1: Primary Pediatric Health Care Professionals Are Missing Most Children with Developmental Concerns

- Palfrey JS, et al (1987)*
 - Only 28.7% of children who required special educational services were identified before they reached school at 5 years of age.
 - Primary pediatric health care providers are to blame for not identifying children with developmental-behavioral disorders.**
 - Led to mandated use of parent-completed developmental screening questionnaires
 - Erosion of confidence in primary pediatric health care professionals' clinical skills.**

*Palfrey JS, et al. *J Pediatr*.1987;111(5):651–659

**Voigt RG and Accardo PJ. Mission Impossible? Blaming Primary Care Providers for Not Identifying the Unidentifiable. *Pediatrics* 2016;138(2):e20160432.

REALITY #1

**Only Lower Prevalence, Higher
Severity Developmental Disorders
Can Be Reliably
Identified Prior to School Age**

Developmental-Behavioral Disorder	Age/Grade of Reliable Identification	Prevalence	Reliably Identifiable Before School Age?
Severe ID (IQ < 50) CP	1 year	0.4% 0.4%	Yes
Mild ID (IQ < 70) ASD	3 years	1.6-2.6% 2.3%	Yes
Slower Learning/Global Learning Disabilities (IQ 70-89)	Kindergarten to 1 st grade	23%	No
Specific Learning Disabilities/ADHD	1 st to 4 th grades	5-10%	No

AAP Developmental Screening Recommendations*

- Standardized screening at well child visits at:
 - 9-months
 - 18-months
 - 30-months
 - 4-5 years
- Autism specific screening at 18 & 24 months

**Lipkin, Macias, COCWD, SODBP. Pediatrics. 2020;145(1):e20193449.

“Evidence” for Developmental Screens?

Screens Have Holes:

- AAP recommends autism-specific screening at 18 months
 - Study of M-CHAT screening of 3793 children at 16-30 months - PPV only 0.11*
 - Study of M-CHAT screening of general population sample of 18 month olds - PPV only 0.015**

*Kleinman JM. Robins DL. Ventola PE, et al. *J Autism & Devo Dis* 2008; 38(5):827-839

** Sternberg N, Bresnahan M, Gunnes N, et al. *Paediatr Perinat Epidemiol* 2014; 28: 255-262

“Evidence” for Developmental Screening? (Don’t ask the USPSTF*)



- “The USPSTF concludes that the current evidence is insufficient to assess the balance of benefits and harms of screening for speech and language delay and disorders in children aged 5 years or younger.”

*Wallace IF, et al. *Pediatrics* 2015; 136: e448-462.

“Evidence” for Autism Screening? (Don’t ask the USPSTF*)



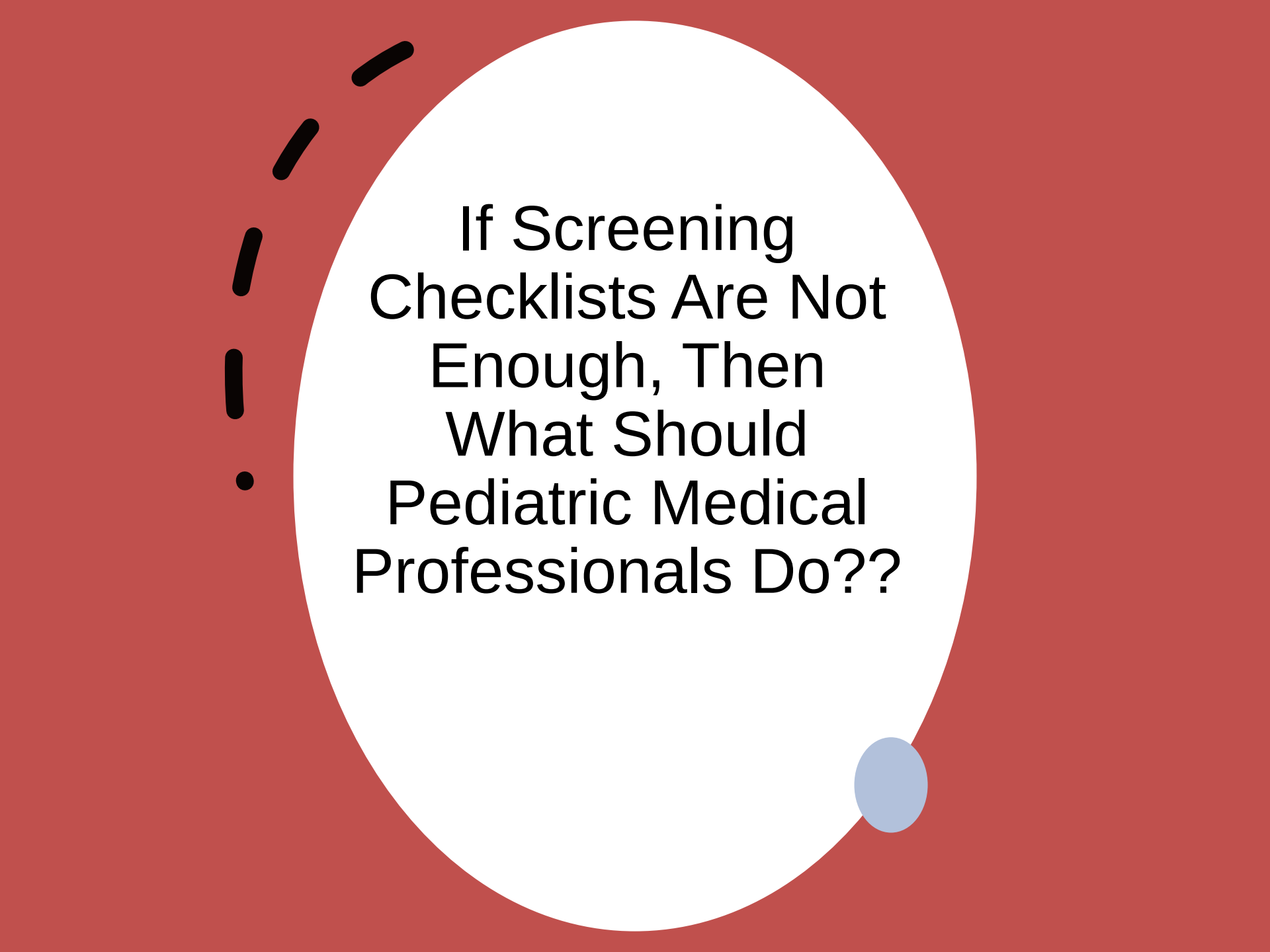
- “The USPSTF concludes that the current evidence is insufficient to assess the balance of benefits and harms of screening for autism spectrum disorder (ASD) in young children...

*Siu AL. *JAMA* 2016; 315: 691-696.

