Don’t Hide Behind a Screen: A Medical Approach to Developmental Assessment & Diagnosis

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Disclosure

- Financial relationships with industry within the last 12 months:
  - None

- Off label uses:
  - None

Objectives

- Define and differentiate developmental screening, surveillance, and evaluation
- Describe the processes that underlie problems in development: delay, dissociation, and deviation
- Take advantage of our nursing, pediatric, or family medicine training and accumulated clinical experience to address chief complaints of developmental concerns (the same way we address every other medical chief complaint).
- Independently make developmental diagnoses across the spectrum and continuum of developmental disabilities (rather than waiting forever for a developmental-behavioral pediatrics consultation!)

Julius Richmond, MD
12th US Surgeon General (1977-81)

- "Child development is the basic science of pediatrics"*

*Richmond JB. *Pediatrics* 1967; 39:649–658

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	Prevalence (%)
Slower Learning (IQ ≤ 89)	23%
Asthma	8.4%
Learning Disabilities	7.7%
AD/HD	6.7%
Other developmental delay/Intellectual Disabilities	4.4 %
Autism Spectrum Disorder	1.7%
Epilepsy	1%
Congenital Heart Disease	1%
Cerebral Palsy	0.4%
Inflammatory Bowel Disease	0.4%
Juvenile rheumatic diseases	0.4%
Diabetes	0.2%
Cancer	0.02%
Cystic Fibrosis	0.04%
Chronic renal disease	0.008%

Need 1675 faculty at TCH

71 Faculty at TCH

*CDC National Center for Health Statistics. www.cdc.gov/nchs; Boyle CA, et al. Pediatrics 2011; 127:1034-1042; Baio J, et al. *MMWR Surveill Summ* 2018; 67: 1-23.

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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?

*Council on Children with Disabilities, et al. *Pediatrics* 2006; 118: 405-420.

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The Basic Science of Pediatrics

- Only 761 subspecialty board-certified in Developmental-Behavioral Pediatrics*
- Extremely long wait lists at developmental evaluation centers

*American Board of Pediatrics, Pediatric Physicians Workforce Data Book 2017-2018, Chapel Hill, NC; American Board of Pediatrics 2018

National Stats: DBP vs Other Subspecialties*

- Currently, there are 711 board-certified pediatric nephrologists nationally
- If it takes 711 nephrologists to take care of 0.008% of children, then it will take **2,221,875** board-certified DBP's to take care of the population with DBP concerns
- Currently, there are only 761 board-certified DBP's
- Shortage of **2,221,114** DBP's

*American Board of Pediatrics, Pediatric Physicians Workforce Data Book 2017-2018, Chapel Hill, NC; American Board of Pediatrics 2018

It's Only Going to Get Worse…

- 2018 AAP/SDBP Workforce Survey:
  - -1/3 of DBP's will retire in the next 3 to 5 years (N = 254 of 761)*

- December 2018 DBP Fellowship Match**:
  - -48 Positions offered
  - -Only 30 (62%) filled

***Bridgemohan C, et al. *Pediatrics* 2018;141(3):e20172164;**
****National Resident Matching Program: Results and Data: Specialties Matching Service 2019 Appointment Year. NRMP, Washington, DC, 2019.**

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The Basic Science of Pediatrics

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

AAP Definition of Screening*

- "Developmental screening is the administration of a brief standardized tool that aids the identification of children at risk of a developmental disorder"

- "Screening tools can be completed by parents and scored by nonphysician personnel"

*Council on Children with Disabilities, et al. *Pediatrics* 2006; 118: 405-420.

American Academy of Pediatrics Developmental Screening Recommendations*

- Standardized screening at well child visits at:
  - -9-months
  - -18-months
  - -24- or 30-months
- Add autism specific screening at 18 & 24 months

*Council on Children with Disabilities, et al. *Pediatrics* 2006; 118: 405-420.

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Screening: Evidence or Mythology?

- 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 (> 70% missed)
  - Subsequently, a perception has developed that primary pediatric health care providers, who are the professionals most responsible for identifying children before school entry, are to blame for missing the vast majority of children with developmental-behavioral disorders.**
  - This has led to mandated use of parent-completed developmental and behavioral screening questionnaires and an 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.

What Can Be Identified Before School Age?

[----------Low prevalence(< 3%)----------][-------High prevalence------]

6 months	12 months	18 months	3 years	Kindergarten	School Age
Vision impairment Hearing impairment	Moderate to severe CP Severe ID	Mild CP Severe Language Disorder Severe ASD	Moderate-Mild ID/ Moderate-Mild Language Disorder Moderate-Mild ASD	Slower Learning/ Global LD (IQ 70-89)	Dyspraxia Specific LD ADHD High Functioning ASD

Is Pediatric Clinical Judgment So Bad??

- US Department of Education's goal:
  - Provide EI services to at least 2% of children < 3 years*
    - Only children whose development is ≥ 2 SD below the mean can be reliably identified before age 3 years
- In 2015: 2.95% of US children < 3 years receiving EI**
- Idea that 70% of children are being missed is a myth!!!

*US Department of Education. FY 2007 program performance plan; 2006. Available at: www.ed.gov/about/reports/annual/2007plan/allprogs.pdf.

**The Early Childhood Technical Assistance Center. Part C National Program Data. Available at: http://ectacenter. org/ partc/ partcdata. asp.

"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.

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Contradictory Definitions

- **Child development - The basic science of pediatrics**

- **Screening - A process carried out by unskilled personnel**, briefly and rapidly, for the purpose of identifying those in need of further evaluation

Other Problems with Over-Reliance on Screening

- **Screening does not make a developmental diagnosis**
  - **Separates those who need further evaluation from those who do not**

- **Screening does not establish pattern of developmental delay**
  - **Static, Acute, Progressive**
  - Critical for both medical workup and therapeutic recommendations

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

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

- Complaints about developmental-behavioral concerns should be treated no differently!!!!!!!

