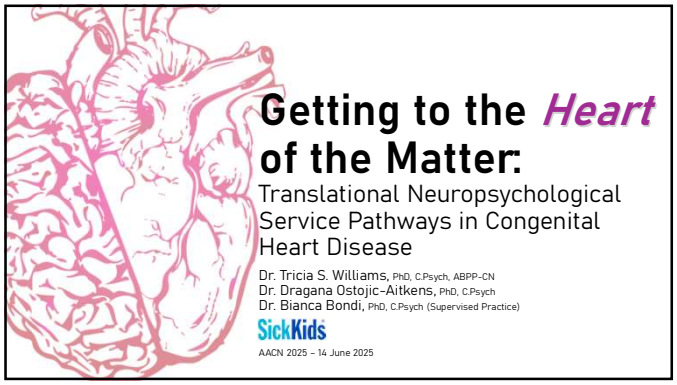

15
MINUTES
EVERY 15 MINUTES
a child is born with a
Congenital Heart Defect (CHD)

1


Getting to the Heart of the Matter:
Translational Neuropsychological Service Pathways in Congenital Heart Disease
Dr. Tricia S. Williams, PhD, C.Psych, ABPP-CN
Dr. Dragana Ostojic-Aitkens, PhD, C.Psych
Dr. Bianca Bondi, PhD, C.Psych (Supervised Practice)
SickKids
AACN 2025 – 14 June 2025

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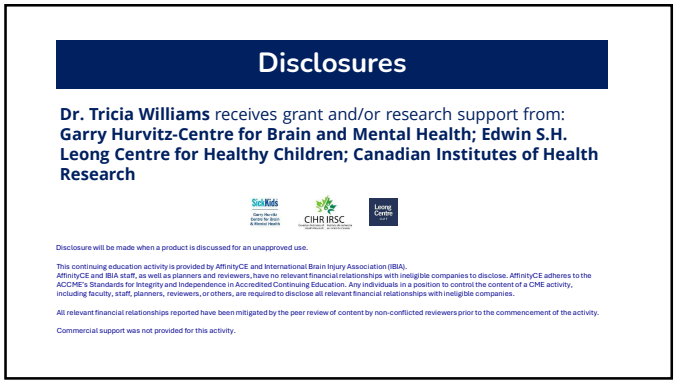
Disclosures
Dr. Tricia Williams receives grant and/or research support from: Garry Hurvitz-Centre for Brain and Mental Health; Edwin S.H. Leong Centre for Healthy Children; Canadian Institutes of Health Research
Disclosure will be made when a product is discussed for an unapproved use.
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Learning Objectives

1. Describe the epidemiological and pathophysiological underpinnings of congenital heart disease, including an overview of the brain-heart connection, comorbid neurological diagnoses, neuropsychological outcomes, and important neonatal, cardiac, operative, and hospitalization related risk factors.
2. Review emerging literature related to the influence of demographic, psychosocial, familial, and sociocultural factors, including social determinants of health, in congenital heart disease, to inform accurate prognoses and precision-based interventions.
3. Demonstrate specific translational science initiatives addressing neuropsychological assessment and surveillance inequities through innovations across Canadian institution, including initiatives that actively embed Fuji's ECLECTIC model centrally within models of neuropsychological services.

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Learning Objectives

1. Describe the anatomy, physiology, and the spectrum of CHD & the Heart Brain Connection

Dr. Dragana Ostojic-Aitkens
PhD, C.Psych

2. List common neurodevelopmental, neuropsychological & psychosocial outcomes

Dr. Bianca Bondi
PhD, C.Psych (Supervised Practice)

3. Apply directions for research and practice to optimize brain health

Dr. Tricia Williams
PhD, C.Psych, ABPP-CN

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Assess **Overarching EDI factors** across all objectives

- Well established disparities in maternal and neonatal services by race and socioeconomic status and their association with neonatal mortality and morbidities (van Daalen et al., 2024)
- Proximal variables related to birth outcomes include access/entry into prenatal and neonatal care, employment opportunities, neighborhood characteristics (Alhusen et al., 2016)
- Neonatal & neuropsychological services also follow-up services lack consistency, accessibility, and cultural humility (Fraiman et al., 2023; Miller et al., 2021)
- Variable access to evaluations by neuropsychologists, occupational therapists or developmental pediatricians depending on factors such as location (Litt et al., 2020).

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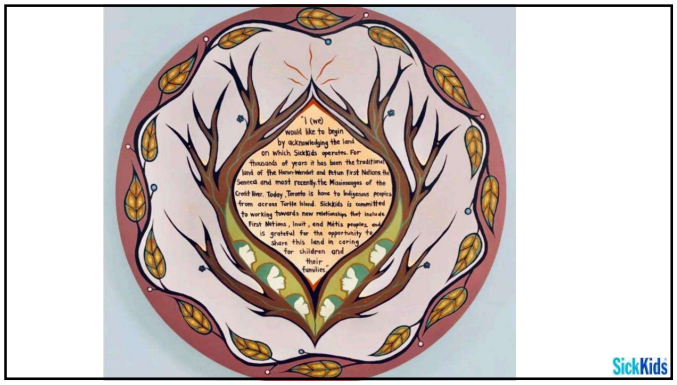
"I (we)
would like to begin
by acknowledging the land
on which SickKids operates. For
thousands of years it has been the traditional
land of the Huron-Wendat and Anishnawbe First Nations the
Haudenosaunee Confederacy and most recently, the Mississaugas of the
Credit River. Today, Toronto is home to Indigenous peoples
from across Turtle Island. SickKids is committed
to working towards new relationships that include
First Nations, Inuit, and Métis peoples, and
is grateful for the opportunity to
share this land in caring
for children and
their
families."
SickKids

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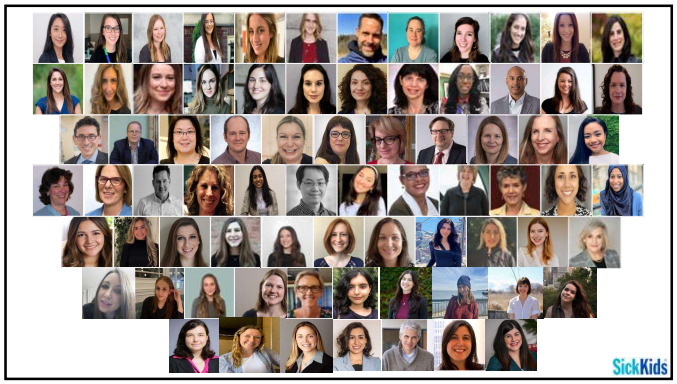
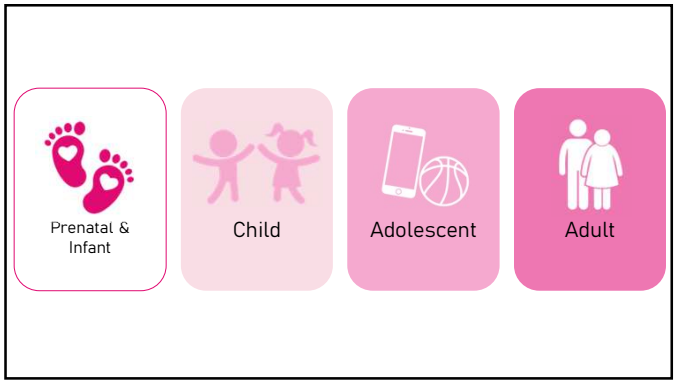

SickKids

8


Prenatal & Infant
Child
Adolescent
Adult

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Circulation

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

Circulation. 2024;149:e997–e1022. DOI: 10.1161/CIR.0000000000001211 March 26, 2024 e997

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CNOC
Cardiac Neurodevelopmental Outcome Collaborative

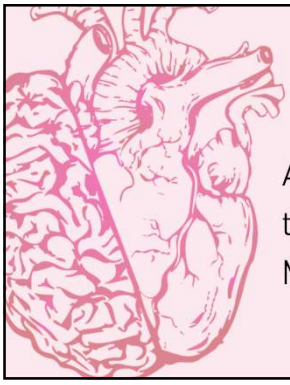
Home | About | Awards | Clinical Registry | Membership | Scientific Sessions | Quick Links | Donate

Working Together to Optimize Neurodevelopment and Quality of Life

Cardiac neurodevelopment includes all aspects of motor, language, cognitive, social-emotional, and psychological development throughout life for individuals with pediatric and congenital heart disease. Children with heart disease can have challenges in one or more of these areas. While some of these challenges are picked up during infancy or early childhood, others may not develop until later childhood, adolescence, or even adulthood. CNOC is a collaborative of clinicians, researchers, patients, and families from across the world working together to address these challenges and improve neurodevelopment, mental health, and quality of life for people of all ages and stages with pediatric and congenital heart disease.

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

11



Anatomy, Physiology, and the Spectrum of CHD: A Medical Overview

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What is CHD?