Expert Opinion about Developmental Screening Tests (Pasquale Accardo, MD)

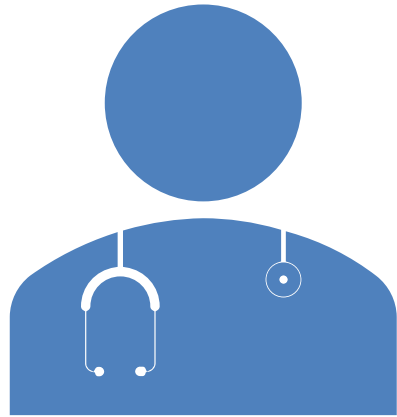
- “Are better than nothing”
- “However, that is probably the only thing they are better than”
- “They have all the limitations inherent in instruments that rely on untrained, biased observers to make difficult judgments on complex behaviors”

Adapted from Accardo PJ. The misdiagnosis of the hyperactive child. In *Attention Deficit Disorders and Hyperactivity in Children*, Accardo PJ, Blondis TA, and Whitman BY, eds., Marcel Dekker, New York, 1991



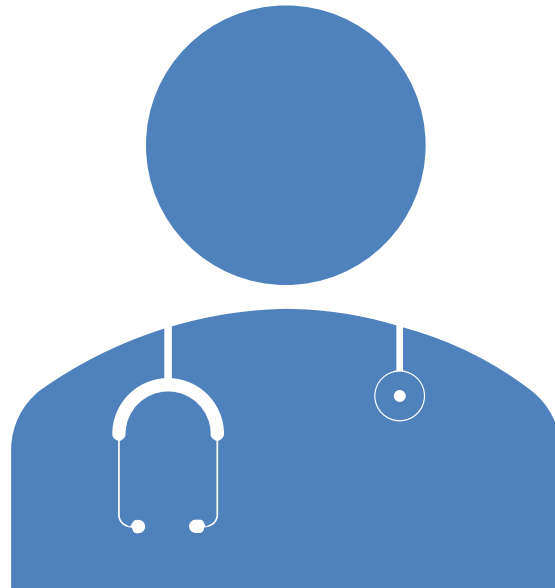
If Screening
Checklists Are Not
Enough, Then
What Should
Pediatric Medical
Professionals Do??

Alternative to Screening: Take Advantage of Our Pediatric Medical Training!!!!



- Diagnoses for all chief complaints in pediatric medicine are made via a detailed history that is confirmed by a detailed examination
- Development should be evaluated, not simply screened!!!

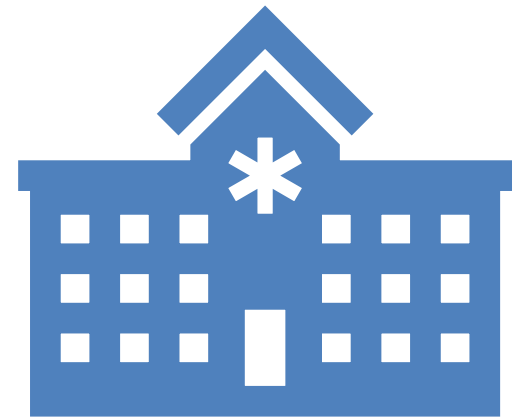
“Evidence” for Clinical Judgment



- Professional organizations indicate that the **GOLD STANDARD** for making developmental-behavioral diagnoses is the **CLINICAL JUDGMENT** of experienced clinicians

Do NOT Undervalue Rigorous Clinical Training, Accumulated Clinical Experience, & Clinical Judgment

- Given the prevalence of developmental-behavioral concerns in every day primary care and subspecialty pediatric practice, **all pediatric health care professionals should be considered experienced clinicians!!!!**



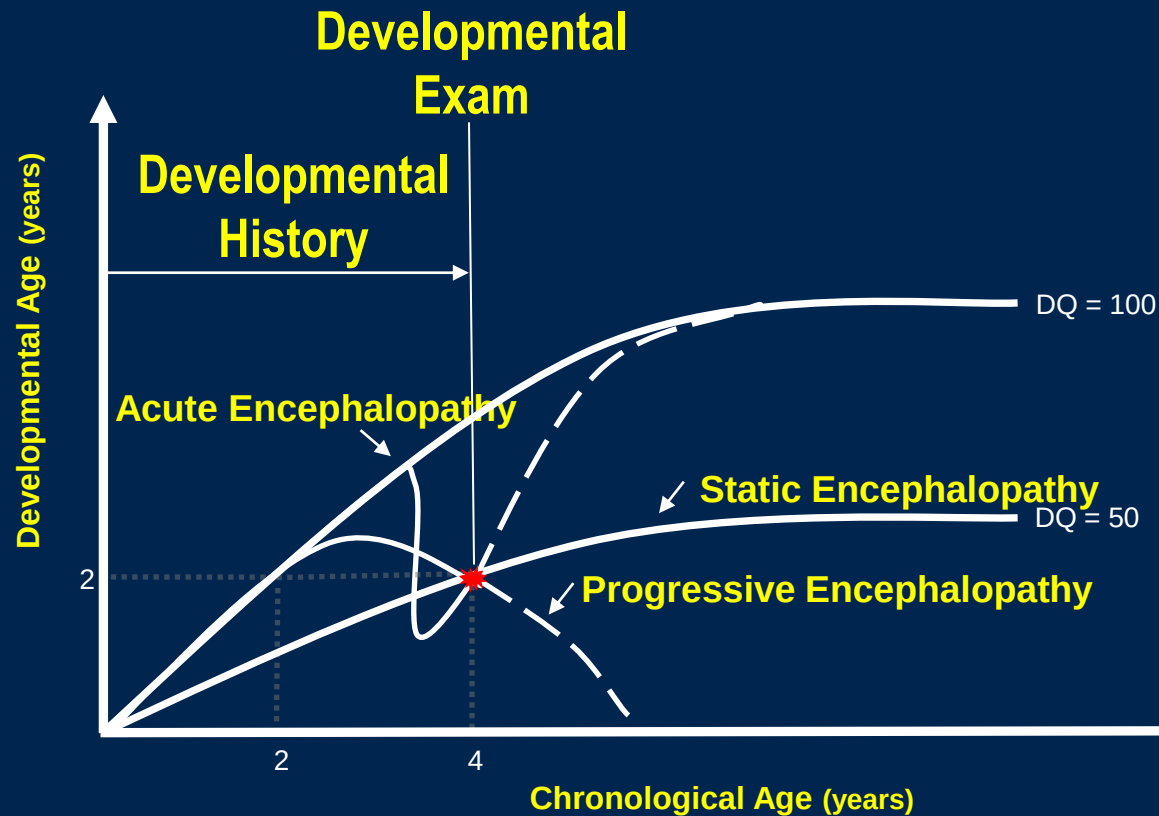
What Do Developmental Pediatricians Do?

