What Parents Need to Know About Cardiac Neurodevelopment

Alexander Tan, Ph.D., ABPP-CN

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Cardiac Neurodevelopmental Outcome Collaborative

01

The latest research on neurodevelopmental outcomes of high-risk CHD

02

Best-practice clinical recommendations for monitoring and evaluation by the AHA

03

How you can support CNOC in its mission to optimize outcomes for all children

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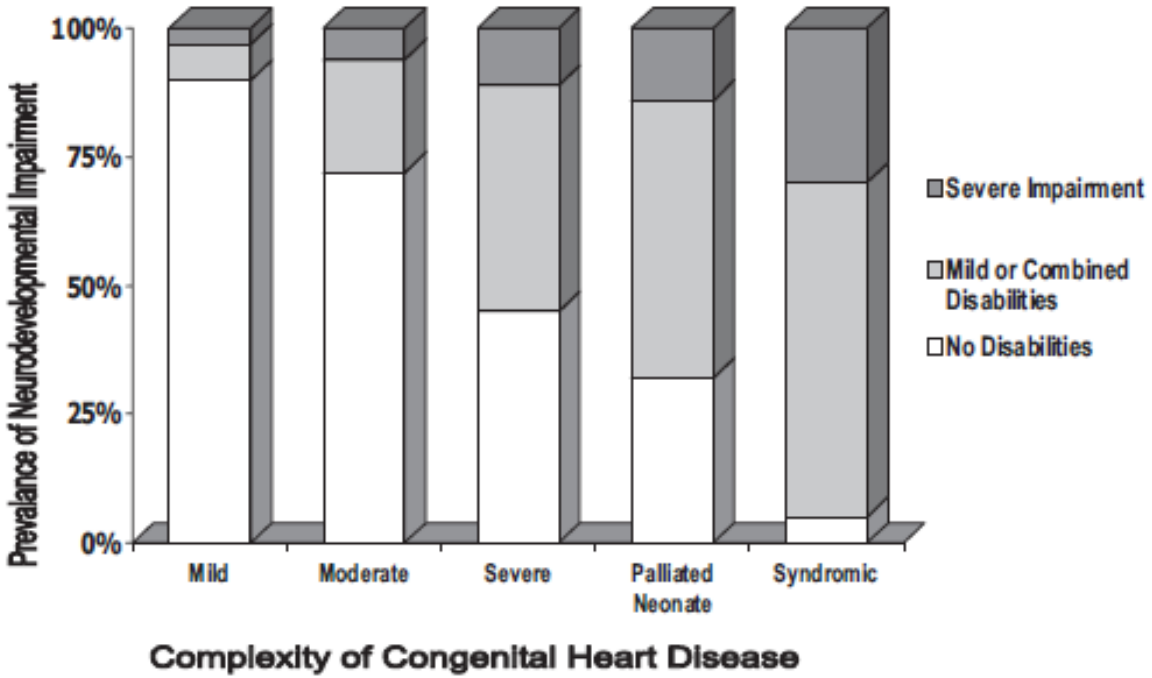
AHA Scientific Statement

Neurodevelopmental Outcomes in Children With Congenital Heart Disease: Evaluation and Management

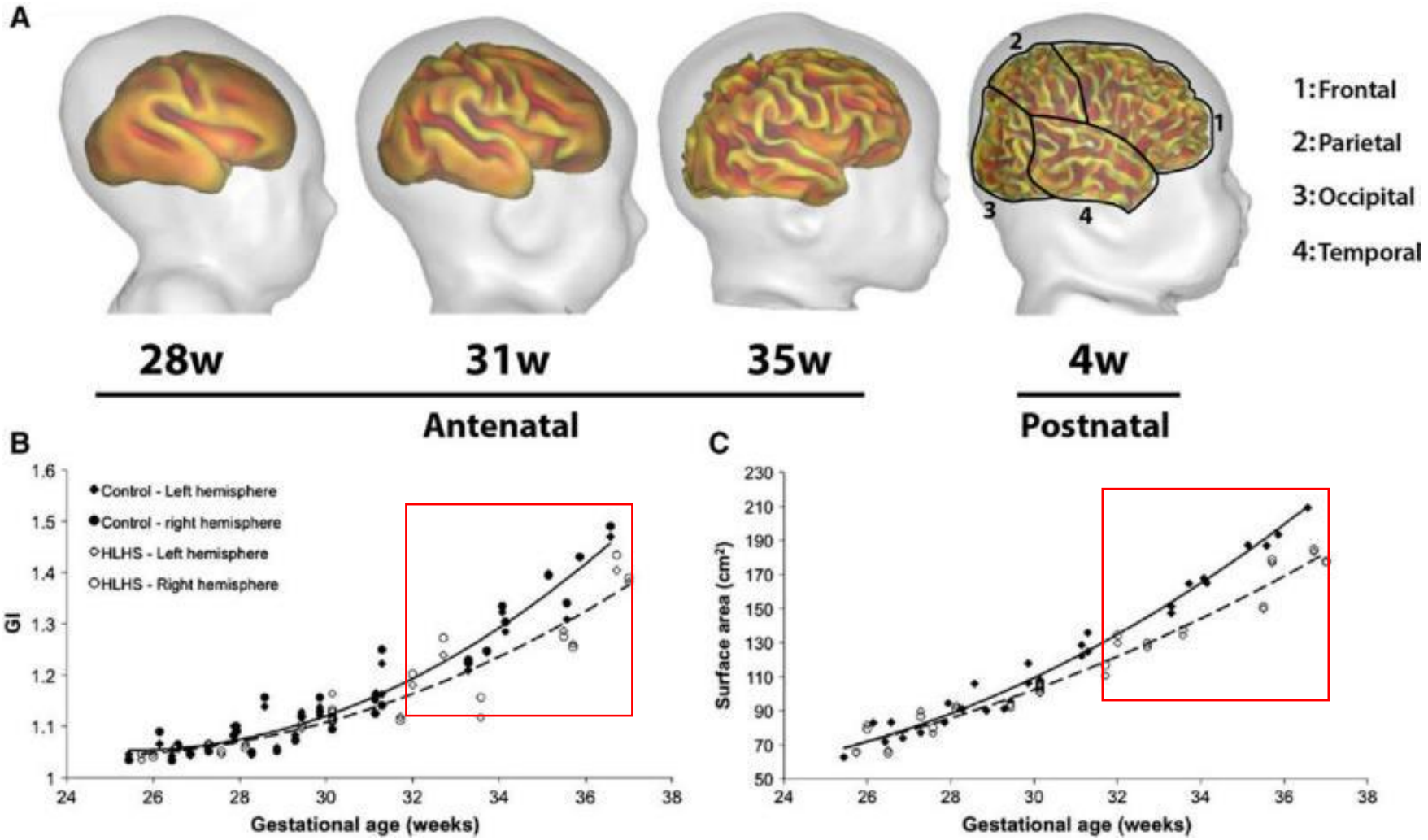
A Scientific Statement From the American Heart Association