AAP Definition of Surveillance

- "Developmental surveillance is a flexible, longitudinal, continuous, and cumulative process whereby knowledgeable health care professionals identify children who may have developmental problems"

Developmental Surveillance

- **AAP Developmental Surveillance***
  - Elicit parental concerns (screen)
  - Identify risk factors
  - Obtain developmental history
  - Make accurate/informed observations of child
  - Document findings
  - Refer for diagnosis

- **Pediatric Medical Training**
  - **Chief complaint**
  - **Developmental History**
  - **Neurodevelopmental Examination**
  - **Make developmental diagnosis**
  - **Document findings**

*Council on Children with Disabilities, et al. *Pediatrics* 2006; 118: 405-420.

Developmental History

- Elicitation of temporal sequence of developmental milestone acquisition within each developmental stream

- Parents are best historians when developmental history focuses on milestones that are **memorable** and milestones that are **temporally current**

Roles of Developmental History

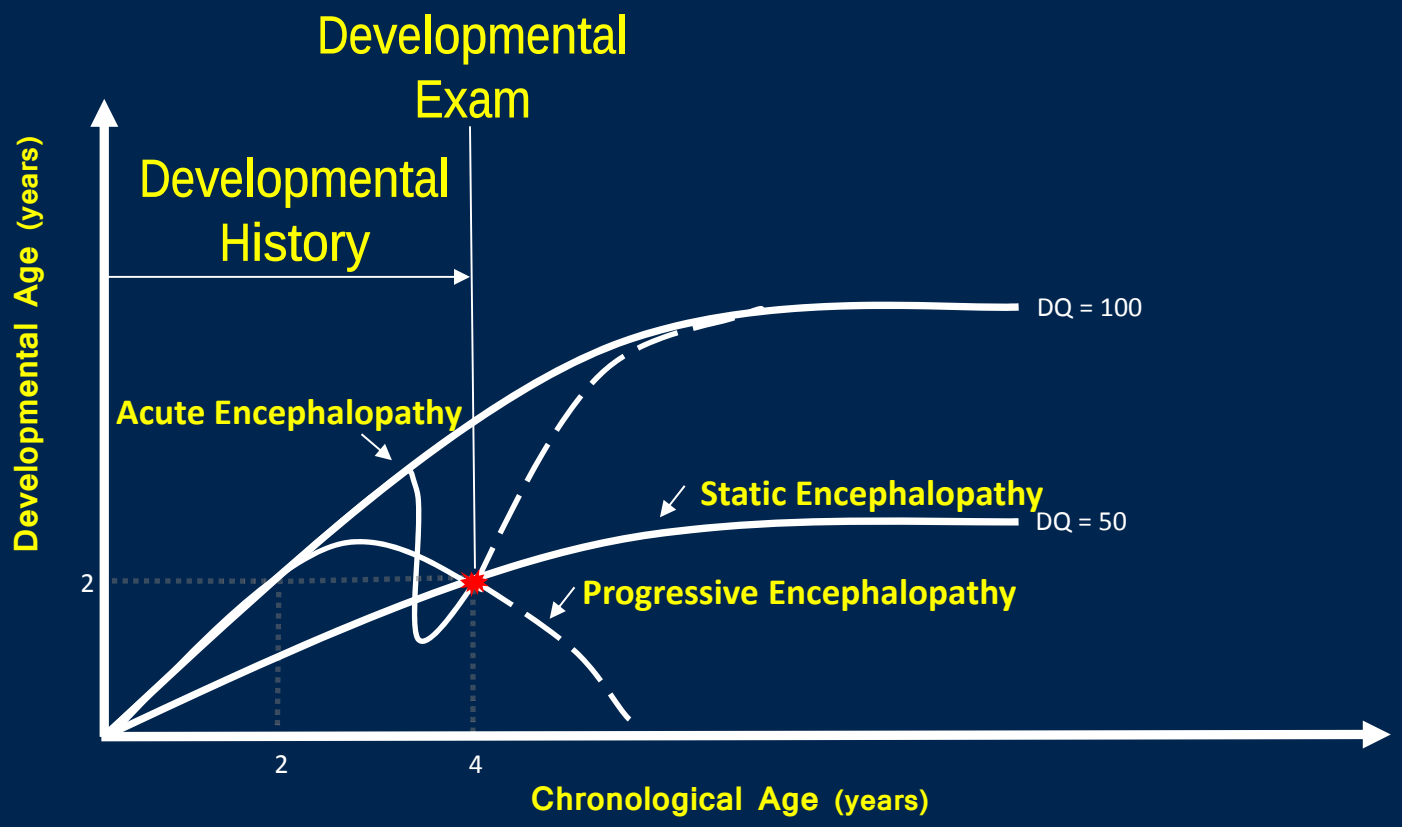
1. Establish pattern of developmental delay

- Static, Acute, Progressive

2. Identify markers of atypical development

- Delay, Dissociation, Deviation

Patterns of Developmental Delay



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Developmental Delay

- Significant lag in one or more streams of development
- **Most commonly represented by a more global delay affecting all streams of development**

Case: 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"

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: 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 at 18 months; feeds self with fork and unzips; can imitate horizontal and vertical strokes; stacks & lines up blocks
  - Speech/Language: Began babbling at 1 year; just started using a specific "Mama" and "Dada" and 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: 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: Intentionally released objects before 1 year. Scribbled at 18 months. Imitates strokes but not correct orientation. Recognized all letters of the alphabet at 18 months
  - Speech/Language: Began babbling at 1 year; currently has a 10 word vocabulary but does not use a specific "Mama" and "Dada"; repeats multiword phrases from videos; does not use gestured language; just started following gestured commands

AAP Definition of Developmental Evaluation

- "Standardized developmental evaluation should be performed when a child fails a screen"*:

- "Pediatric subspecialists such as neurodevelopmental pediatricians, developmental-behavioral pediatricians, child neurologists, pediatric physiatrists, or child psychiatrists can perform the developmental diagnostic evaluation"*

*Council on Children with Disabilities, et al. *Pediatrics* 2006; 118: 405-420.