- Elicit comprehensive medical, family, psychosocial, and developmental/behavioral/educational histories
- Complete neurodevelopmental examinations (including physical exam, neurologic exam, & standardized developmental testing) to:
 - ◉ Make descriptive developmental diagnoses
 - ◉ Attempt to determine underlying medical etiologies
 - ◉ Review findings with families and develop a plan for and assist patients/families in accessing community-based early intervention, therapeutic, and special educational services
- Developmental Pediatricians are the “Generalists” of the interdisciplinary team
 - ◉ Need to make referrals to Psychology, PT, OT, Speech/Language, Social Work as needed
- As physicians, we are trained to evaluate a higher volume of patients
- Refer back to PCP with detailed plan of action

Developmental History

- Elicitation of temporal sequence of developmental milestone acquisition within each developmental stream
 - **Establish pattern of developmental delay**
 - ⊙ Static, Acute, Progressive
 - **Identify markers of atypical development**
 - ⊙ Delay, Dissociation, Deviation

Patterns of Developmental Delay



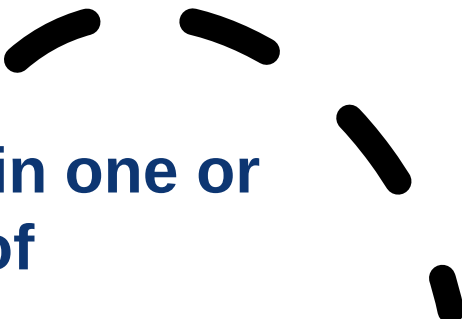
Developmental History

Frank R. Brown III, PhD, MD

- “There is no such thing as a poor historian; there are only poor history takers”
- “Parents are best historians when developmental history focuses on milestones that are memorable and milestones that are temporally current”



Developmental Delay

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- **Significant lag in one or more streams of development**
 - **Most common presentation: global delay affecting all streams of development**

Case 1: Developmental Delay

2 year old boy fails a developmental screen
("not talking")

- Developmental History:
 - **Gross Motor:** Sat at 1 year; just starting to take independent steps
 - **Visual Perceptual/Fine Motor/Adaptive:** Began reaching for objects at 1 year; just began to uncover hidden toys and to release objects intentionally
 - **Speech/Language:** Began babbling at 1 year; just started using a specific "Mama" and "Dada" and pointing to indicate need

Developmental Dissociation

- Difference between developmental rates of two streams of development, with one stream significantly more delayed
- Dissociation is atypical compared to more global developmental delay



Case 2: Developmental Dissociation

2 year old boy fails a developmental screen ("not talking")

- **Gross Motor:** Walked at 1 year; ran at 18 months; just started to jump
- **Visual Perceptual/Fine Motor/Adaptive:** Intentionally released objects before 1 year; scribbled soon after 1 year and can now imitate horizontal and vertical strokes
- **Speech/Language:** Began babbling at 1 year; just started using a specific "Mama" and "Dada" & does not say any other words; just started following gestured commands

Developmental Deviation

- Deviation from the sequence of typical milestone acquisition within a stream of development
- Acquiring higher level developmental milestones before accomplishing lower level developmental milestones
- Deviation is more atypical than dissociation or delay



Case 3: Developmental Deviation

2 year old boy fails a developmental screen
("not talking")

- **Gross Motor:** Walked at 1 year; ran at 18 months; just started to jump
- **Visual Perceptual/Fine Motor/Adaptive:** Scribbled soon after 1 year. Stacks & lines up blocks. Imitates strokes, not in appropriate orientation. Completes shape sorters. Recognized all letters of the alphabet at 18 months.
- **Speech/Language:** Began babbling at 1 year; currently has 5 word vocabulary (names of colors) but does not use a specific "Mama" and "Dada"; repeats multiword phrases from videos; does not use gestured language; just started following gestured but not ungestured commands

Medical Developmental Examination

- Physical Exam
 - Focus on neurological exam, dysmorphic features
- Direct developmental testing across streams of development
 - Used to confirm developmental history
- Developmental History + Developmental Exam = Developmental Diagnosis (descriptive diagnosis)
- Medical Laboratory Workup (etiological diagnosis)



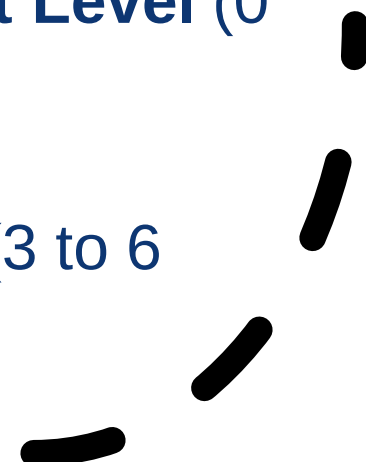
2 year old boy fails a developmental screen
("not talking")

- **Developmental History:** Static pattern of globally delayed acquisition of developmental milestones at 50% the expected rate
- **Neurodevelopmental Exam:**
 - ⊙ **Gross Motor:** Walks independently, but frequently falls. Still crawls.
 - ⊙ **Visual Perceptual/Fine Motor/Adaptive:** Releases cube into cup. Makes crayon mark. Doesn't scribble.
 - ⊙ **Speech/Language:** Follows gestured but not ungestured command.

**Neurodevelopmental
Exam
to Confirm
Developmental
History
for Case 1**

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Examples of Standardized Developmental Evaluation Measures for Pediatric Health Care Providers

- **CPT 96112: Developmental Testing (first hour)**
 - **CPT 96113: Each additional hour (for administration, scoring, interpretation, report writing)**
 - **Capute Scales:** Cognitive Adaptive Test/Clinical Linguistic and Auditory Milestone Scale (**CAT/CLAMS**) (1 to 36 months)
 - **PEDS-DM Assessment Level** (0 to 7 years, 11 months)
 - **Gesell Developmental Observation-Revised** (3 to 6 years)
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- Four thick, black, curved lines of varying lengths and orientations arranged in a cluster in the bottom right corner of the slide.

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Why Consider Laboratory Testing to Establish an Etiological Diagnosis?

- Peace of mind for families in knowing cause of developmental difficulties
- Prevent other associated medical problems
- Provide specific genetic counseling for families
- Eliminate need for further unnecessary (standard and nonstandard) testing and treatments

Medical Model of Developmental Diagnosis

- Chief complaint
 - Failed developmental screen
- Developmental history
 - Identify pattern of developmental delay (static, acute, progressive)
 - Identify delay, dissociation, deviation
- Neurodevelopmental exam
 - Confirm developmental history
- Make developmental diagnosis
- Medical workup to determine etiological diagnosis

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Developmental Diagnosis

- **2 components:**
 1. Descriptive developmental diagnosis
 2. Etiological diagnosis

Etiologic & Descriptive Diagnoses for Developmental Disorders

Etiologic Diagnosis

NEUROBIOLOGIC FACTORS

Genetics/Epigenetics
Prematurity
Structural Brain Anomalies
Metabolic
Toxic
Hypoxic-Ischemic
Infectious/Inflammatory
Traumatic Brain Injury

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ENVIRONMENTAL EXPERIENCES

Developmental Stimulation
Quality Preschools/Schools
Social/Structural Determinants of Health
Family Economic Hardship
“ACE’s/Toxic Stress”
Abuse/Neglect
Caregiver Mental Illness
Exposure to Violence