Abnormalities in the development of the heart
(chambers, walls, valves, or nearby blood vessels)

Among the most common birth defects

Different types depending on which part is impacted

Cassidy et al., 2018

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Causes of CHD: Risk Factors

Maternal illness or infection

Maternal drug/alcohol consumption

Environmental exposures/ pollutants

Genetic conditions

Heart and Stroke Foundation of Canada; Peyvandi et al., 2020; Patt et al., 2023; Sood et al., 2024

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Genetic Influences

Canadian Journal of Cardiology

The Genetics of Neurodevelopment in Congenital Heart Disease

Established genetic syndromes with both CHD and NDD	Genetic modifiers of neurodevelopment in syndromes	Genetic associations of neurodevelopement in non-syndromic CHD
Trisomy 21	*RUNX1* *DYRK1*	Genes with rare variant associations: *FLT4* *NOTCH1* *HAND1* *HAND2* *COUP1F* *RBPJK2* *CHD7** *CHD8** *KMT2D** *PTPN11** *SOS1** Genes with common variant associations: *APOE* *MIB.2*
Trisomy 18	*TGIF*	
22q11.2 deletion syndrome	*HIRA* *NR3C1* *TBX-1* *COMT* *PRODH* *DGCR8*	
Noonan Syndrome	*PTPN11** *RAF1* *SOS1** *KRAS* *LZTR1*	
Costello Syndrome	*HRAS*	
Cardio-facio-cutaneous Syndrome	*BRAF* *HRAS* *MAP2K1* *MAP2K2*	
CHARGE Syndrome	*CHD7**	
Mowat-Wilson Syndrome	*ZEB2**	
Kabuki Syndrome	*KMT2D**	

*genes implicated in both with or without an established genetic syndrome

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Heart Anatomy: Blood Flow

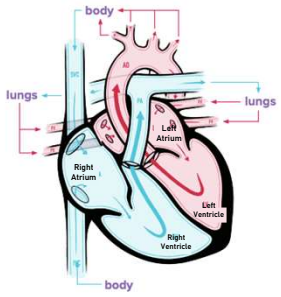

Image: Western Canadian Children's Heart Network
(https://wcchn.ca/parents-familles/chd-knowledge-information-hub/heart-diagrams-and-learning-tools/)

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Heart Anatomy: Veins & Arteries

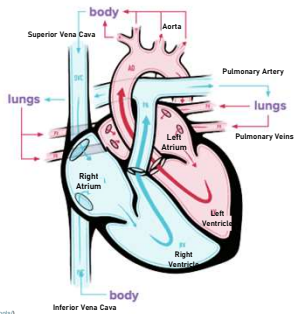

Image: Western Canadian Children's Heart Network
(https://wcchn.ca/parents-familles/chd-knowledge-information-hub/heart-diagrams-and-learning-tools/)

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Heart Anatomy: Valves

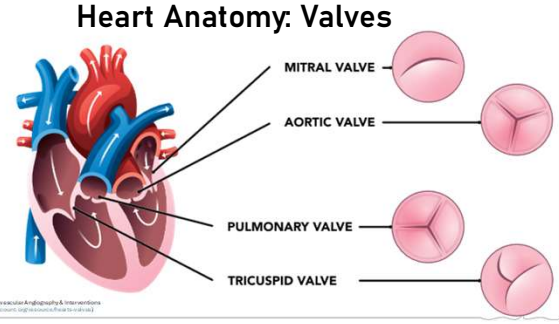

Image: Society for Cardiovascular Angiography & Interventions
(https://www.scai.org/resource/how-to-valves)

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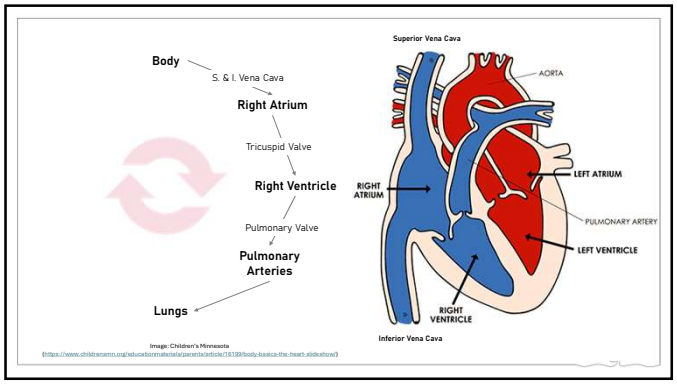
Body
S. & I. Vena Cava
Right Atrium
Tricuspid Valve
Right Ventricle
Pulmonary Valve
Pulmonary Arteries
Lungs
Superior Vena Cava
AORTA
LEFT ATRIUM
RIGHT ATRIUM
PULMONARY ARTERY
LEFT VENTRICLE
RIGHT VENTRICLE
Inferior Vena Cava
Image: Children's Minnesota
(https://www.childrensmn.org/educationmaterials/parents/article/16199/body-basics-the-heart-slideshow/)

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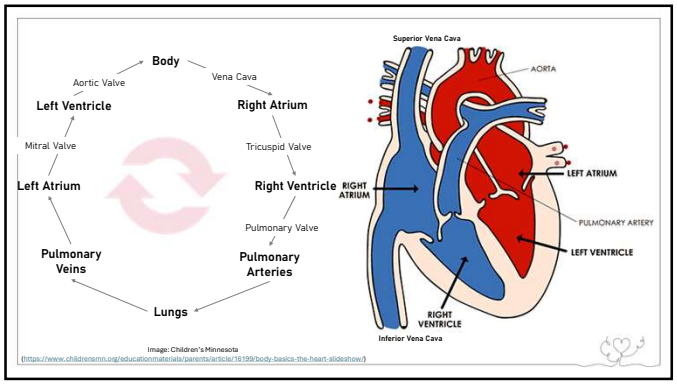
Body
Aortic Valve
Left Ventricle
Mitral Valve
Left Atrium
Pulmonary Veins
Lungs
Vena Cava
Right Atrium
Tricuspid Valve
Right Ventricle
Pulmonary Valve
Pulmonary Arteries
Superior Vena Cava
AORTA
LEFT ATRIUM
RIGHT ATRIUM
PULMONARY ARTERY
LEFT VENTRICLE
RIGHT VENTRICLE
Inferior Vena Cava
Image: Children's Minnesota
(https://www.childrensmn.org/educationmaterials/parents/article/16199/body-basics-the-heart-slideshow/)

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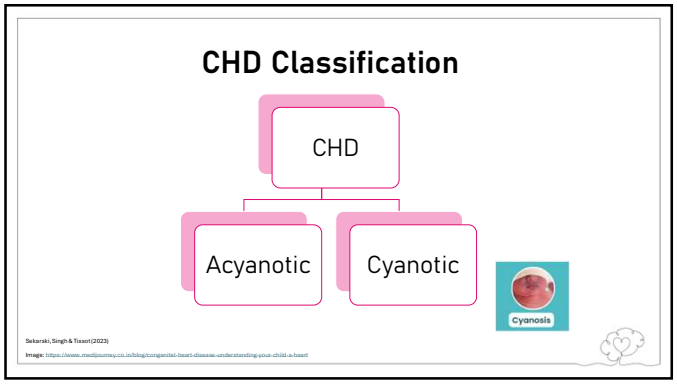
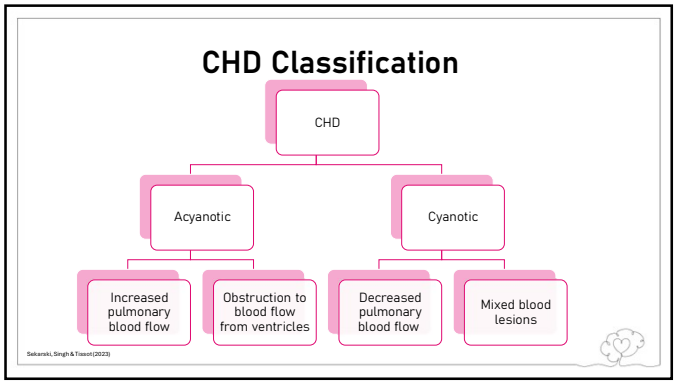
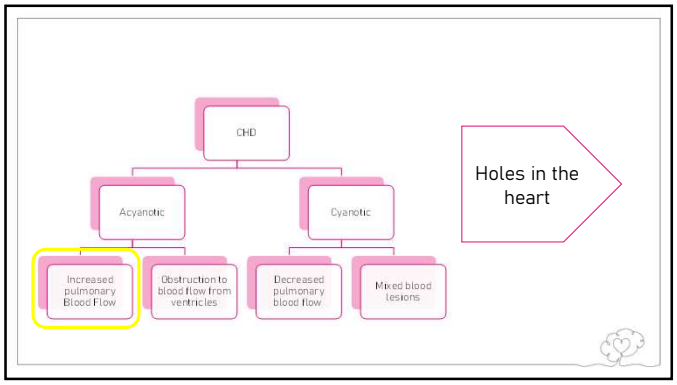

CHD Classification
CHD
Acyanotic
Cyanotic
Cyanosis
Sekarski, Singh & Tissot (2023)
Image: https://www.medijourney.co.in/blog/congenital-heart-disease-understanding-your-child-s-heart

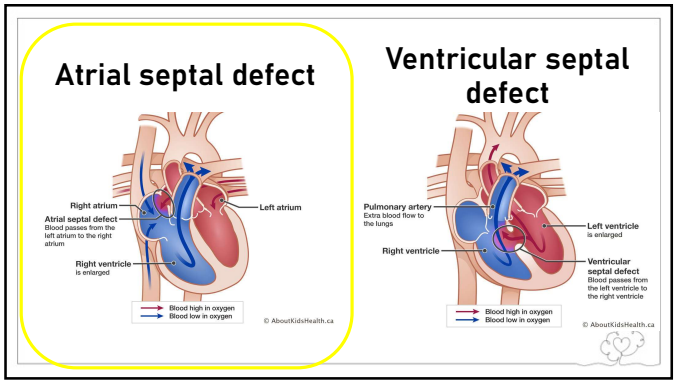
21


CHD Classification
CHD
Acyanotic
Cyanotic
Increased pulmonary blood flow
Obstruction to blood flow from ventricles
Decreased pulmonary blood flow
Mixed blood lesions
Sekarski, Singh & Tissot (2023)