This statement has been approved by the American Academy of Pediatrics.

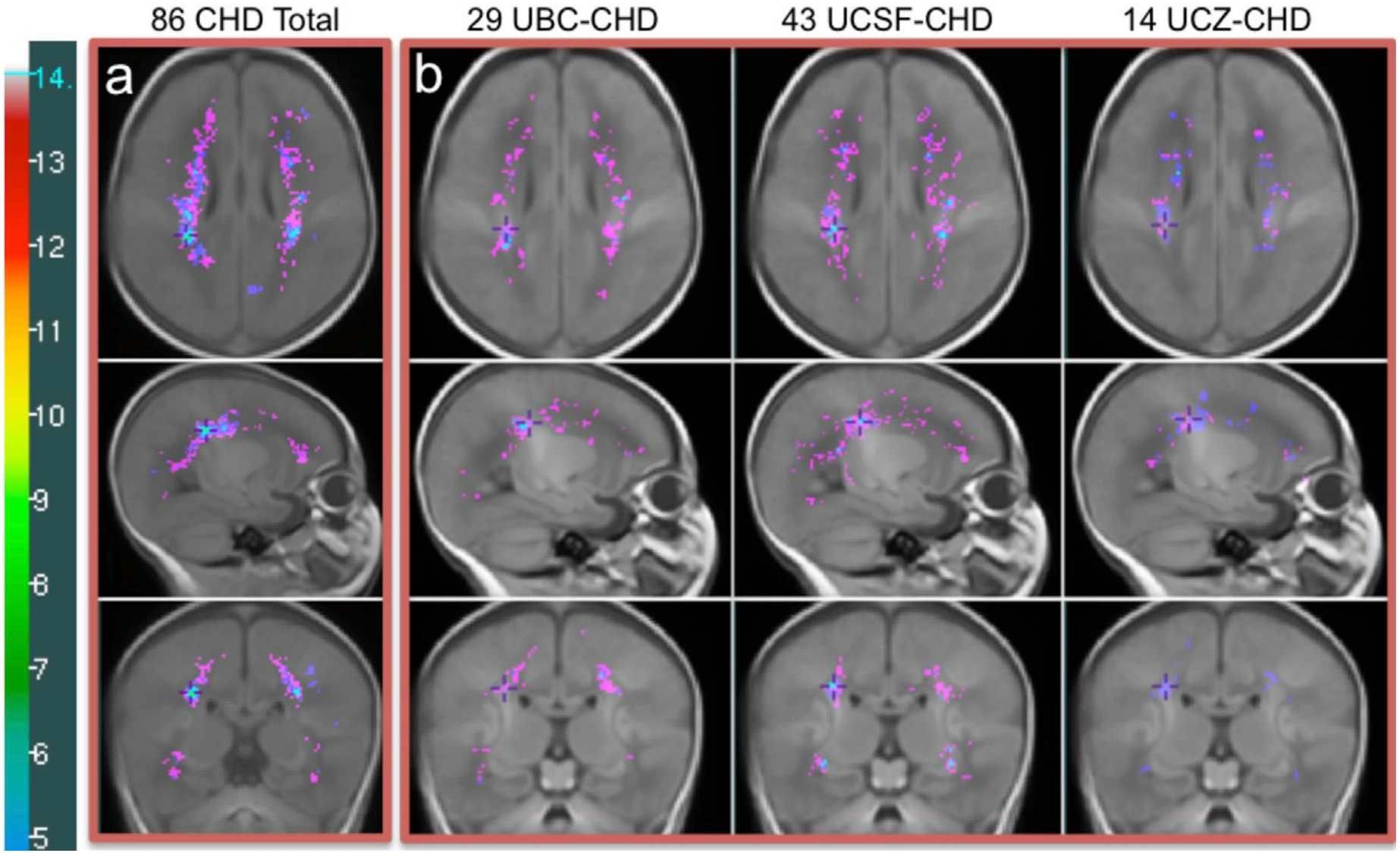
Bradley S. Marino, MD, MPP, MSCE, FAHA, Co-Chair; Paul H. Lipkin, MD; Jane W. Newburger, MD, MPH, FAHA; Georgina Peacock, MD, MPH; Marsha Gerdes, PhD; J. William Gaynor, MD; Kathleen A. Mussatto, PhD, RN; Karen Uzark, PhD, CNP, FAHA; Caren S. Goldberg, MD, MS; Walter H. Johnson, Jr, MD; Jennifer Li, MD; Sabrina E. Smith, MD, PhD; David C. Bellinger, PhD; William T. Mahle, MD, FAHA, Co-Chair; on behalf of the American Heart Association Congenital Heart Defects Committee of the Council on Cardiovascular Disease in the Young, Council on Cardiovascular Nursing, and Stroke Council