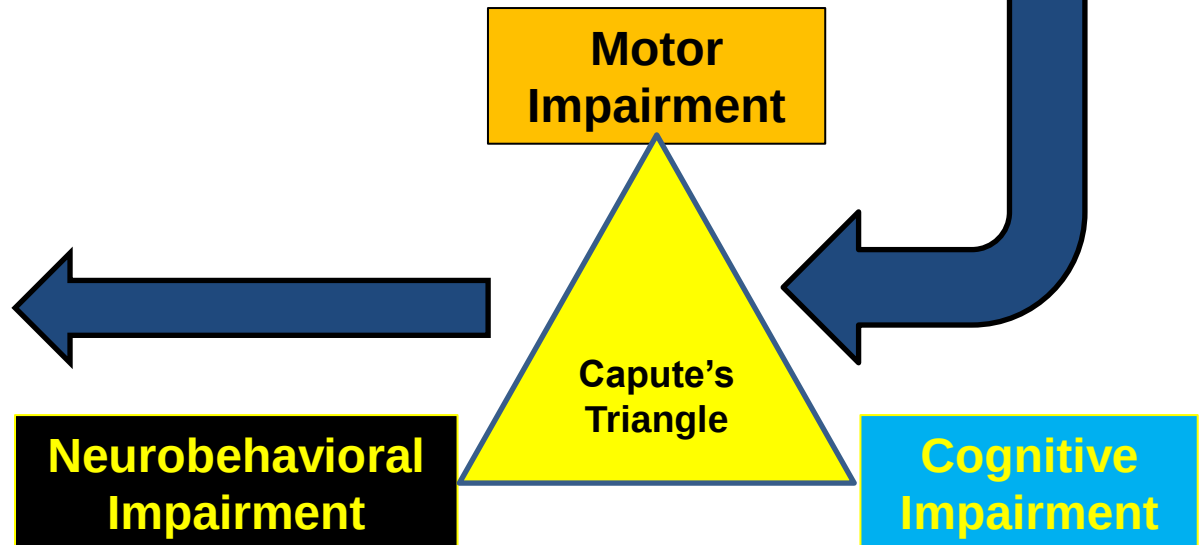
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**Developmental
Brain
Dysfunction**

Descriptive Diagnosis

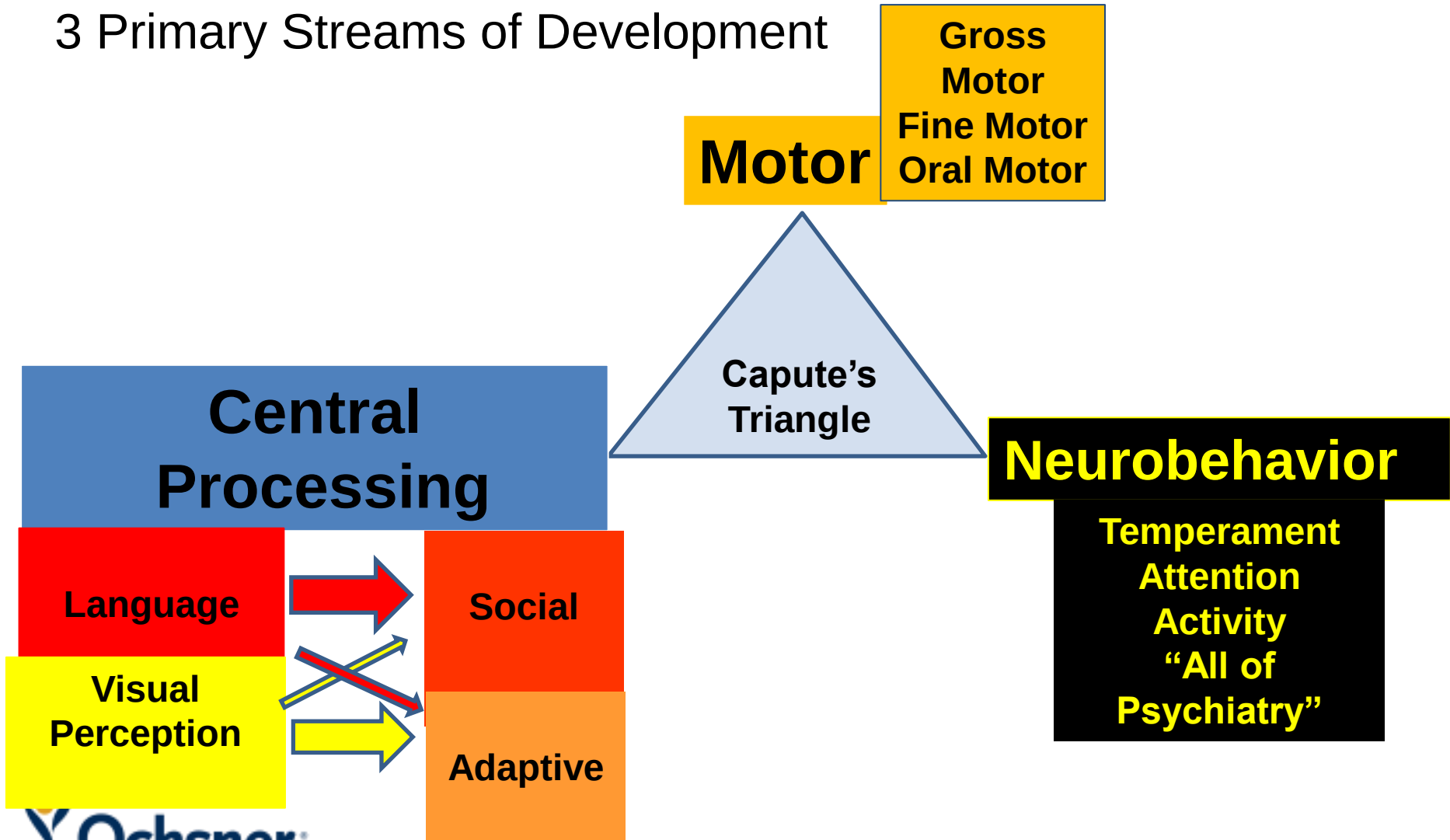
Spectrum/Continuum of
Developmental-Behavioral
Disorders

Learning Disorder
AD/HD
Speech/Language Disorder
Dysgraphia/Dyspraxia
Intellectual Disability
Autism Spectrum Disorder
Cerebral Palsy