22


CHD
Acyanotic
Cyanotic
Increased pulmonary Blood Flow
Obstruction to blood flow from ventricles
Decreased pulmonary blood flow
Mixed blood lesions
Holes in the heart

23


Atrial septal defect
Right atrium
Left atrium
Atrial septal defect
Blood passes from the left atrium to the right atrium
Right ventricle
is enlarged
Blood high in oxygen
Blood low in oxygen
© AboutKidsHealth.ca
Ventricular septal defect
Pulmonary artery
Extra blood flow to the lungs
Left ventricle
is enlarged
Right ventricle
Ventricular septal defect
Blood passes from the left ventricle to the right ventricle
Blood high in oxygen
Blood low in oxygen
© AboutKidsHealth.ca

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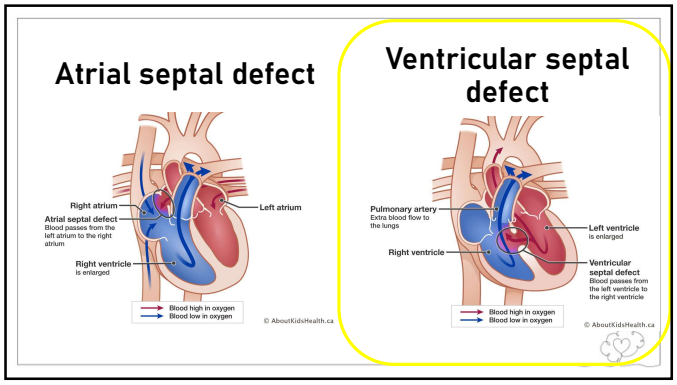
Atrial septal defect
Right atrium
Left atrium
Atrial septal defect
Blood passes from the left atrium to the right atrium
Right ventricle
is enlarged
Blood high in oxygen
Blood low in oxygen
© AboutKidsHealth.ca
Ventricular septal defect
Pulmonary artery
Extra blood flow to the lungs
Left ventricle
is enlarged
Right ventricle
Ventricular septal defect
Blood passes from the left ventricle to the right ventricle
Blood high in oxygen
Blood low in oxygen
© AboutKidsHealth.ca

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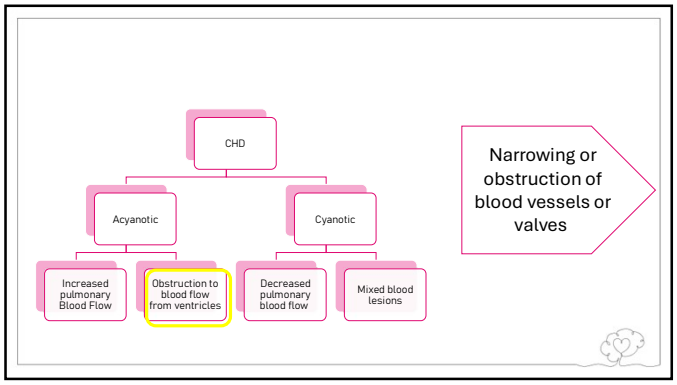
CHD
Acyanotic
Cyanotic
Increased pulmonary Blood Flow
Obstruction to blood flow from ventricles
Decreased pulmonary blood flow
Mixed blood lesions
Narrowing or obstruction of blood vessels or valves

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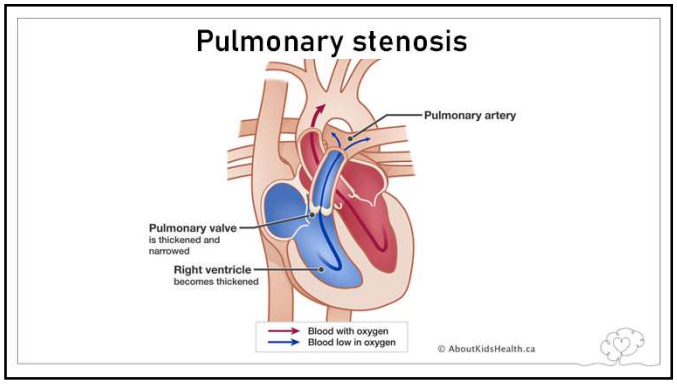
Pulmonary stenosis
Pulmonary artery
Pulmonary valve
is thickened and narrowed
Right ventricle
becomes thickened
Blood with oxygen
Blood low in oxygen
© AboutKidsHealth.ca

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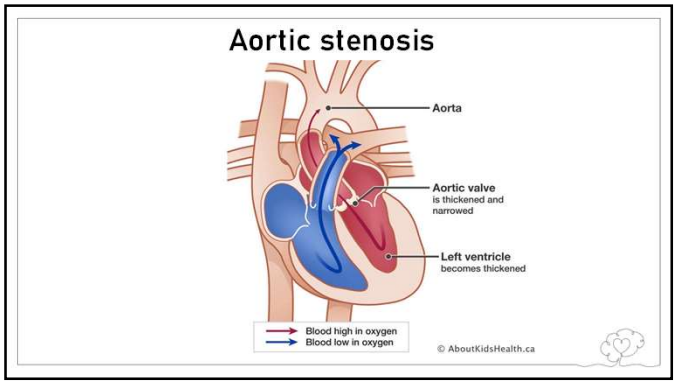
Aortic stenosis
Aorta
Aortic valve
is thickened and narrowed
Left ventricle
becomes thickened
Blood high in oxygen
Blood low in oxygen
© AboutKidsHealth.ca

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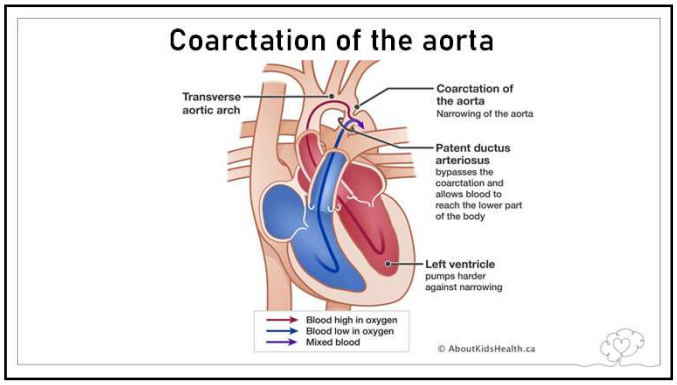
Coarctation of the aorta
Transverse aortic arch
Coarctation of the aorta
Narrowing of the aorta
Patent ductus arteriosus
bypasses the coarctation and allows blood to reach the lower part of the body
Left ventricle
pumps harder against narrowing
Blood high in oxygen
Blood low in oxygen
Mixed blood
© AboutKidsHealth.ca

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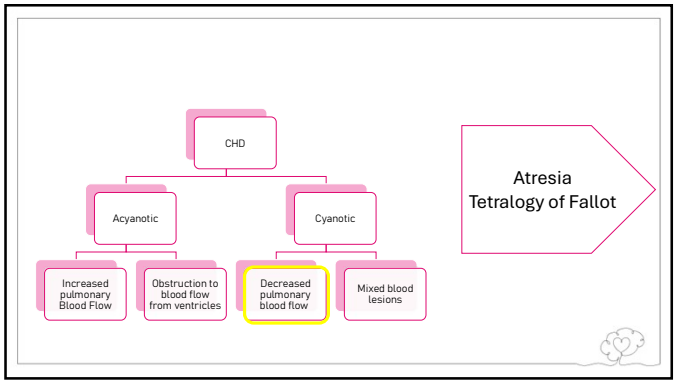
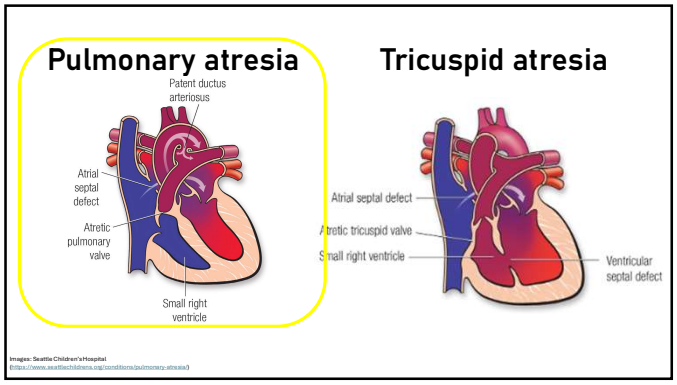

CHD
Acyanotic
Cyanotic
Increased pulmonary Blood Flow
Obstruction to blood flow from ventricles
Decreased pulmonary blood flow
Mixed blood lesions
Atresia
Tetralogy of Fallot

30


Pulmonary atresia
Patent ductus arteriosus
Atrial septal defect
Atretic pulmonary valve
Small right ventricle
Tricuspid atresia
Atrial septal defect
Atretic tricuspid valve
Small right ventricle
Ventricular septal defect
Images: Seattle Children's Hospital
(https://www.seattlechildrens.org/conditions/pulmonary-atresia/)