Marino et al., 2012



Claessens et al., 2017; Morton et al., 2017; Ortinual et al., 2022



Claessens et al., 2017; Guo et al., 2019; Kelly et al., 2019

Table 1
Risk factors for neurodevelopmental concerns in the congenital heart disease population

Timeframe	Risk Factors for Neurodevelopmental Concerns
Prenatal	Genetic predisposition to CHD Genetic abnormalities and syndromes Impaired *in-utero* hemodynamics Placental abnormalities
Neonatal transition	Prematurity (<37 weeks) Neonatal transition Acidosis and hypoxemia
Cardiac intervention	Exposure to CPB and DHCA Use of ECMO and VAD Use of volatile anesthetics
Postoperative recovery	Unstable hemodynamics and AP shunt steal History of cardiopulmonary resuscitation Prolonged hospitalization (>2 weeks) Perioperative seizures Psychological stress (separation from family; medical trauma)
Across the lifespan	Long-term cyanosis (with or without cardiac surgery) Neuroimaging abnormalities Microcephaly (<2 standard deviations) Repeated hospitalizations, operations, and catheterizations End-organ injury (ie, liver, kidneys) Need for heart transplant Pacemaker or ICD placement

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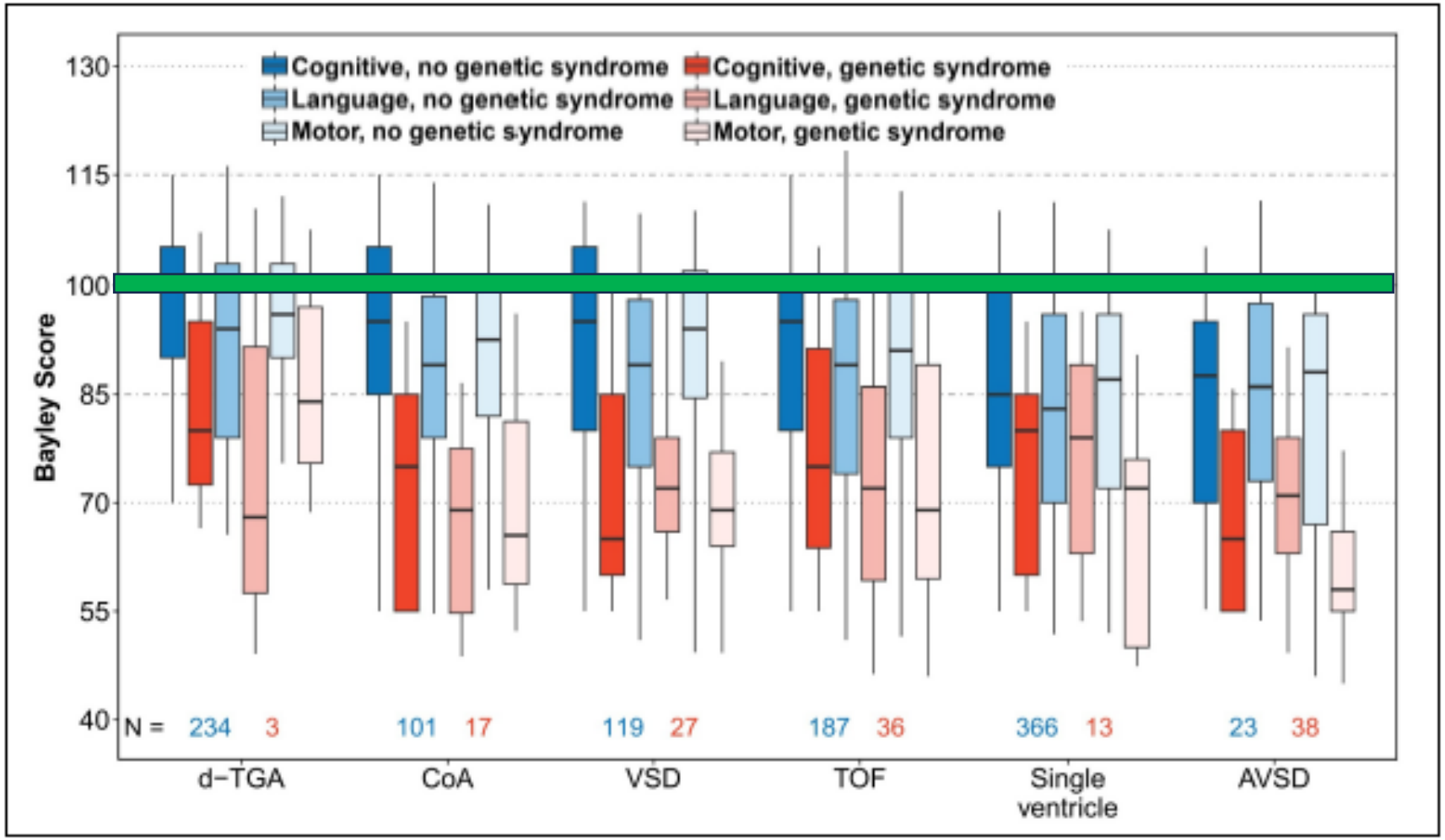
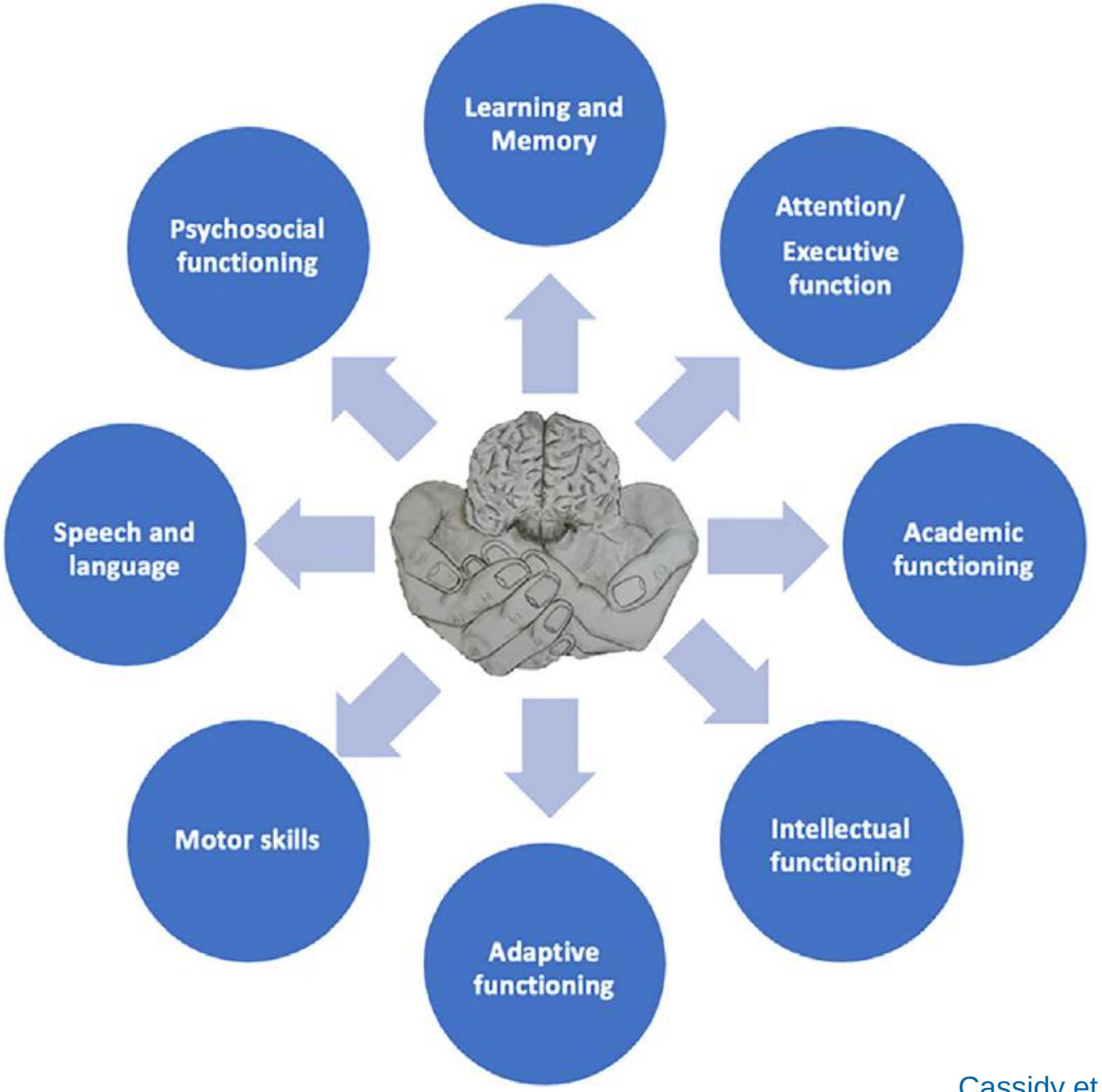
Patel et al., 2023

ssessments in 1249 patients across 27 centres

Figure 2: Diagnosis. BSID standard scores by cardiac diagnostic group. Within each cardiac diagnostic group, sample sizes are presented for assessments from subjects with and without genetic syndrome. D-TGA = dextrotrasposition of the great arteries, CoA = coarctation of the aorta, VSD = ventricular septal defect, TOF = tetralogy of Fallot, AVSD = atrioventricular septal defect