Developmental Diagnosis: Capute's Triangle

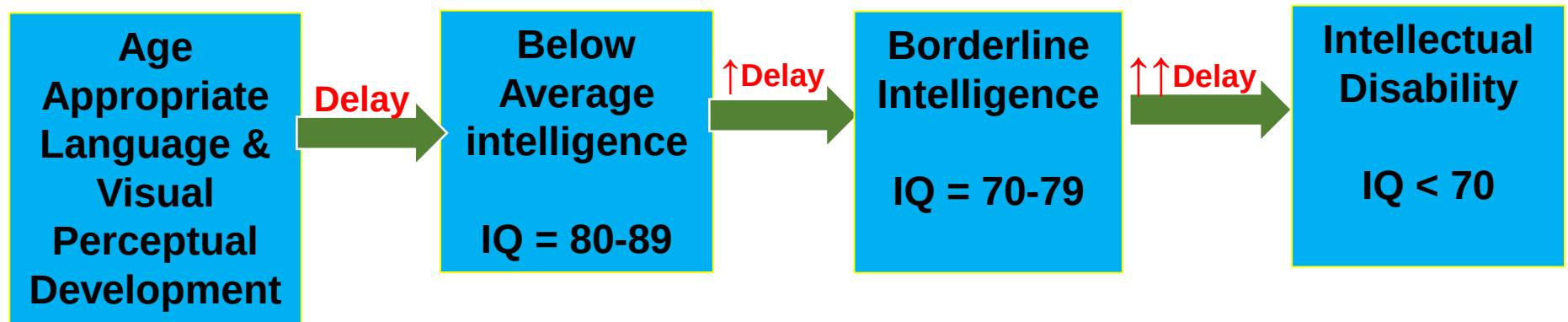
3 Primary Streams of Development



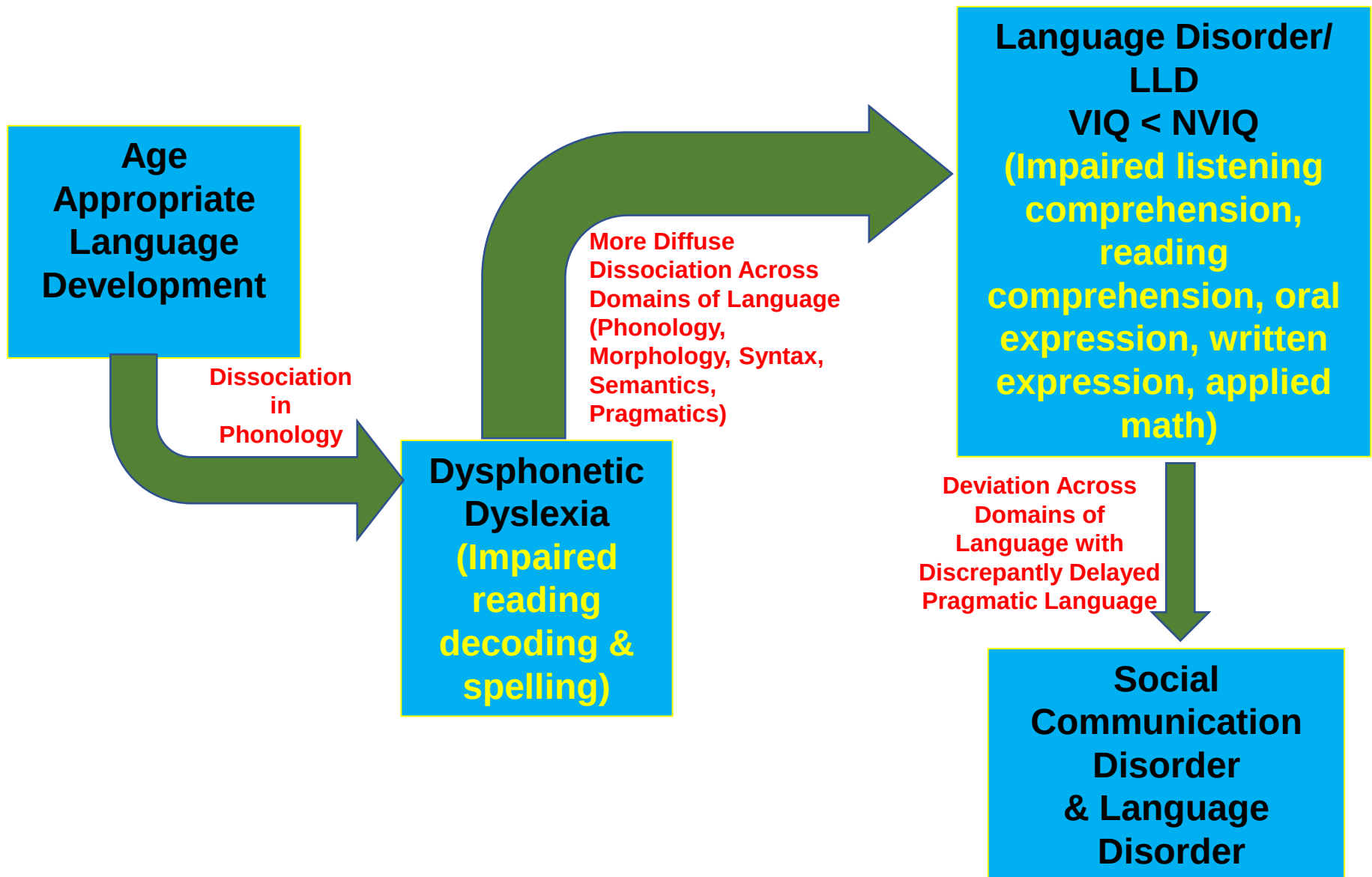
Key Neurodevelopmental Principle #1

- **Spectrum of disability within each stream**
 - Mild disabilities predominate over severe disabilities
 - The more severe the developmental-behavioral disability, the earlier it can be reliably identified