Medical Training: Neurodevelopmental Exam

- In medical model, neurodevelopmental exam done to confirm developmental history
- Traditional neurologic examination + developmental evaluation
- Can be performed by all primary pediatric health care professionals

Case: Neurdevelopmental Exam

- 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.

Examples of Standardized Neurodevelopmental Evaluation Measures for Pediatric Health Care Providers

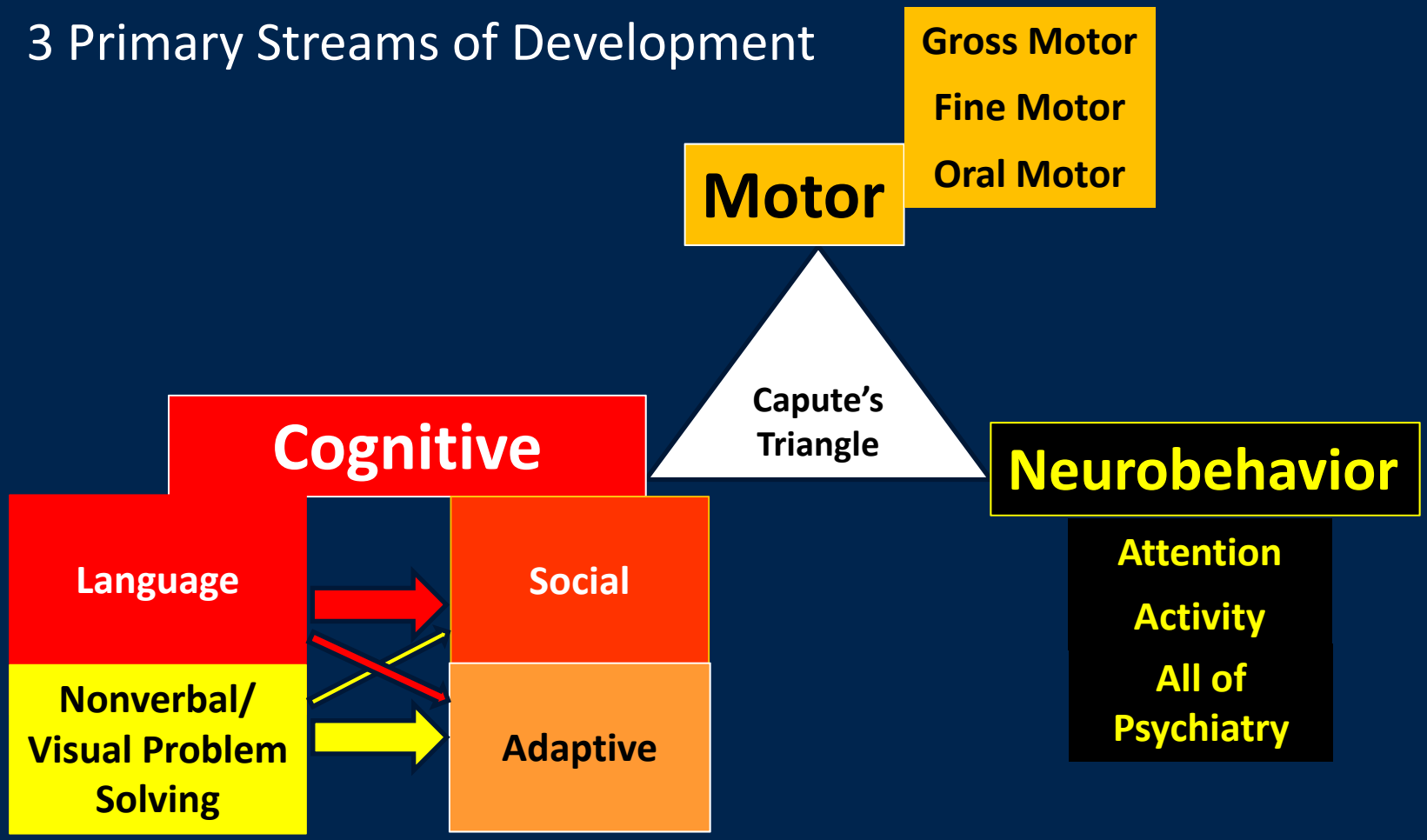
- **CPT 96112 – Developmental Testing (>30 minutes for administration, interpretation and creation of report)**
  - -**Capute Scales**: Cognitive Adaptive Test/Clinical Linguistic and Auditory Milestone Scale (**CAT/CLAMS**)
  - -**PEDS-DM Assessment Level**
  - -**Gesell Developmental Observation-Revised**

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 within the spectrum & continuum of developmental-behavioral disorders**

Developmental Diagnosis: Capute's Triangle

3 Primary Streams of Development



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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