Seed et al., 2023



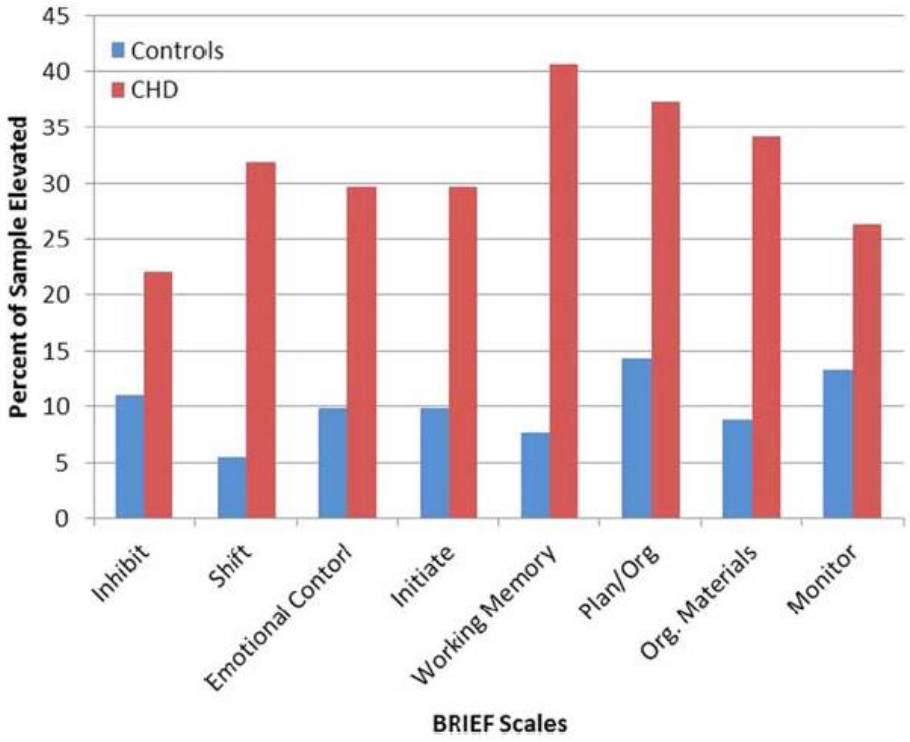
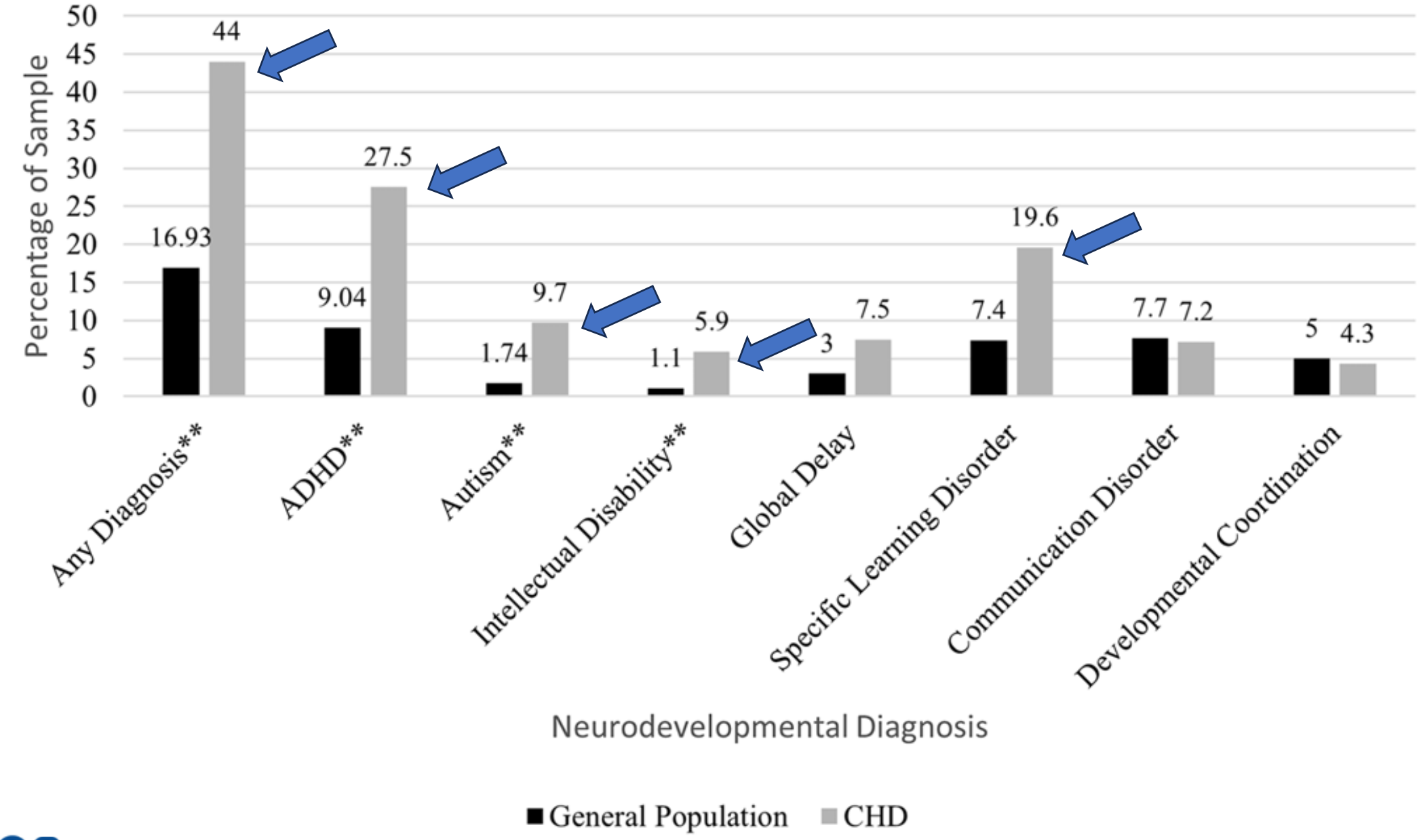


FIGURE 1 Prevalence of executive dysfunction: percent of the sample reporting clinically significant elevations (T score ≥ 65) on the BRIEF.