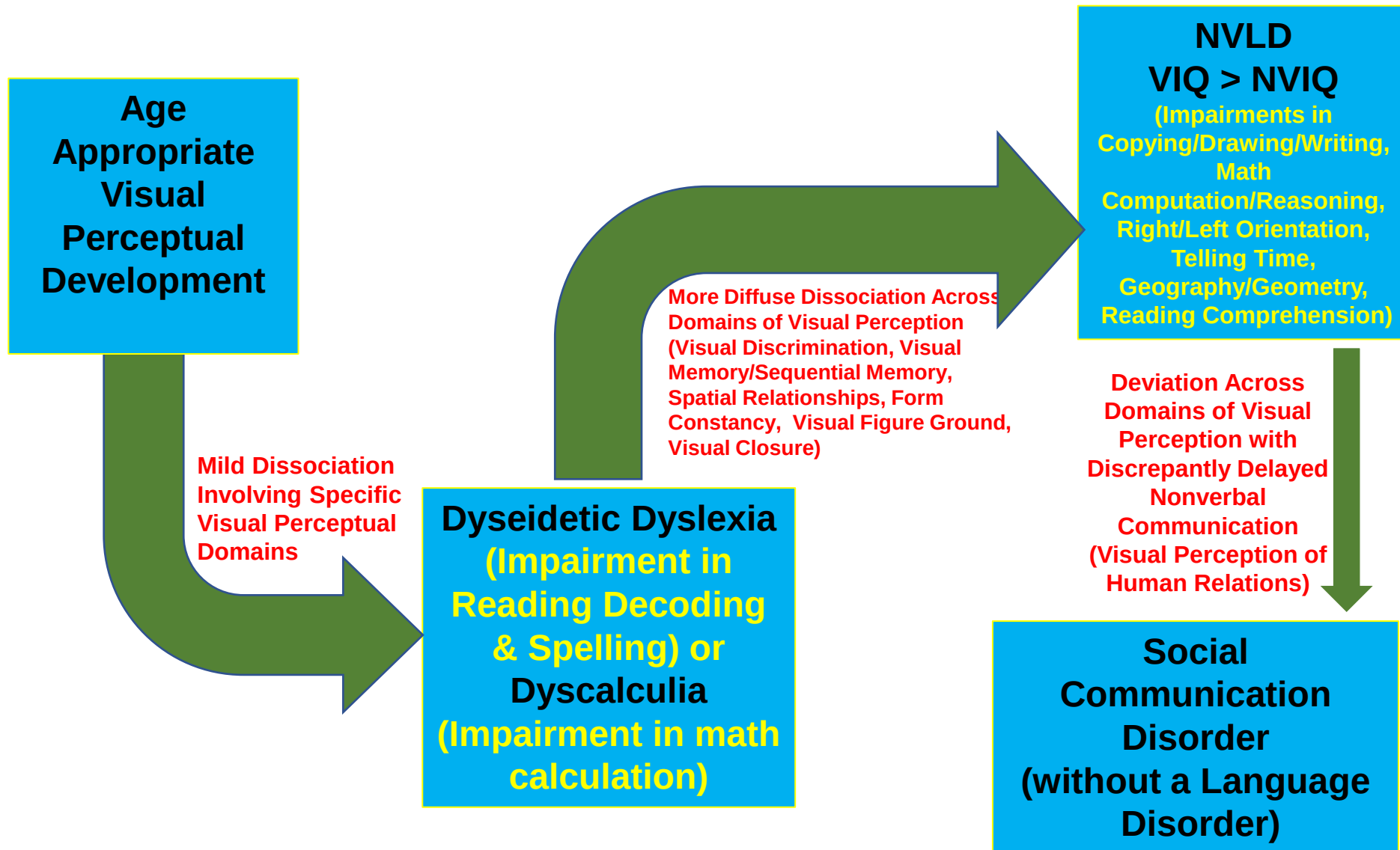
SPECTRUM OF GLOBAL CENTRAL PROCESSING (LANGUAGE & VISUAL PERCEPTUAL) DELAY



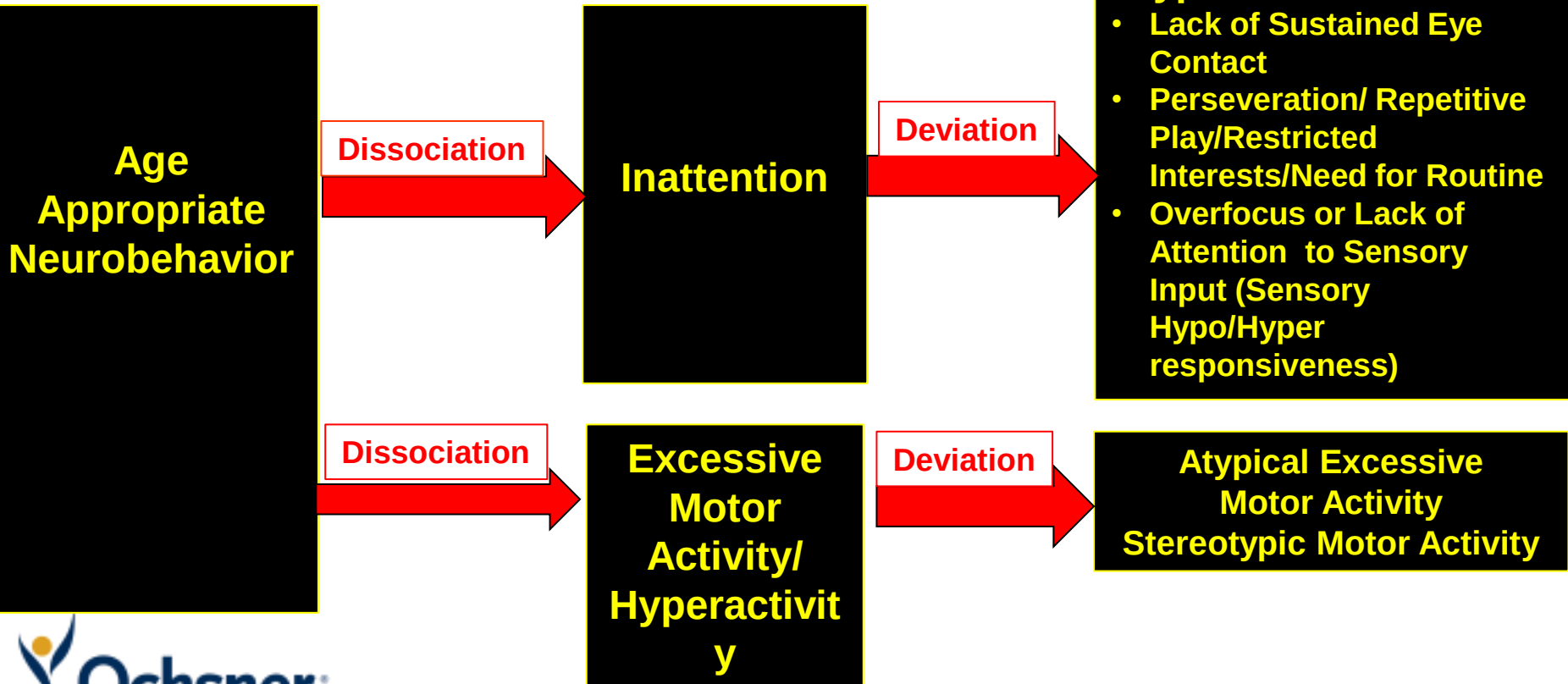
SPECTRUM OF LANGUAGE DISSOCIATION & DEVIATION