Key Neurodevelopmental Principle #2

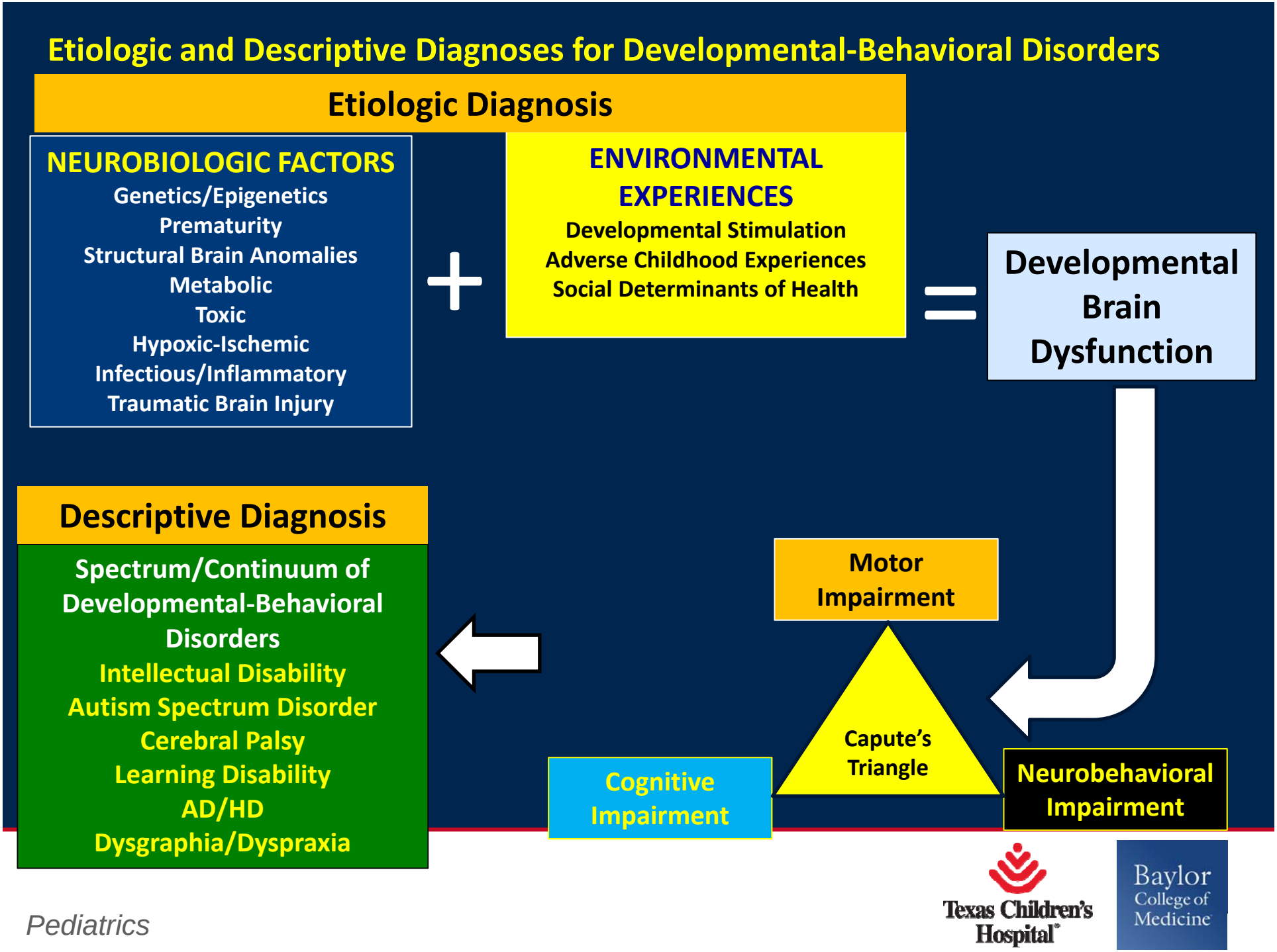
- **Continuum of disability across streams**
  - Presenting developmental complaint most often just the "tip of the iceberg"
  - Diffuse/global developmental-behavioral dysfunction more prevalent than focal dysfunction
  - Developmental-behavioral co-morbidities are the rule rather than the exception

Key Neurodevelopmental Principle #3

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

Developmental Diagnosis

- Developmental diagnosis has 2 components:
  - -Etiological diagnosis
  - -Descriptive developmental diagnosis



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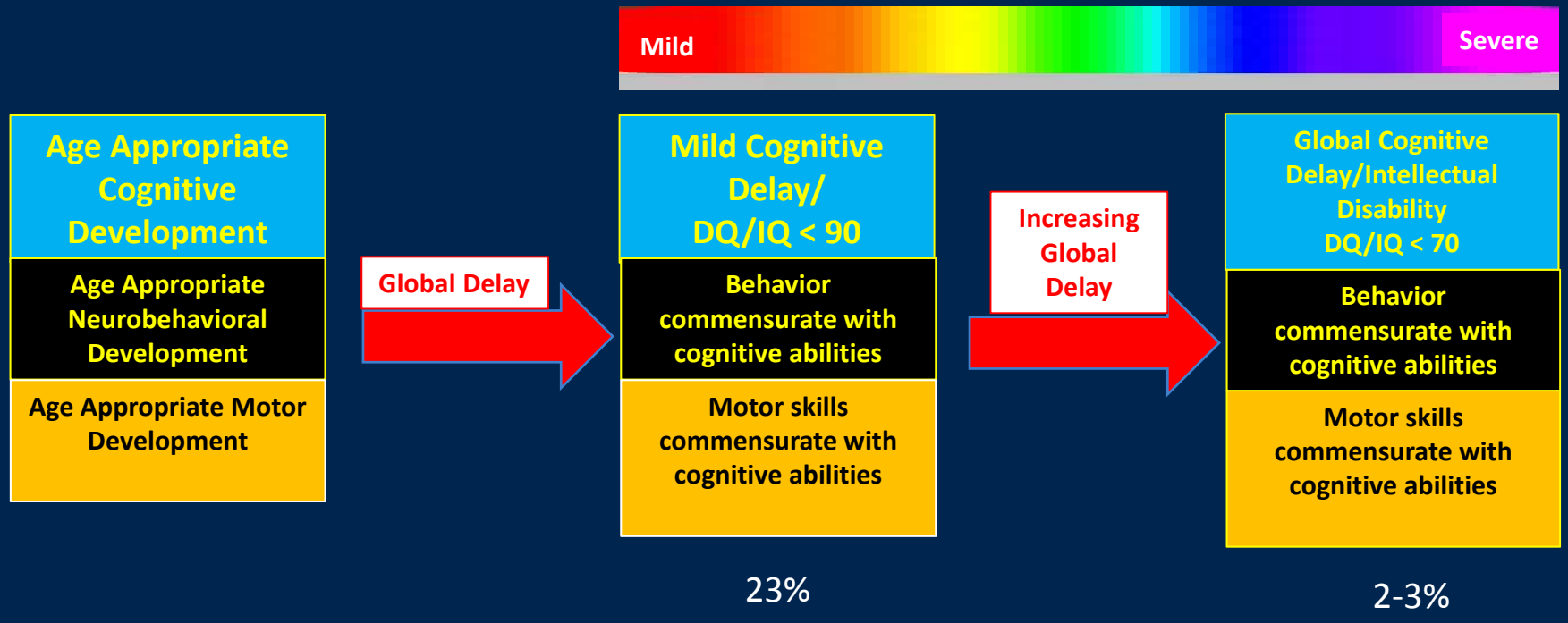
Key Neurodevelopmental Principle #1