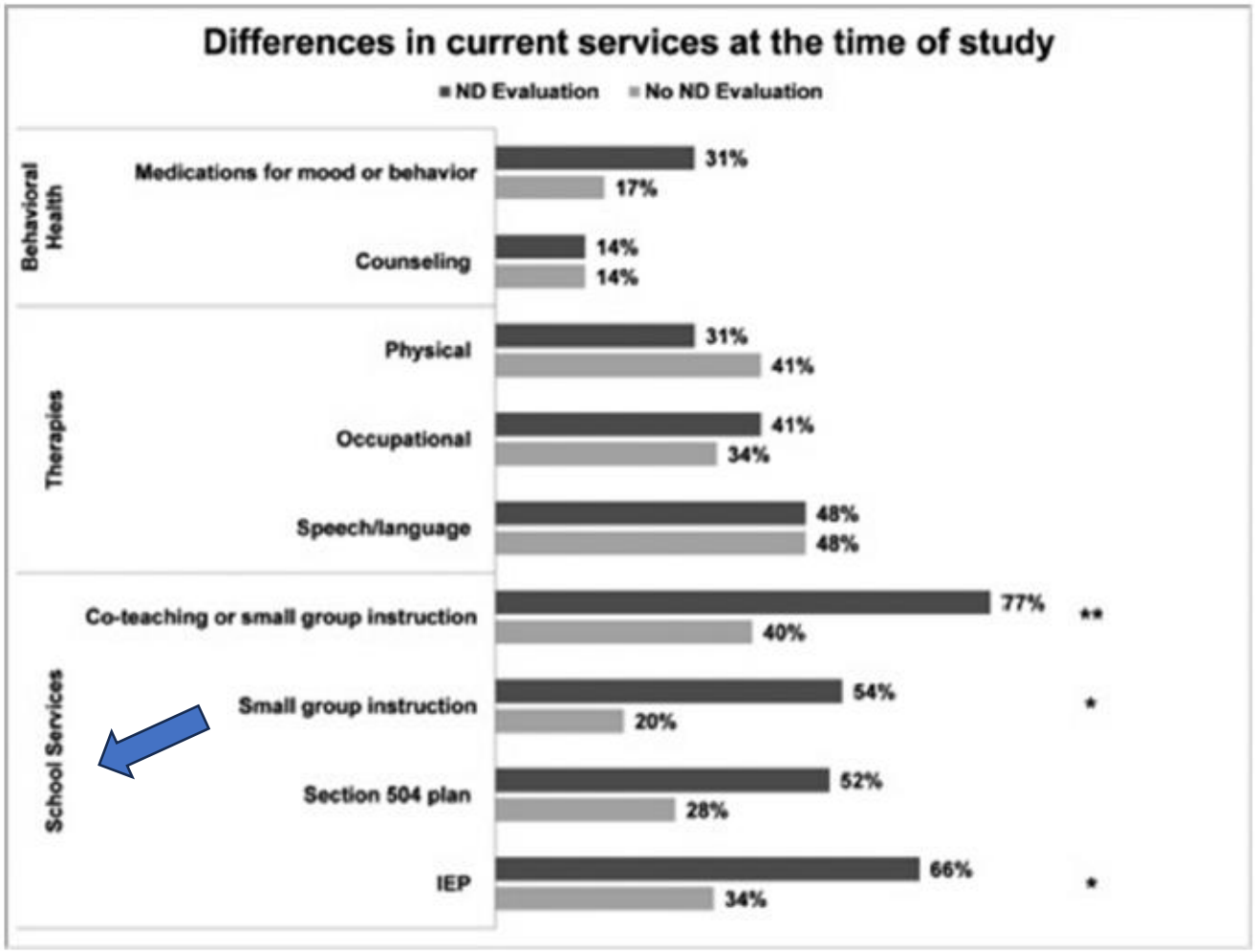
Cassidy et al., 2018; Patel et al., 2023; Sanz et al., 2016; Tan et al., 2022



Loblein et al., 2023

Table 3. Third-Grade Educational Outcomes fo Congenital Heart Defects Versus Children Witho Structural Birth Defect

	No Structural Birth Defects (ref)	Congenital Heart Defect
End-of-grade tests: does not meet standards		
Reading	n=6302; 31.3%	n=2780; 39.9%
Math	n=6326; 21.1%	n=2798; 25.5%
Either	n=6341; 37.5%	n=2803; 44.6%
Both	n=6287; 14.8%	n=2775; 20.8%
Third-grade retention	n=6341; 2.0%	n=2803; 2.8%
Receipt of exceptional services	n=6341; 12.5%	n=2803; 20.5%



Cassidy et al., 2018; Alam et al., 2021; Oster et al., 2017

TABLE 3 K-SADS-PL Psychiatric Diagnoses of Adolescents With Sin

Psychiatric Diagnosis	All (n = 156)	
	Lifetime	Current
Any psychiatric disorder[a]	102 (65)**	71 (46)**
Anxiety disorders	55 (35)**	35 (22)*
Separation anxiety disorder	18 (12)*	11 (7)
Simple phobia	11 (7)	6 (4)
Social phobia/avoidant disorder	26 (17)**	13 (8)*
Generalized anxiety disorder	10 (6)	10 (6)
Panic disorder[b]	2 (1)	2 (1)
Obsessive-compulsive disorder[b]	5 (3)	2 (1)
Posttraumatic stress disorder[b]	1 (1)	0
Adjustment disorder with anxious mood[b]	2 (1)	1 (1)
Mood disorders	20 (13)	6 (4)
Major depressive disorder	8 (5)	2 (1)
Adjustment disorder with depressed mood	8 (5)	0
Dysthymia[b]	4 (3)	3 (2)
Depressive disorder NOS[b]	1 (1)	1 (1)