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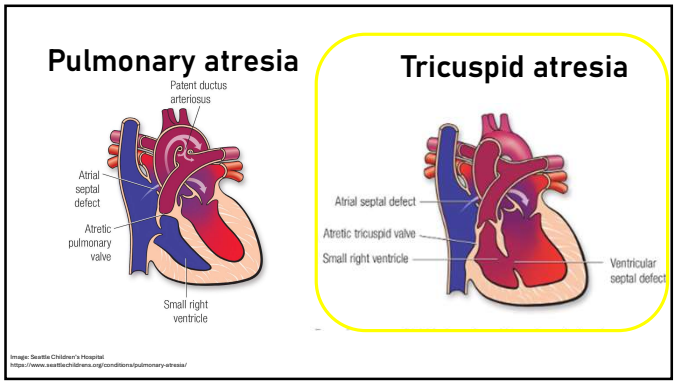
Pulmonary atresia
Patent ductus arteriosus
Atrial septal defect
Atretic pulmonary valve
Small right ventricle
Tricuspid atresia
Atrial septal defect
Atretic tricuspid valve
Small right ventricle
Ventricular septal defect
Image: Seattle Children's Hospital
https://www.seattlechildrens.org/conditions/pulmonary-atresia/

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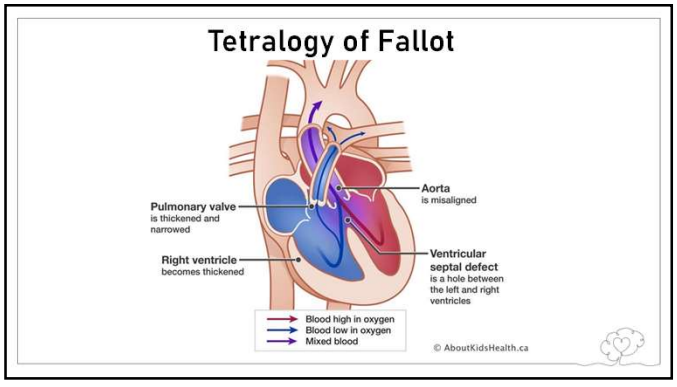
Tetralogy of Fallot
Pulmonary valve is thickened and narrowed
Right ventricle becomes thickened
Aorta is misaligned
Ventricular septal defect is a hole between the left and right ventricles
Blood high in oxygen
Blood low in oxygen
Mixed blood
© AboutKidsHealth.ca

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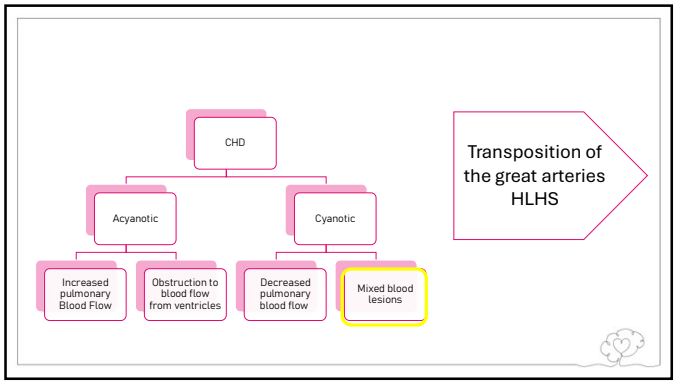
CHD
Acyanotic
Cyanotic
Increased pulmonary Blood Flow
Obstruction to blood flow from ventricles
Decreased pulmonary blood flow
Mixed blood lesions
Transposition of the great arteries HLHS

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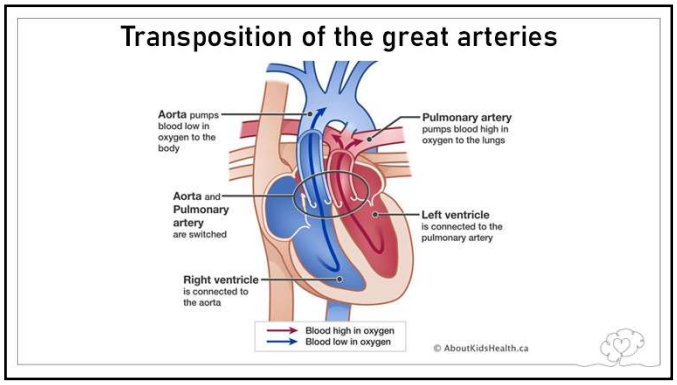
Transposition of the great arteries
Aorta pumps blood low in oxygen to the body
Pulmonary artery pumps blood high in oxygen to the lungs
Aorta and Pulmonary artery are switched
Left ventricle is connected to the pulmonary artery
Right ventricle is connected to the aorta
Blood high in oxygen
Blood low in oxygen
© AboutKidsHealth.ca

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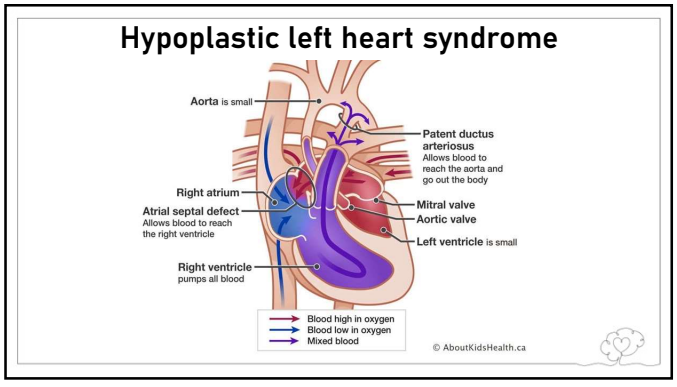
Hypoplastic left heart syndrome
Aorta is small
Patent ductus arteriosus
Allows blood to reach the aorta and go out the body
Right atrium
Atrial septal defect
Allows blood to reach the right ventricle
Mitral valve
Aortic valve
Left ventricle is small
Right ventricle pumps all blood
Blood high in oxygen
Blood low in oxygen
Mixed blood
© AboutKidsHealth.ca

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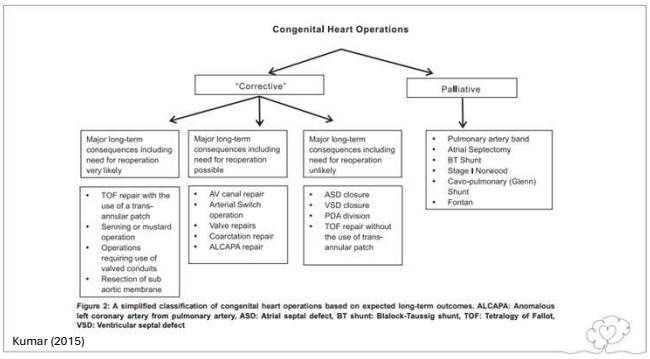

Kumar (2015)

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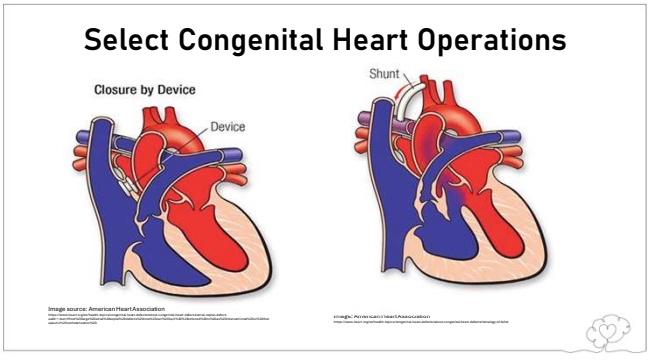

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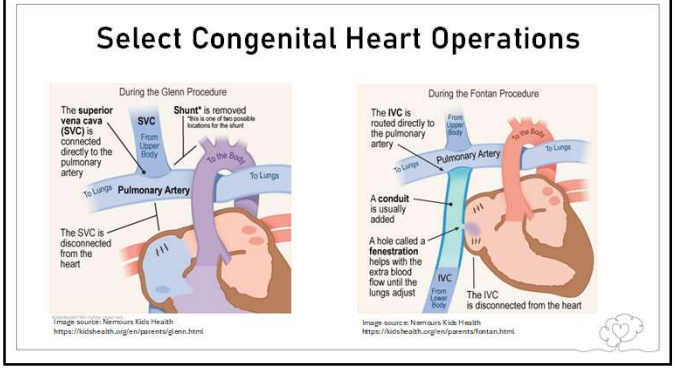

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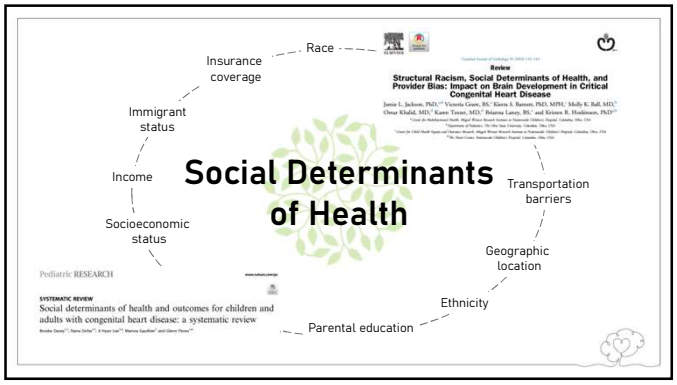
Race
Insurance coverage
Immigrant status
Income
Socioeconomic status
Social Determinants of Health
Transportation barriers
Geographic location
Ethnicity
Parental education
Review
Structural Racism, Social Determinants of Health, and Provider Bias: Impact on Brain Development in Critical Congenital Heart Disease
Pediatric RESEARCH
SYSTEMATIC REVIEW
Social determinants of health and outcomes for children and adults with congenital heart disease: a systematic review

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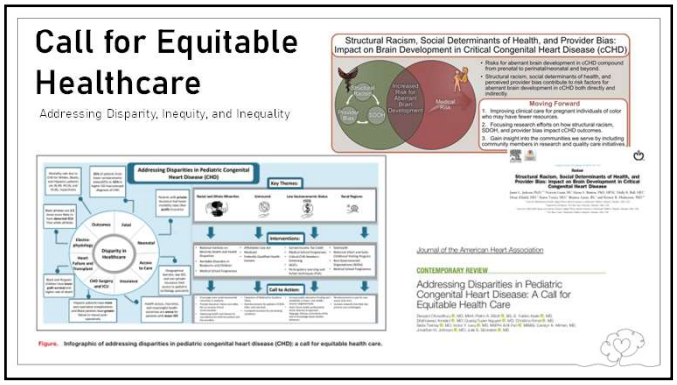
Call for Equitable Healthcare
Addressing Disparity, Inequity, and Inequality
Structural Racism, Social Determinants of Health, and Provider Bias: Impact on Brain Development in Critical Congenital Heart Disease (cCHD)
Moving Forward
1. Improving clinician care for pregnant individuals of color who may have fewer visits.
2. Focusing research efforts on how structural racism, SDOH, and provider bias impact cCHD outcomes.
3. Gain insight into the communities we serve by including community members in research and quality care initiatives.
Addressing Disparities in Pediatric Congenital Heart Disease (CHD)
Key Themes
Interventions
Call to Action
Journal of the American Heart Association
CONTEMPORARY REVIEW
Addressing Disparities in Pediatric Congenital Heart Disease: A Call for Equitable Health Care
Figure. Infographic of addressing disparities in pediatric congenital heart disease (CHD): a call for equitable health care.