- Spectrum of disability within each stream

SPECTRUM OF GLOBAL DEVELOPMENTAL DELAY



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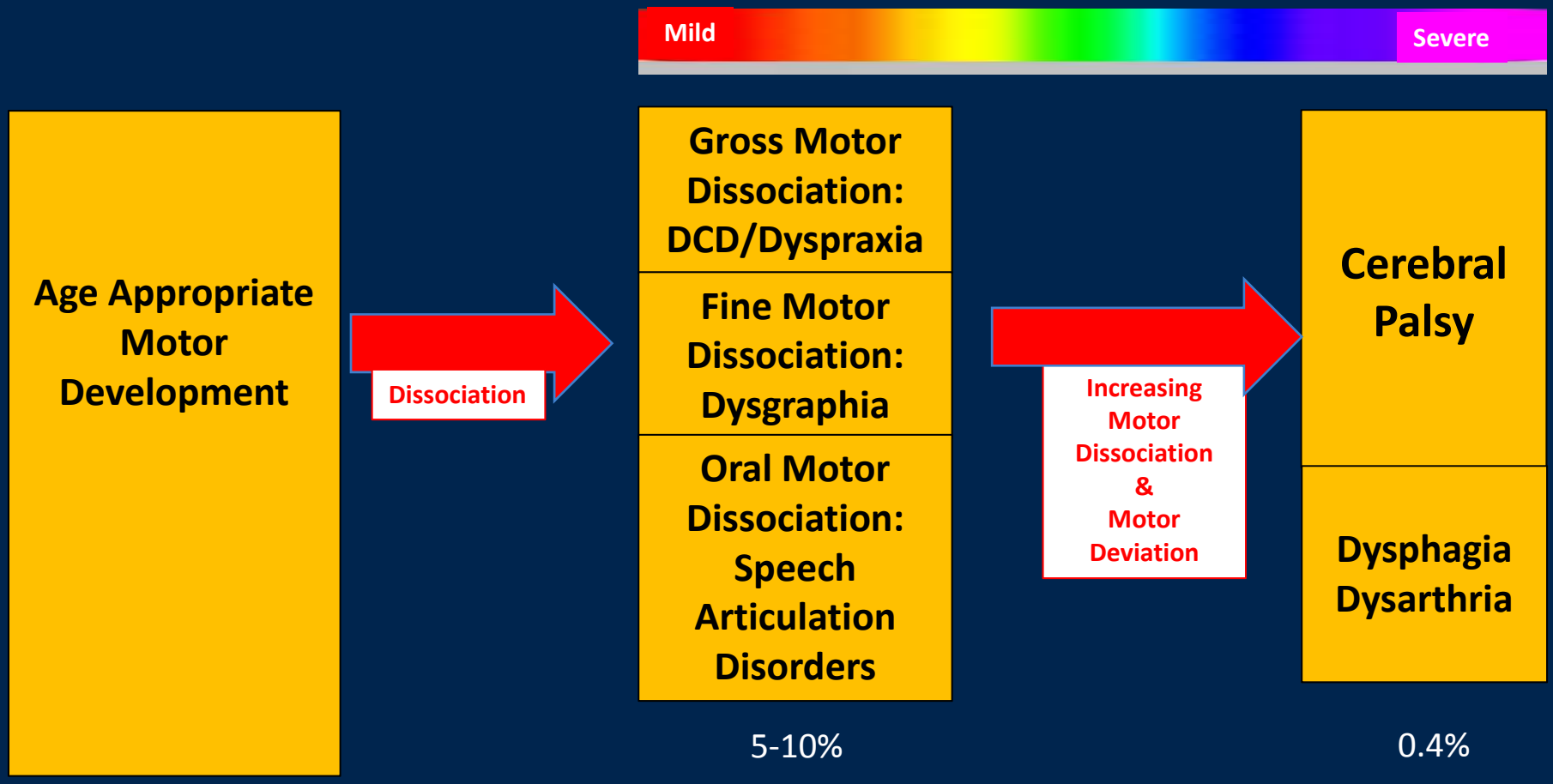
SPECTRUM OF MOTOR DISSOCIATION & DEVIATION