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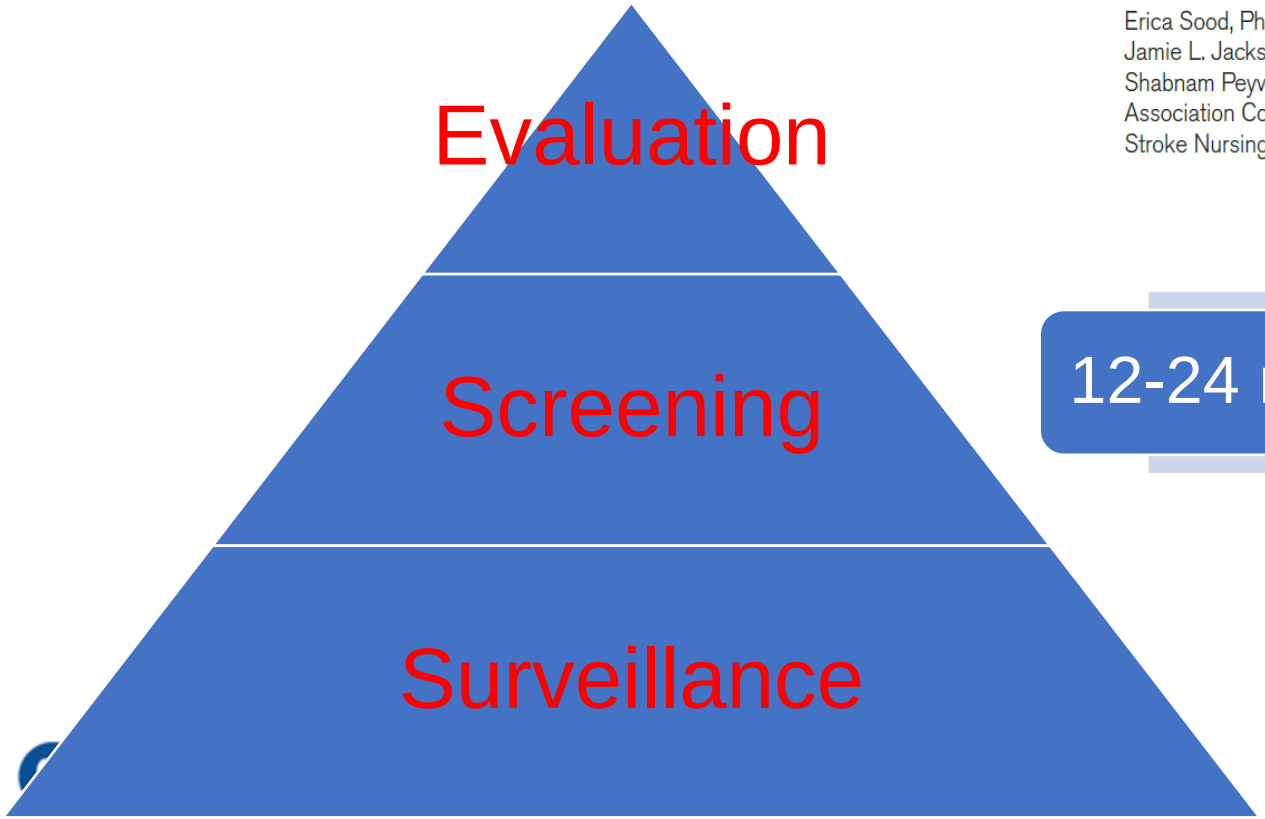
DeMaso et al., 2017

AHA SCIENTIFIC STATEMENT

Neurodevelopmental Outcomes for Individuals With Congenital Heart Disease: Updates in Neuroprotection, Risk-Stratification, Evaluation, and Management: A Scientific Statement From the American Heart Association

Endorsed by the Cardiac Neurodevelopmental Outcome Collaborative

Erica Sood, PhD, Vice Chair; Jane W. Newburger, MD, MPH, FAHA; Julia S. Anixt, MD; Adam R. Cassidy, PhD, ABPP; Jamie L. Jackson, PhD; Richard A. Jonas, MD; Amy J. Lisanti, PhD, RN, CCNS, FAHA; Keila N. Lopez, MD, MPH; Shabnam Peyvandi, MD, MAS, FAHA; Bradley S. Marino, MD, MPP, MSCE, MBA, FAHA, Chair; on behalf of the American Heart Association Council on Lifelong Congenital Heart Disease and Heart Health in the Young and the Council on Cardiovascular and Stroke Nursing



12-24 months

3-5 years

11-12 years

Effects of Implementing a Standardized Surveillance Program on Cardiac Neurodevelopmental Program Referral Completion

Heather Hennrick[1] · Elizabeth Miller[2] · Wyman W. Lai[2,3] · Viannae Carmona Nelkin[1] · Ana-Mercedes Flores[1] · Marissa Olson[2] · Dianne Kong[1] · Alexander Tan[1,2]

Items
1. Have you been told or were you concerned that your child was behind in learning to talk or walk?
2. Do you feel that your child has trouble with focusing or remembering things?
3. Are you or your child's teacher concerned about your child's ability to learn or their grades?
4. Are you concerned about your child's emotions or behaviors?
5. Would you like your child to be monitored for future problems?
6. Would you like your child to be considered for a Cardiac Neurodevelopmental Clinic evaluation?