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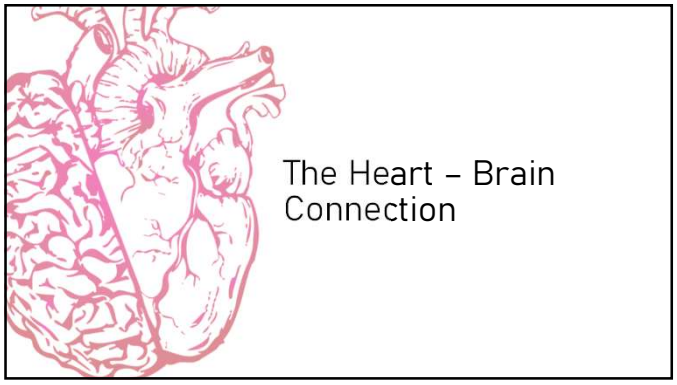
The Heart – Brain Connection

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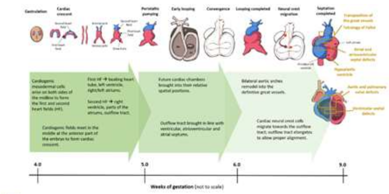
Development of the Heart



genes

MDPI

Review

The Role of Epigenetics in Congenital Heart Disease

- Onset of heart development is in early gestational period
- Heart is the first functional organ to develop
- Brain development co-occurs, but extends well into the third trimester and postnatally

Cassidy et al. 2018; Peyvandi and Rollins, 2023

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Fetal Brain

Table 1. Common brain abnormalities noted on MRI among fetuses and/or neonates with complex congenital heart disease

Domain: MRI modality	Abnormality
Qualitative brain development: visual inspection	• Ventriculomegaly/asymmetry[22] • Dysmature myelination[13,65] • Delayed sulcation[13,65]
Brain volumes: morphometry	• ↓ Global and regional brain volumes[14,19,21,23]
Microstructural brain development: diffusion tensor imaging	• ↑ Apparent diffusion coefficient[12] • ↓ Fractional anisotropy[12]
Metabolic brain development: spectroscopy	• ↓ N-acetyl aspartate–choline ratio[14] • ↑ Lactate[14]
Oxygenation/nutrient delivery: Functional MRI, cardiovascular MRI	• ↓ Oxygen consumption[44] • ↓ Oxygen delivery[44] • ↓ Tissue oxygenation[27,28]

↓, Decreased; ↑, Increase. MRI, magnetic resonance imaging.

Review

Fetal Brain Development in Congenital Heart Disease

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Fetal Brain

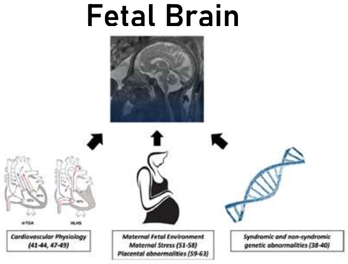

Figure 3. Contributors to delayed brain development *in utero*. The etiology of prenatal delayed brain development in congenital heart disease is thought to be multifactorial with contributions from cardiovascular physiology, genetic differences, and an adverse maternal-fetal environment. d-TGA, dextro-transposition of the great arteries; HLHS, hypoplastic left heart syndrome.

Peyvandi and Rollins, 2023

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Infant Brain

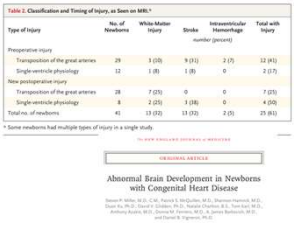
Table 2. Classification and Timing of Injury, as Seen on MRI.*

Type of Injury	No. of Newborns	White-Matter Injury	Stroke	Intraventricular Hemorrhage	Total with Injury
		number (percent)			
Preoperative injury					
Transposition of the great arteries	29	3 (10)	9 (31)	2 (7)	12 (41)
Single-ventricle physiology	12	1 (8)	1 (8)	0	2 (17)
New postoperative injury					
Transposition of the great arteries	28	7 (25)	0	0	7 (25)
Single-ventricle physiology	8	2 (25)	1 (38)	0	4 (50)
Total no. of newborns	41	13 (32)	11 (32)	2 (5)	25 (61)

* Some newborns had multiple types of injury in a single study.

ORIGINAL ARTICLE

Abnormal Brain Development in Newborns with Congenital Heart Disease

- Brain dysmaturation increases risk for neonatal brain injury (e.g., white matter injury, microhemorrhage, ischemic lesions)
- Widespread brain abnormalities and injury) pre- and post-surgery
- Focal brain injuries are the "tip of the iceberg" – some neurodevelopmental sequelae unexplained

Mahle et al., 2002; Marelli et al., 2016; Miller et al., 2017; Peyvandi and Rollins, 2023

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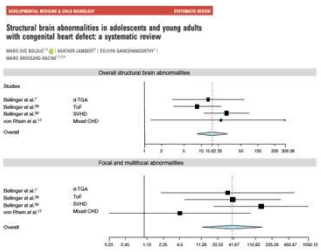
Child and Adolescent Brain


Structural brain abnormalities in adolescents and young adults with congenital heart defect: a systematic review

Overall structural brain abnormalities

Focal and multifocal abnormalities

- More likely to have brain abnormalities than typically developing peers
- Delayed volumetric brain growth
- Alterations in cortical organization
- Difference in white matter microstructural integrity and organization
- Focal/multi-focal abnormalities

Bolduc et al., 2018; Bonthrone et al., 2021; Brossard-Racine and Panigrahy, 2023; Marelli et al., 2017

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Aging Brain in CHD

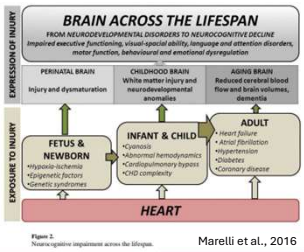

Figure 2.
Neurocognitive impairment across the lifespan.

Marelli et al., 2016

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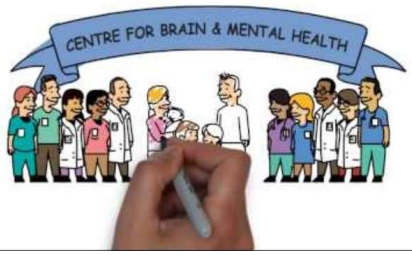

Video: The Hospital for Sick Children Centre for Brain and Mental Health (https://www.youtube.com/watch?v=UlLqvUdVrv5c)

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Neurodevelopmental & Neuropsychological Outcomes of CHD

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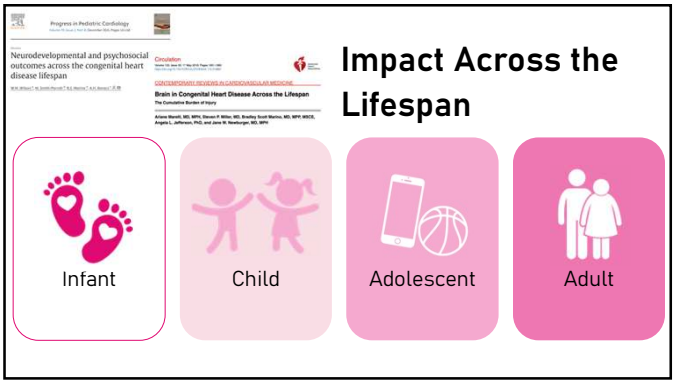

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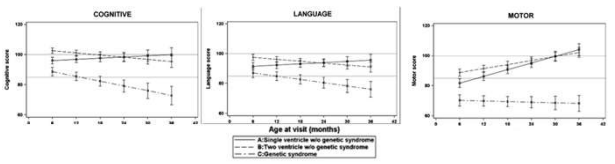
Infant

- Cognitive, speech/language, and motor delays

PEDIATRICS

Risk and Prevalence of Developmental Delay in Young Children With Congenital Heart Disease

75% had developmental delay in ≥1 domain at ≥1 assessments



52

Infant

- Cognitive, speech/language, and motor delays

PEDIATRICS

Neurodevelopmental Outcomes After Cardiac Surgery in Infancy

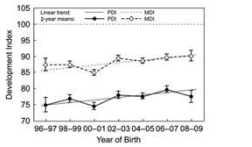


FIGURE 2
Standardized PDI and MDI means by year of birth. The standardized means plot the predicted PDIs and MDIs and SE bars based on a model with year of birth category adjusting for center, cardiac class, and other statistically significant predictors at the mean value of the covariates. Overlaid are standardized means plots based on continuous year of birth. The horizontal dotted line represents the normative mean of 100 for both PDI and MDI.