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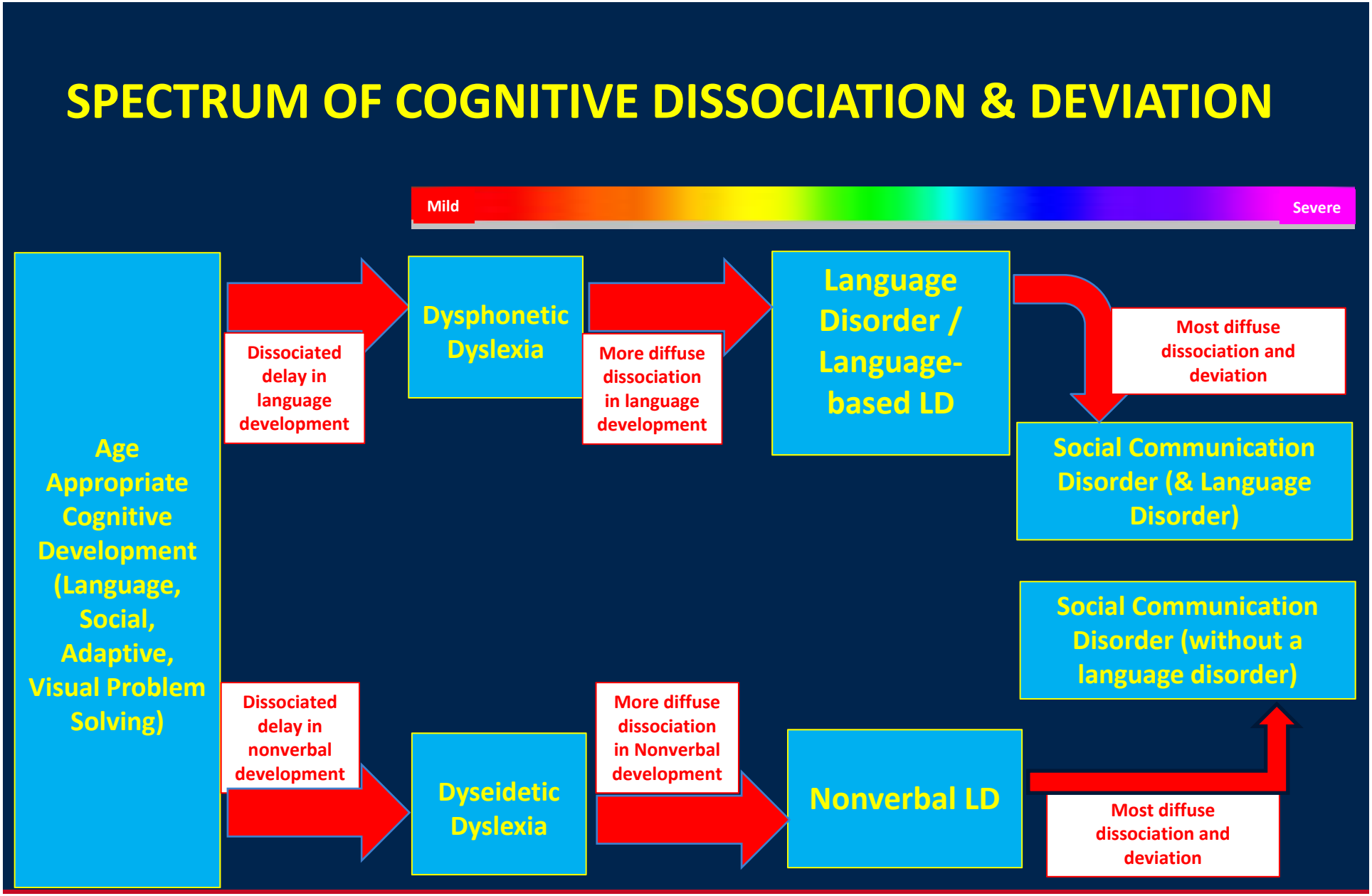
SPECTRUM OF COGNITIVE DISSOCIATION & DEVIATION



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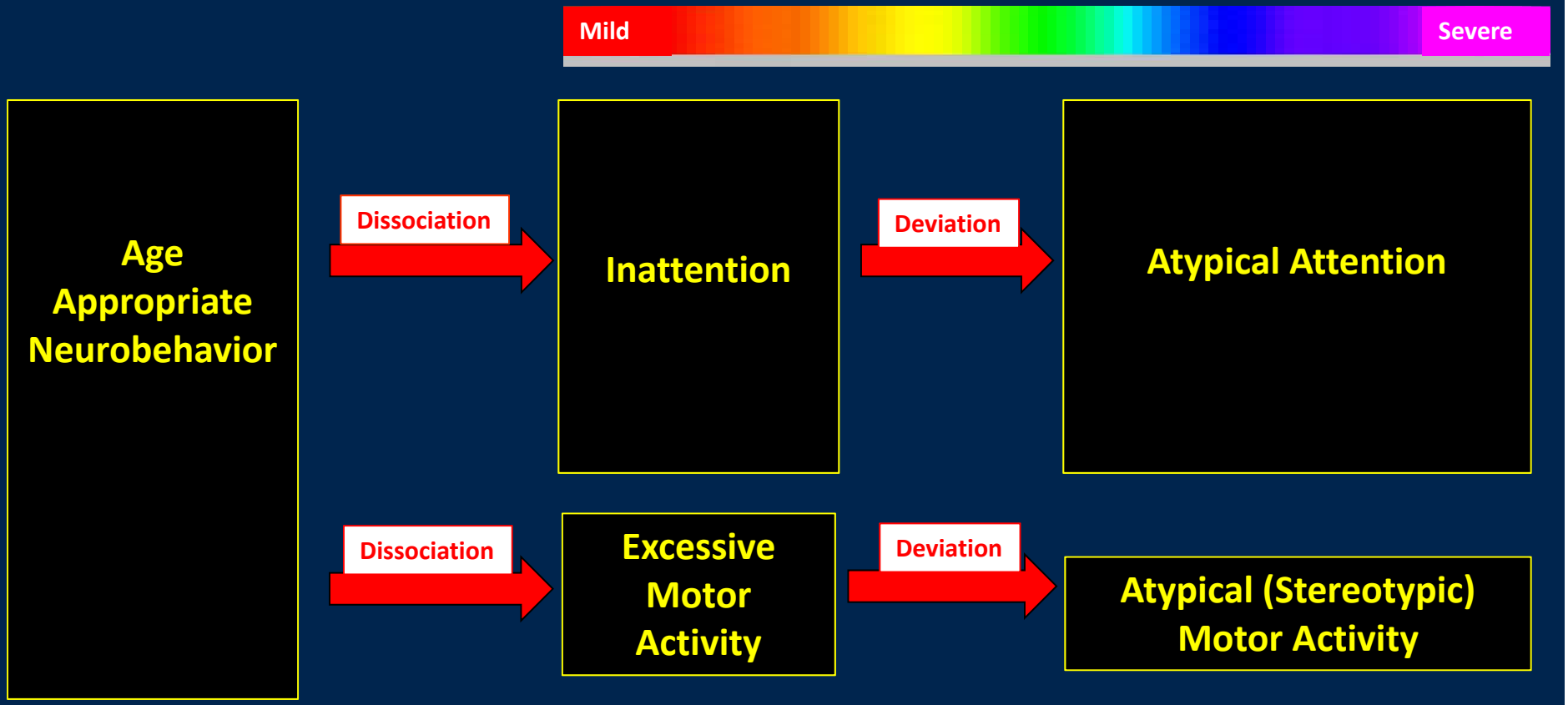
SPECTRUM OF NEUROBEHAVIORAL DISSOCIATION & DEVIATION