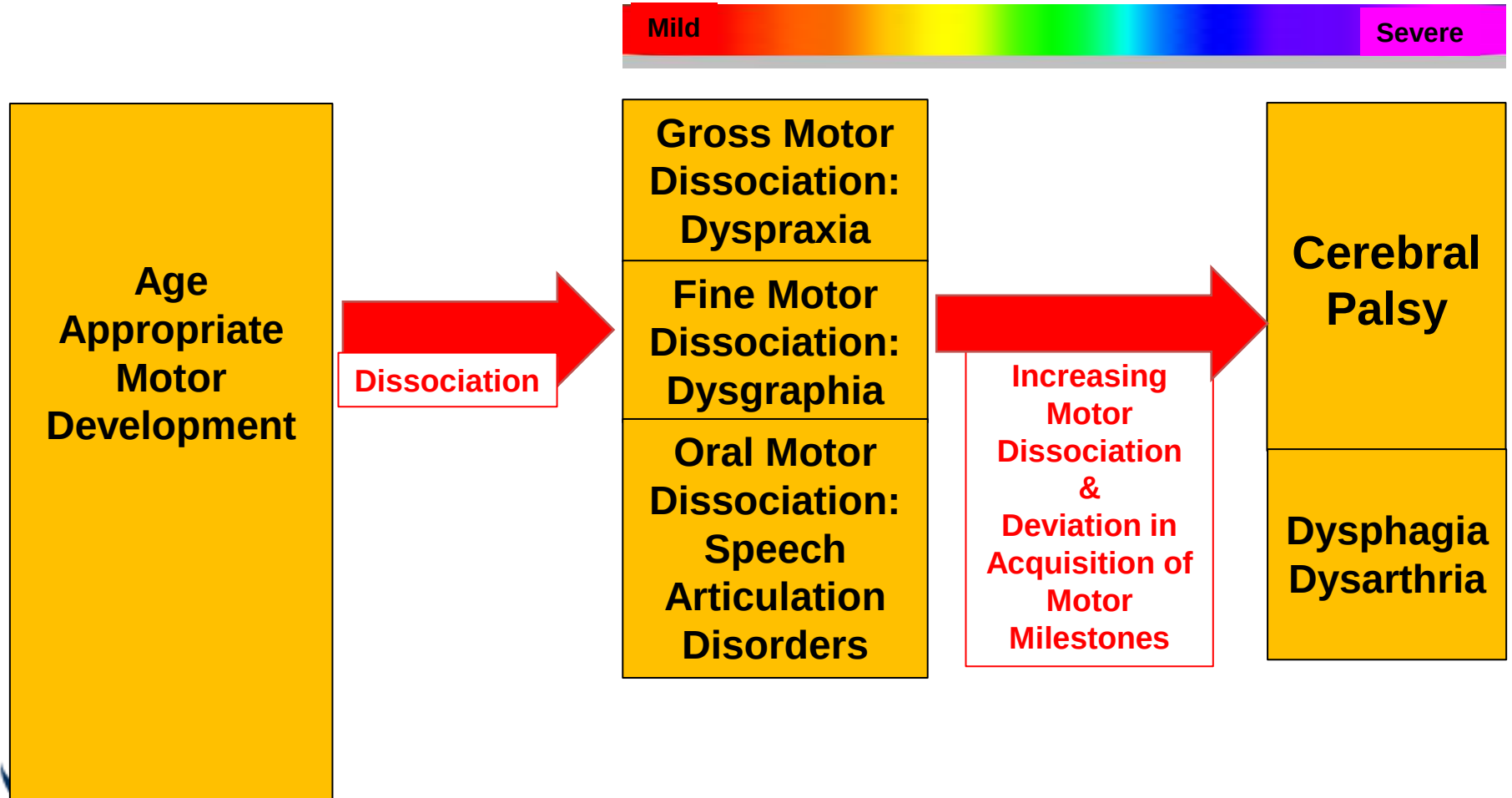
SPECTRUM OF VISUAL PERCEPTUAL DISSOCIATION AND DEVIATION



SPECTRUM OF NEUROBEHAVIORAL DISSOCIATION & DEVIATION



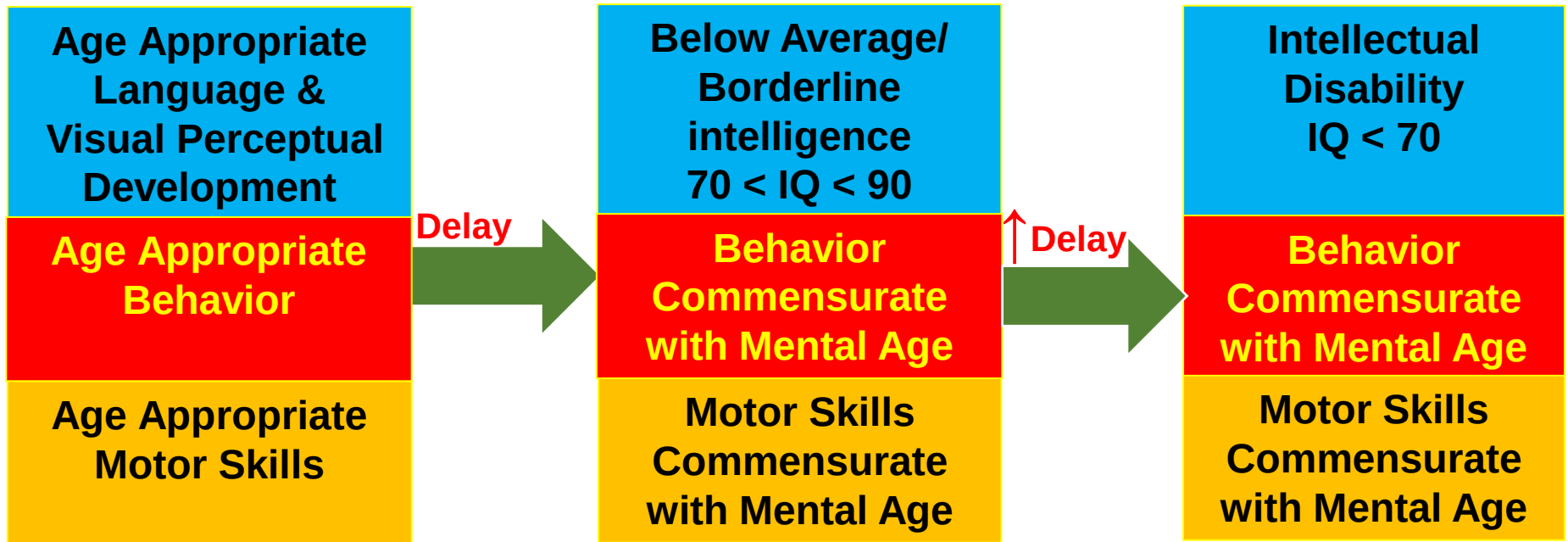
SPECTRUM OF MOTOR DISSOCIATION & DEVIATION