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Risk Factors in Infancy:

- Prematurity
- Low birth weight
- Feeding delay
- Growth failure
- Developmental delay in infancy/toddlerhood
- Need for neonatal cardiac surgery

Canadian Journal of Cardiology

The Genetics of Neurodevelopment in Congenital Heart Disease

(Cassidy et al., 2017; Patt et al., 2023; Sood et al., 2024)

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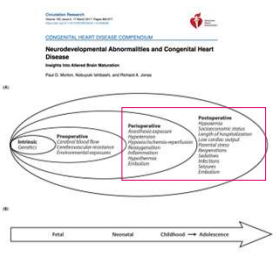
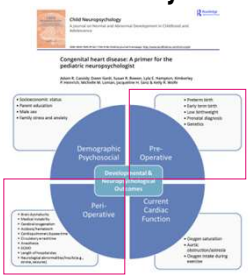
Operative Risk Factors in Infancy:





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Operative Risk Factors in Infancy:

(Morton et al., 2017; Cassidy et al., 2017; Sood et al, 2024)

Peri-Operative

- Anesthesia exposure
- Hypotension
- Hypoxia/ischemia-reperfusion
- Reoxygenation
- Inflammation
- Hypothermia
- Seizures
- Embolism, stroke
- Acidosis/hematocrit
- Cardiopulmonary bypass time
- Circulatory arrest time
- Cardiopulmonary resuscitation
- Mechanical support (ECMO, VAD)
- Heart transplantation

Post-Operative

- Hypoxemia
- Length of post-op hospitalization
- Low cardiac output
- Re-operations
- Sedative exposure
- Infections
- Seizures
- Embolism, stroke

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- Intellectual/cognitive functioning
- Speech-language
- Fine motor
- Academic achievement

Early Childhood

(Sood et al., 2024; Cassidy et al., 2017; Phillips et al., 2023)

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Childhood/Adolescence

- Intellectual/cognitive functioning
- Speech-language
- Motor
- Academic achievement
- Attention
- Executive functioning
- Processing speed
- Visuospatial processing
- Memory and learning

(Sood et al., 2024; Cassidy et al., 2017; Phillips et al., 2023)

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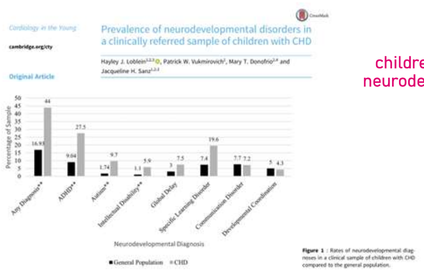
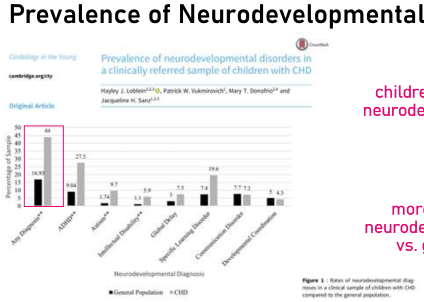
Prevalence of Neurodevelopmental Disorders



>50%
children aged 6+ received a neurodevelopmental diagnosis

59

Prevalence of Neurodevelopmental Disorders

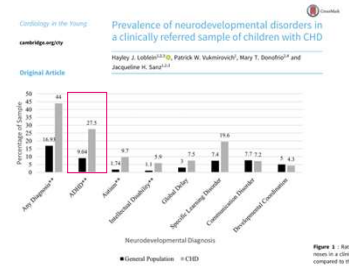


>50%
children aged 6+ received a neurodevelopmental diagnosis

5x
more likely to receive a neurodevelopmental diagnosis vs. general population

60

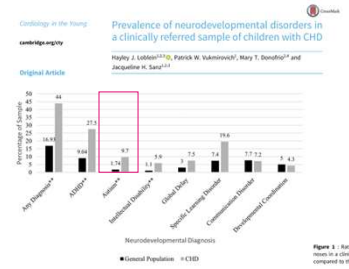
Prevalence of Neurodevelopmental Disorders



4x
more likely to receive an ADHD diagnosis vs. general population

61

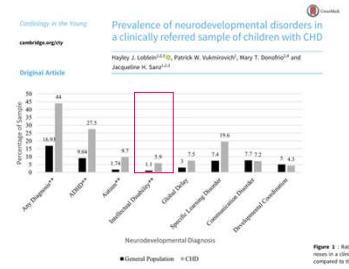
Prevalence of Neurodevelopmental Disorders



6x
more likely to receive an ASD diagnosis vs. general population

62

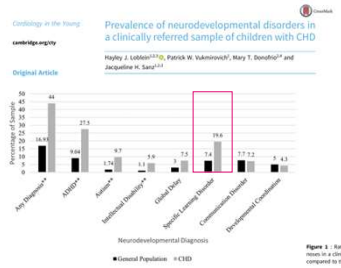
Prevalence of Neurodevelopmental Disorders



5x
more likely to receive an ID diagnosis vs. general population

63

Prevalence of Neurodevelopmental Disorders



3x
more likely to receive an LD diagnosis vs. general population

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Prevalence of Neurodevelopmental Disorders

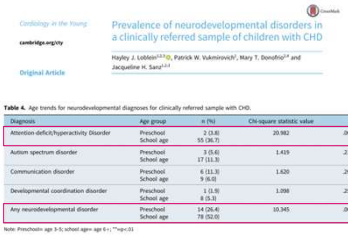

Table 4. Age trends for neurodevelopmental diagnoses for clinically referred sample with CHD.

Diagnosis	Age group	n (%)	Chi-square statistic value	p	Odds ratio
Attention-deficit/hyperactivity Disorder	Preschool School age	2 (3.8) 55 (36.7)	20.982	.001**	14.763
Autism spectrum disorder	Preschool School age	3 (5.6) 17 (11.3)	1.419	.234	2.130
Communication disorder	Preschool School age	6 (11.3) 9 (6.0)	1.620	.203	.500
Developmental coordination disorder	Preschool School age	1 (1.9) 8 (5.3)	1.098	.295	2.930
Any neurodevelopmental disorder	Preschool School age	14 (26.4) 78 (52.0)	10.345	.001**	3.018

Note: Preschool= age 3-5; school age= age 6-11 **p<.01

3x
more likely to receive a neurodevelopmental diagnosis in childhood/adolescence vs. preschool

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Risk Factors in Childhood/Adolescence

*"Neuropsychological profiles can **vary** and **do not** reliably conform to a singular pathognomonic **neurobehavioral signature**."*

- Sood et al., 2024 AHA

- Genetic abnormalities/ syndromes
- CHD type and severity
  - Surgery in infancy with cardiopulmonary bypass
  - Chronic cyanosis
  - Single-ventricle CHD
  - 3-stage surgical palliation vs. surgical correction
- Patient-specific factors

(Sood et al., 2024; Cassidy et al., 2017)

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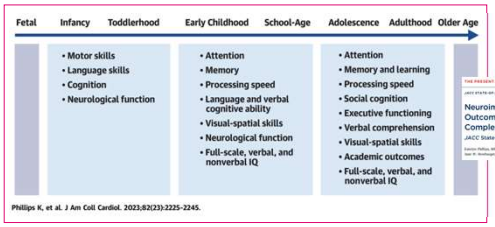
Cumulative Impact Across Development



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Adulthood

- Self management skills
- Disease management
- Educational attainment
- Employment status
- Economic self-sufficiency
- Early and late -onset dementia risk
- Impact to interpersonal relationships
- Quality of life
- Mental health

(Kovacs et al., 2020; Cohen et al., 2018; Wilson et al., 2015)

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Neuropsychological Profiles

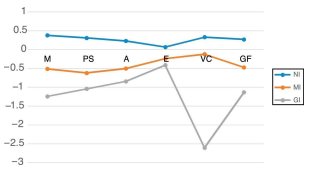

Figure 1 Mean performance of the three clusters in different neurocognitive domains. A: attention; EF: executive function; GF: global cognitive function; GI: globally impaired cluster; M: memory; MI: moderately impaired cluster; NI: non-impaired cluster; PS: processing speed; VC: visuoconstructive.