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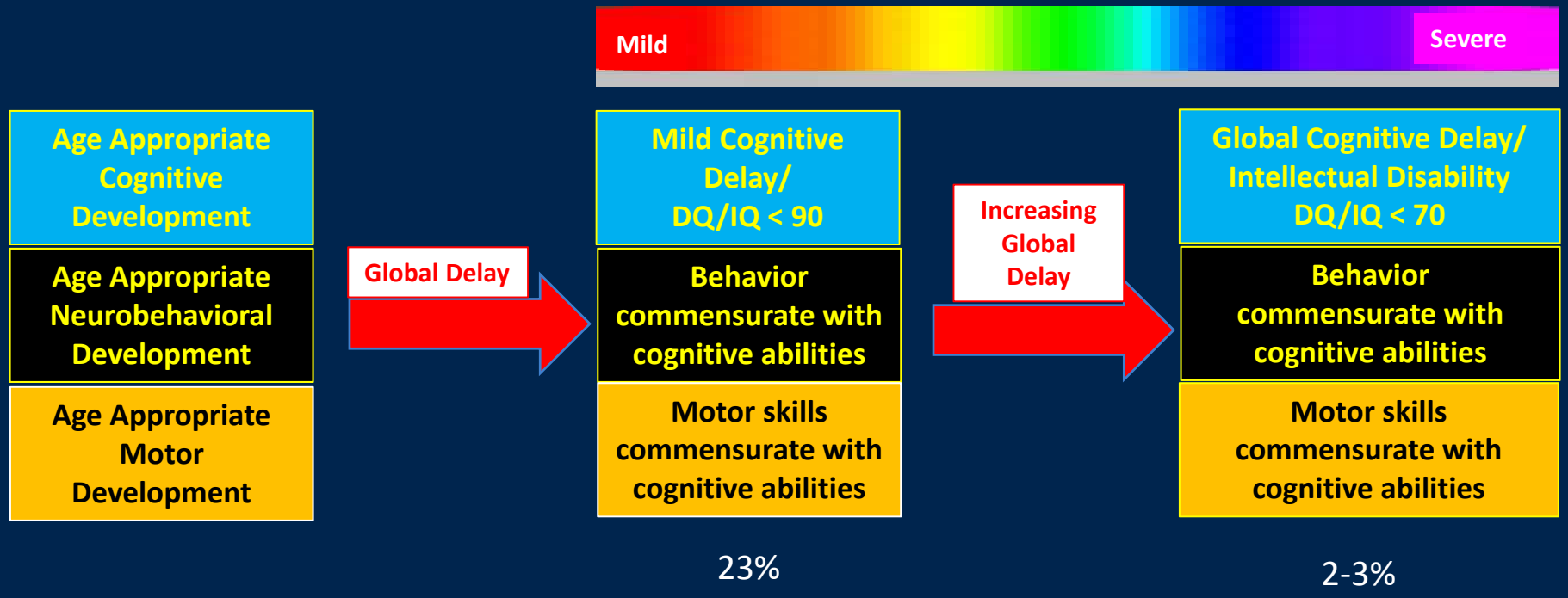
Developmental Diagnoses

- Continuum of disability across streams

SPECTRUM/CONTINUUM OF GLOBAL DEVELOPMENTAL DELAY



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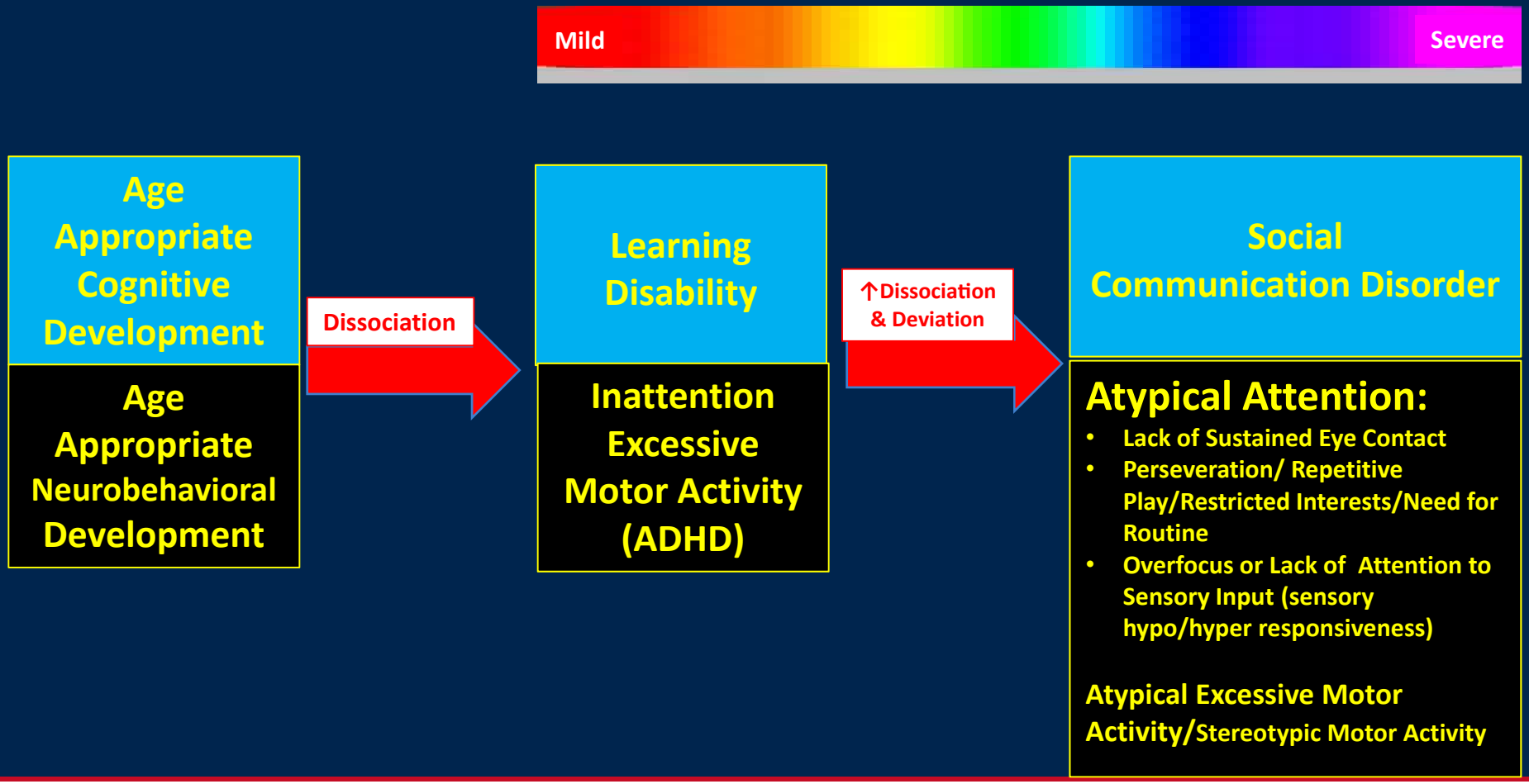
CONTINUUM OF COGNITIVE & NEUROBEHAVIORAL DISSOCIATION AND DEVIATION