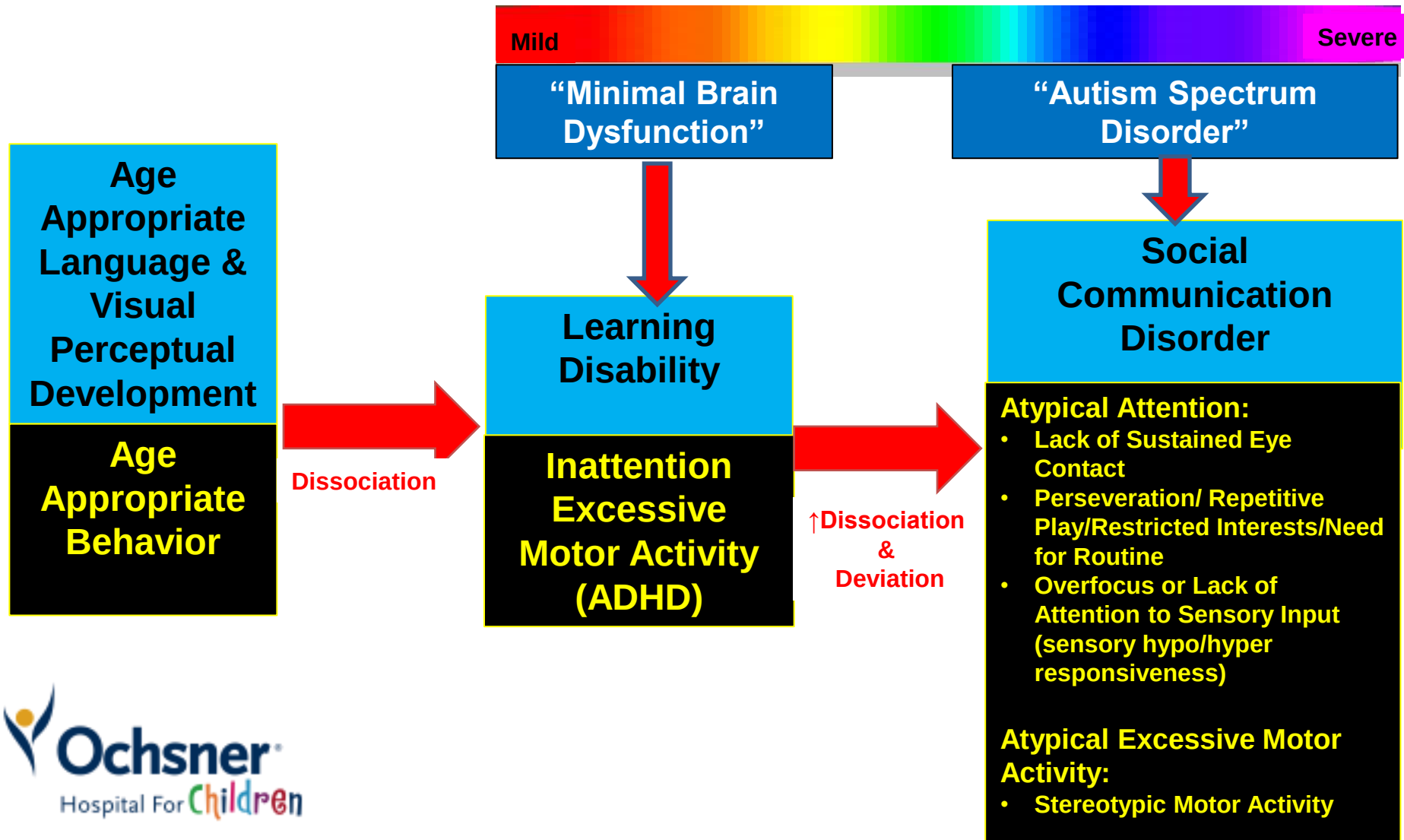
Key Neurodevelopmental Principle #2

- **Continuum of disability across streams**
 - ⦿ Presenting developmental complaint most often just the “tip of the iceberg”
 - ⦿ Diffuse/global developmental-behavioral dysfunction more prevalent than focal dysfunction
 - ⦿ Developmental-behavioral co-morbidities are the rule rather than the exception

SPECTRUM/CONTINUUM OF GLOBAL DEVELOPMENTAL DELAY



SPECTRUM/CONTINUUM OF CENTRAL PROCESSING & NEUROBEHAVIORAL DISSOCIATION AND DEVIATION

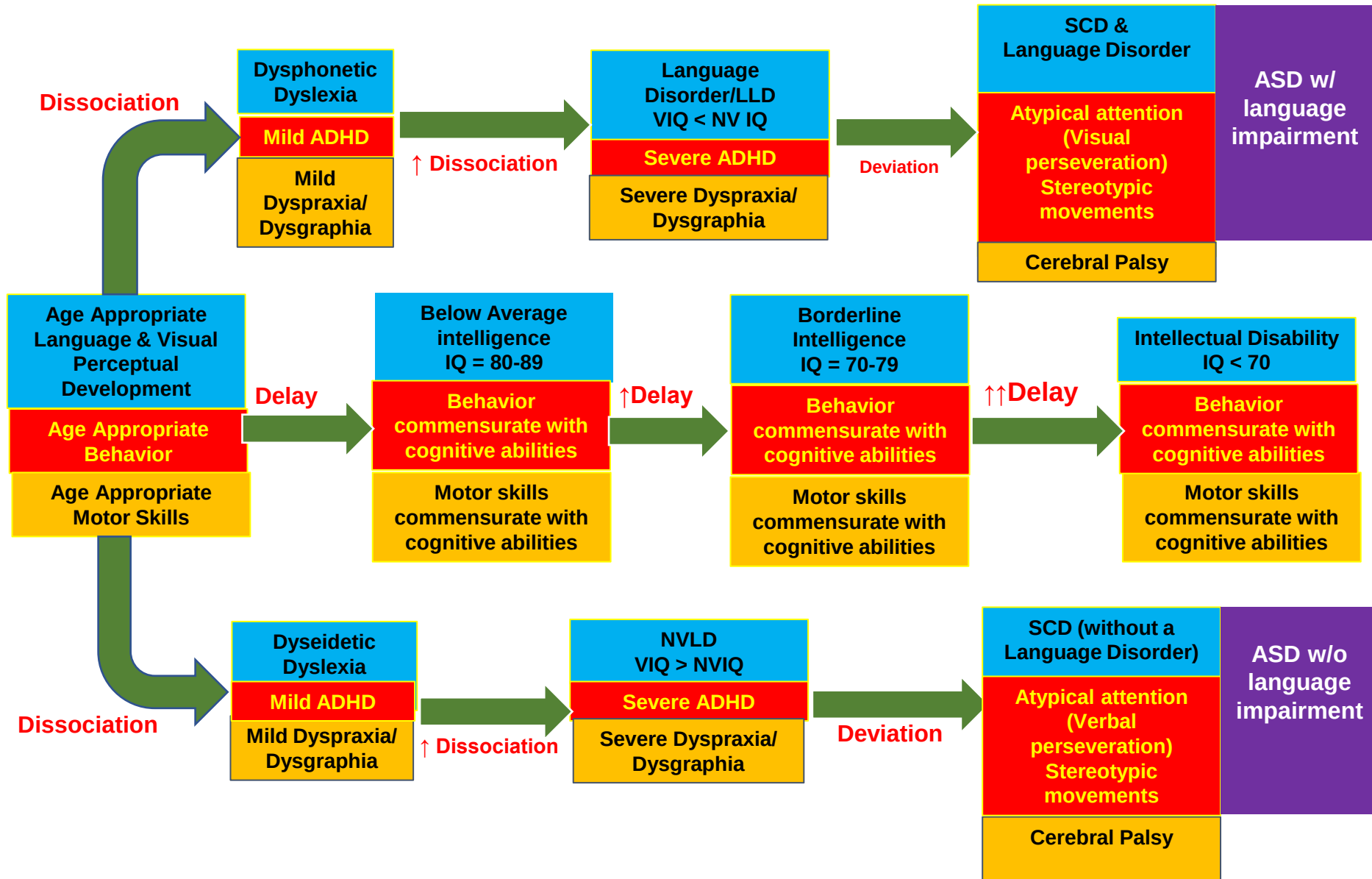


Key Neurodevelopmental Principle #3

- **Delay, dissociation, and deviation reflect atypical CNS processing**
 - The more delayed, dissociated, and deviated the central processing, the more atypical the behavior should be expected to be



SPECTRUM & CONTINUUM OF DEVELOPMENTAL DISABILITIES



Conclusions

- **Child development is the basic science of pediatric medical practice** and should be clinically evaluated and not simply screened
- **Gold standard** for making developmental-behavioral diagnoses is the **clinical judgment of experienced clinicians**
- Developmental-behavioral disorders are most prevalent chronic problems in pediatric medicine; thus, **all pediatric health care professionals should be experienced clinicians** (especially given inaccessibility of developmental-behavioral pediatricians to whom to refer)



Take Home Summary: Just Remember “3”

- 3 patterns of developmental delay (Static, Acute, Progressive)
- 3 markers of developmental concern (Delay, Dissociation, Deviation)
- 3 primary developmental streams (Central Processing, Neurobehavior, Motor)
- 3 primary neurodevelopmental principles:
 - Spectrum of disability within each stream
 - Continuum of disability across streams
 - Increasing dissociation and deviation reflects increasingly atypical development - the more atypical the central processing, the more atypical the behavior should be expected to be