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Hennrick et al., 2024

- Clinical Interview
- Test Administration
- Feedback and Recommendations
- Comprehensive Report

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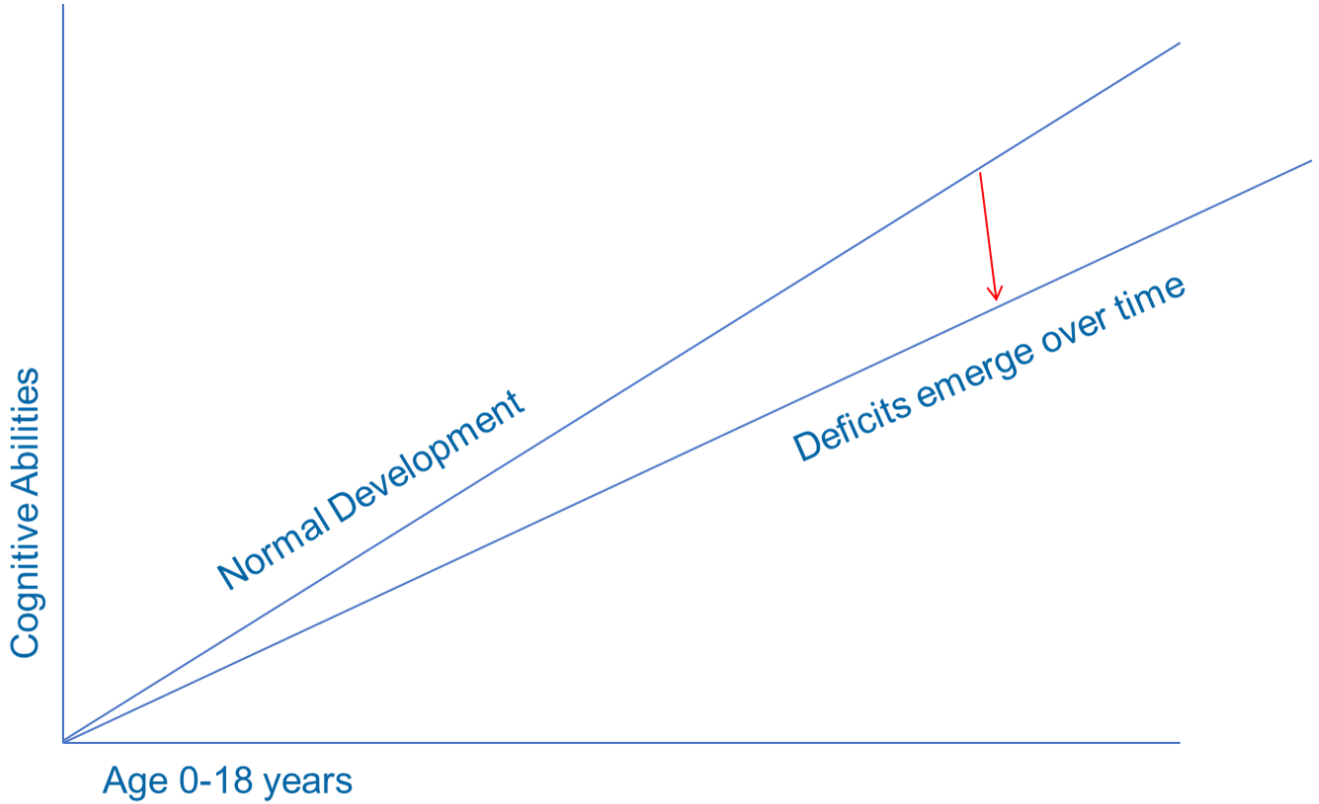
- Provide a cognitive profile of **strengths and weaknesses**
- Assess **brain integrity**
- Identify **relevant diagnoses**
- Orient the family toward **appropriate intervention**
- Monitor **change in performance over time**



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New surveillance program for congenital heart disease patients yields vast improvements in neurodevelopmental care

Published on: September 29, 2022
Last updated: September 29, 2022

The Cardiac Neurodevelopmental Clinic (CNC) at CHOC's Heart Institute is helping patients like Grace make vast improvements with their neurodevelopment.

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Surveillance program for patients with congenital heart disease a success

Published on: June 10, 2024
Last updated: October 8, 2024

In novel program, congenital heart disease patients are being monitored at CHOC for longtime success.

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Cardiac Neurodevelopmental Outcome Collaborative

"The Cardiac Neurodevelopmental Outcome Collaborative was founded in 2016; its mission is to determine and implement best practices of neurodevelopmental and psychosocial services for individuals with paediatric and congenital heart disease and their families through clinical, quality improvement, and research initiatives."

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52	1,410	73
Hospitals and Universities	Clinicians and Researchers	Patients and Family Members

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Latest in Cardiac Neurodevelopment

CLINICAL REGISTRY
All About the Heart-Brain Connection

PATIENTS AND FAMILIES
What to Know and How to Get Involved

SCIENTIFIC SESSIONS
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SPECIAL INTEREST GROUPS
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STANDING COMMITTEES

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COMMUNICATIONS

COMMUNITY OUTREACH

DATABASE AND IMPLEMENTATION

DIVERSITY, EQUITY AND INCLUSION

FINANCE COMMITTEE

LEARNING AND RESOURCE

PROGRAM AND MEETINGS

PUBLICATIONS

QUALITY IMPROVEMENT

RESEARCH

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