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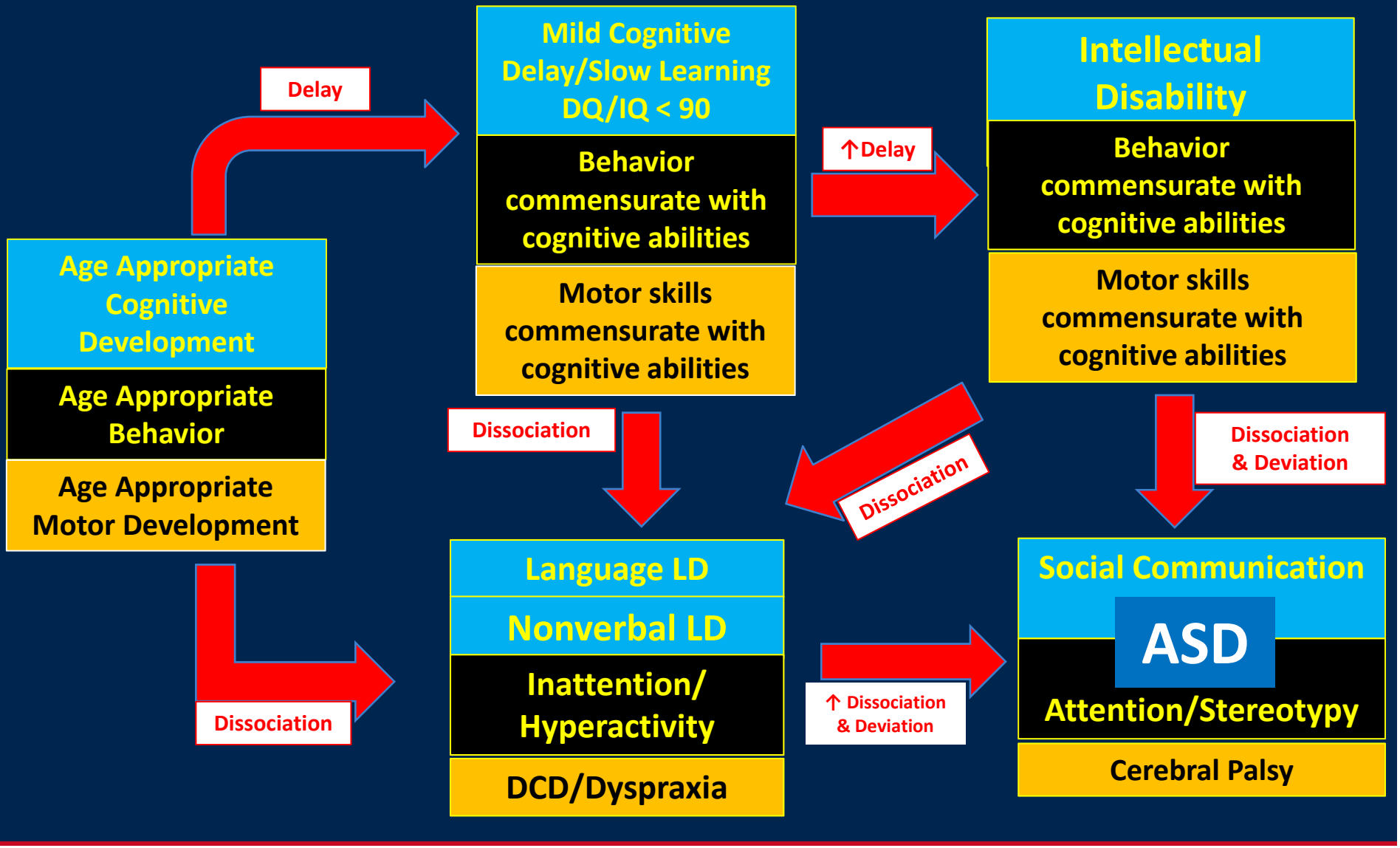
Spectrum and Continuum of Developmental Disabilities



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Summary

- Child development is basic science of pediatrics
- 3 patterns of developmental delay (Static, Acute, Progressive)
- 3 markers of developmental concern (Delay, Dissociation, Deviation)
- Increasing dissociation and deviation reflects atypical development – (The more dissociated and deviated the development, the more atypical the behavior should be expected to be)
- 3 primary developmental streams (Cognitive, Neurobehavior, Motor)
- Spectrum of disability within each stream (Mild disability predominates over severe)
- Continuum of disability across streams (Associated developmental deficits are the rule rather than the exception)