- Patients (age 12-30) with CHD had poorer neuropsychological profiles than healthy controls across all domains
- Three phenotypes:
  - NI – non-impaired
  - MI – moderately impaired
  - GI – globally impaired
- Phenotypes sensitive to social, neonatal, and psychological adjustment variables

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Neurodevelopmental Outcomes

2024 Scientific Statement from the American Heart Association

Table 1. Executive Summary of Key Updates

Section	Updates
Extent of the Problem	Updated information about survival rates and size of the affected population
	Updated information about change in neurodevelopmental outcomes over time
	Updated information about neurodevelopmental trajectories and impacts across the life span
Risk Categories for Developmental Delay or Disorder in Individuals With Congenital Heart Disease	Risk categories are now assigned sequentially from Risk Category 1 to 3 to 5
	Updated information that further supports Risk Categories 1 and 2
	Substantially revised Risk Category 3, requiring sequential clinical criteria assessment, including the need for intervention or hospitalization secondary to congenital heart disease and 1 or more factors that increase neurodevelopmental risk
	Removed Risk Category 4 (other conditions determined at the discretion of the medical home providers)
	Clarified that risk categories are intended to identify those individuals for whom congenital heart disease may have significantly contributed to their risk of developmental delay or disorder
Factors That Increase Neurodevelopmental Risk in Individuals With Congenital Heart Disease	Added new risk factors based on new knowledge (eg, fetal and perinatal factors, social and family factors, factors related to growth and development)
	Updated information about genetic predisposition and surgical and perioperative factors that support prior impressions
	Clarified that risk factors increase neurodevelopmental risk in individuals with congenital heart disease (ie, not only those in Risk Category 3)
	Added a new section on emerging risk factors
How to Protect Those at Risk for Developmental Delay or Disorder	Added a new section on promising neuroprotective strategies
Risk Stratification, Referral, and Evaluation	Updated the algorithm for risk stratification of individuals with congenital heart disease into high or low risk for developmental delay or disorder
	Updated the algorithm for referral, evaluation, and management of individuals at high risk
	Provided new content on individualized and culturally sensitive approaches to evaluation
	Added current recommendations by the Cardiac Neurodevelopmental Outcome Collaborative for age-based evaluation
	Added a new section on evaluation in adulthood
	Added a new section on evaluation through telehealth
	Added current recommendations by the American Academy of Pediatrics for developmental surveillance and screening
Management of Developmental Delay or Disorder in Individuals with Congenital Heart Disease	Updated information about management of developmental delay or disorder in infants, children, and adolescents
	Added a new section on management of neuropsychological deficits in adults

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Neurodevelopmental Outcomes

2024 Scientific Statement from the American Heart Association

Factors that Increase Risk

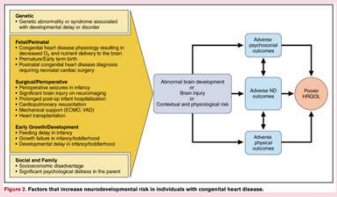

Figure 2. Factors that increase neurodevelopmental risk in individuals with congenital heart disease.

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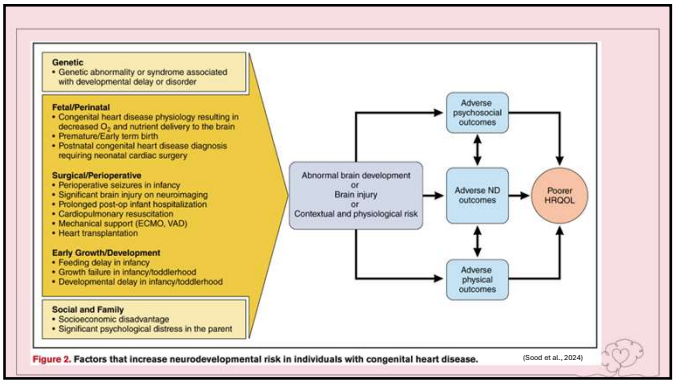

Figure 2. Factors that increase neurodevelopmental risk in individuals with congenital heart disease. (Sood et al., 2024)

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Neurodevelopmental Outcomes

2024 Scientific Statement from the American Heart Association


Circulation

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

Risk Stratification

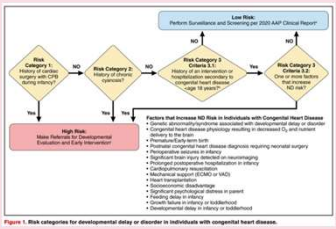

Figure 1. Risk categories for developmental delay or disorder in individuals with congenital heart disease.

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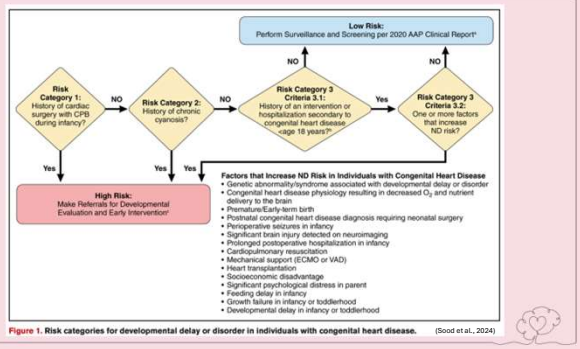

Figure 1. Risk categories for developmental delay or disorder in individuals with congenital heart disease. (Sood et al., 2024)

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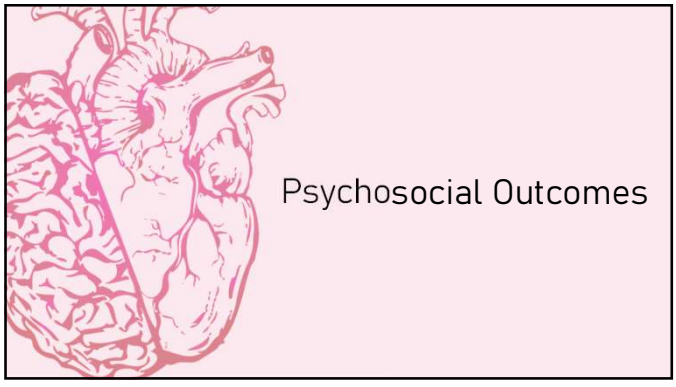

Psychosocial Outcomes

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Psychosocial Outcomes

(Sood et al., 2024; Cassidy et al., 2017; Kovacs et al., 2020; Cohen et al., 2018; Wilson et al., 2015)

Adaptive Functioning

Quality of Life

Health-related Overall

Mental Health/Internalizing

Depression Withdrawal

Anxiety Somatization

Behavioural/Externalizing

Aggression Defiance

ADHD Hyperactivity

Social

Social cognition ASD

Psychiatric

PTSD

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Psychosocial Outcomes

- Shared origins of psychological and neurodevelopmental outcomes
- Span across the lifespan – particular risk at adolescent/early adulthood transition
- Compounded challenges of adulthood

AHA SCIENTIFIC STATEMENT

Psychological Outcomes and Interventions for Individuals With Congenital Heart Disease: A Scientific Statement From the American Heart Association

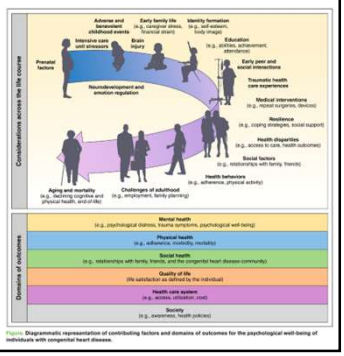

Figure. Diagrammatic representation of contributing factors and domains of outcomes for the psychological well-being of individuals with congenital heart disease.

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Psychosocial Outcomes

- Shared origins of psychological and neurodevelopmental outcomes
- Span across the lifespan – particular risk at adolescent/early adulthood transition
- Compounded challenges of adulthood

AHA SCIENTIFIC STATEMENT

Psychological Outcomes and Interventions for Individuals With Congenital Heart Disease: A Scientific Statement From the American Heart Association

- Self management skills
- Disease management
- Educational attainment
- Employment status
- Economic self-sufficiency
- Early and late -onset dementia risk
- Impact to interpersonal relationships
- Quality of life
- Mental health

(Kovacs et al., 2020; Cohen et al., 2018; Wilson et al., 2015)

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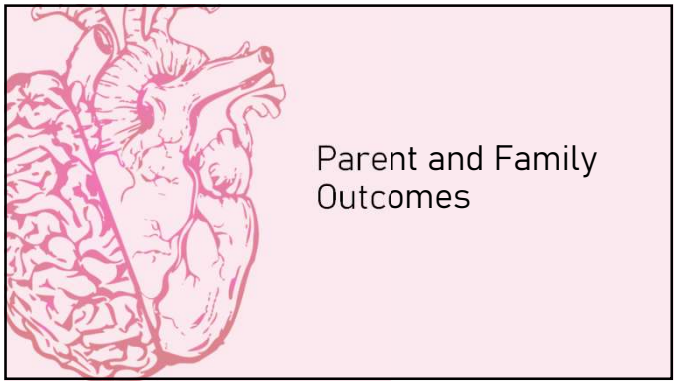

Parent and Family Outcomes

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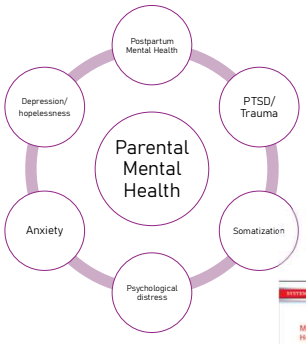

Impact on Parents & Caregivers

- High risk periods:
  - Time of diagnosis
  - Acutely following cardiac surgery
- Persist long-term

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Impact on Families

(Jackson et al., 2015, 2018; Wei et al., 2015; Alkan et al., 2017; Sood et al., 2021)

- Parent/Child Relationship
  - Responsivity
  - Attachment
- Parenting
  - Stress
  - Parenting style (authoritative, permissive)
  - Behaviours
- Family Stress/Coping
  - Finances
  - Routine interruptions
  - Communication
  - Conflict
  - Isolation
  - Childcare needs
- Family Quality of Life

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Moderating Factors of Neurodevelopmental, Psychosocial, Parent, and Family Outcomes

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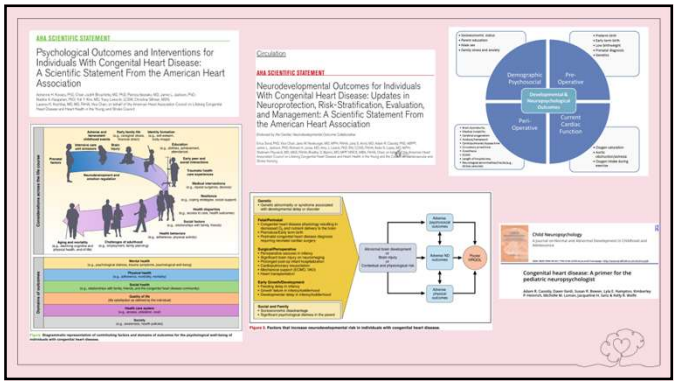

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Social Determinants of Health

- Several socioeconomic parameters were associated with neurodevelopment, independently of genetic syndrome
  - Household income
  - Unemployment
  - Low-income status

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Social Determinants of Health

- Lower SES associated with worse neurodevelopmental outcomes from early childhood through adolescence

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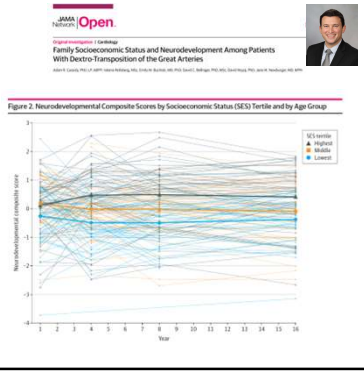
Social Determinants of Health

- Lower SES associated with worse neurodevelopmental outcomes from early childhood through adolescence



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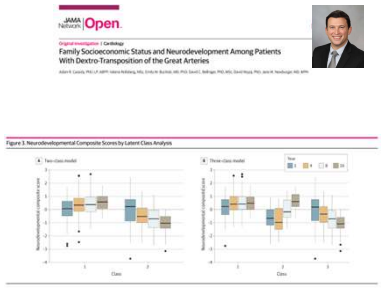
Social Determinants of Health

- Declining neurodevelopmental status over time associated with lower SES and younger maternal age at childbirth, and lower maternal IQ



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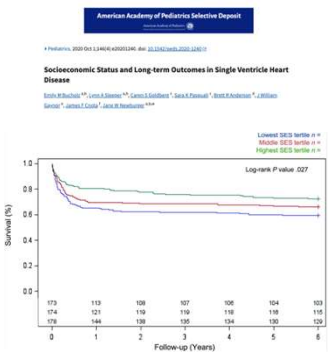
Social Determinants of Health

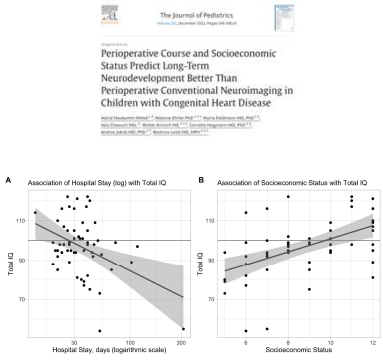
- **Lower SES** associated with increased risk of long-term mortality
- **Lower SES** associated with worse neurodevelopmental outcomes (adaptive behavior, problem-solving, fine motor, and communication skills) and functional status outcomes at 6 years-post Norwood



88

Social Determinants of Health

- Neither postoperative total brain volume nor perioperative brain injury severity predicted total IQ, but **SES** (P < .001) and **longer hospital stay** (P = .004) did



89

Directions for Research and Practice to Optimize Brain Health

90

"Critical next steps must include efforts to prevent and mitigate developmental delays and disorders."

- Sood et al., 2024 AHA

91

Prevention & Intervention Across the Lifespan

Prenatal & Infant

Child & Family

Older Child & Adolescent

92

Prenatal & Medical Protective Factors

Prenatal detection & preparation

Timing of delivery & delivery room practices

Timing of cardiac surgery

Good technical operation

Minimizing Cardiopulmonary Bypass

Monitoring of Cerebral Perfusion and Oxygen

Neurocardiac Collaborative care

93

Prenatal Psychological Support

"As soon as I heard, I stopped listening, everything was a blur"

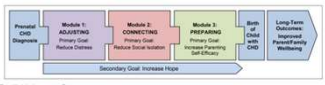


Figure 1. HEARTPrep Modular Intervention Design.

Partnering With Stakeholders to Inform the Co-Design of a Psychosocial Intervention for Prenatally Diagnosed Congenital Heart Disease

User-Centered Development of HEARTPrep, a Digital Health Psychosocial Intervention for Prenatally Diagnosed Congenital Heart Disease

"Participants appreciated the ability to just talk to someone who knew about congenital heart disease."

Erica Sood, PhD

94

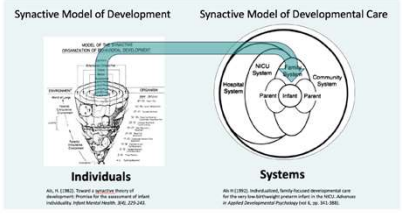
Individualized Developmental & Family-Centered Inpatient Care

"Parents weren't consistently holding their infants"
- Jones et al., 2025

95

Newborn Individualized Developmental Care and Assessment Program (NIDCAP)

Figure 1



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Increasing Individualized Developmental Care using NIDCAP for infants in Cardiac ICU

Individualized Family Centered Developmental Care: An Essential Model to Address the Unique Needs of Infants with Congenital Heart Disease

Caring for hearts and minds: a quality improvement approach to individualized developmental care in the cardiac intensive care unit

Samantha Butler, PhD

97

Supporting Transition from Hospital to Home

98

Neurodevelopmental Surveillance

CNOC Recommended Batteries

Figure 1. Congenital heart disease neurodevelopmental assessment domains for birth through 5 years of age.
*Denotes extended battery

99

Recommended CHD Test Domains

Table 3. Domains for Age-Based Developmental Evaluation

Age	Domain
Birth–5 y	Developmental history (milestones, feeding, sleep, therapies)
	Growth
	Cognitive
	Speech-language (receptive, expressive, sound production, social-pragmatic)
	Motor (fine, gross)
	School readiness
	Attention
	Executive functions
	Emotional and behavioral functioning
	Social skills
	Adaptive skills
School age and adolescence	Developmental and school history
	Intelligence
	Academic achievement
	Attention
	Executive functions
	Memory
	Speech-language
	Visual-spatial processing
	Motor
	Emotional and behavioral functioning
	Social skills
	Adaptive skills

100

Risk Stratification & Neurodevelopmental & Neuropsychological Follow Up

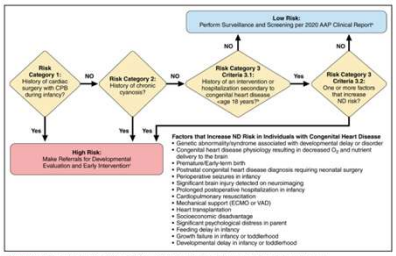


Figure 1. Risk categories for developmental delay or disorder in individuals with congenital heart disease.

101

102

"The main difference in CHD outcomes, is almost always related to inadequate access to care"

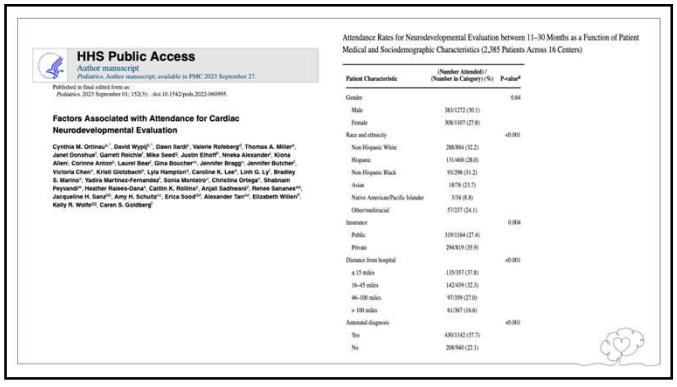
- Anshor, Sartika & Diantina, 2024

103

1 in 3 children attend neurodevelopmental evaluation!

- Ortinau et al., 2023

104



HHS Public Access

Author manuscript

Pediatrics. Author manuscript; available in PMC 2023 September 27.

Published in final edited form as:

Pediatrics. 2023 September 01; 152(3): . doi:10.1542/peds.2022-060995.

Factors Associated with Attendance for Cardiac Neurodevelopmental Evaluation

Cynthia M. Ortinau[1,*], David Wypij[2,*], Dawn Ilardi[2], Valerie Rolnitzky[2], Thomas A. Miller[2], Janet Donohue[2], Garrett Reichle[2], Mike Seed[3], Justin Elhoff[3], Nneka Alexander[2], Kiona Allen[2], Corinne Anton[2], Laurel Bear[2], Gina Boucher[2], Jennifer Bragg[2], Jennifer Butcher[2], Victoria Chen[2], Kristi Glotzbach[2], Lyia Hampton[2], Caroline K. Lee[2], Linh G. Ly[2], Bradley S. Marino[4], Yadira Martinez-Fernandez[5], Sonia Montano[2], Christina Ortega[2], Shabnam Peyvandi[6], Heather Raines-Dana[2], Caitlin K. Rollins[7], Anjali Sadhwani[7], Renee Sanares[2,8], Jacqueline H. Sanz[2,9], Amy H. Schultz[2,7], Erica Sood[2,7], Alexander Tan[2,8], Elizabeth Willen[2], Kelly R. Wolfe[2,9], Caren S. Goldberg[1]

Attendance Rates for Neurodevelopmental Evaluation between 11–30 Months as a Function of Patient Medical and Sociodemographic Characteristics (2,385 Patients Across 16 Centers)

Patient Characteristic	(Number Attended) / (Number in Category) (%)	P-value[a]
Gender		0.64
Male	383/1272 (30.1)	
Female	308/1107 (27.8)	
Race and ethnicity		<0.001
Non-Hispanic White	288/894 (32.2)	
Hispanic	131/468 (28.0)	
Non-Hispanic Black	93/298 (31.2)	
Asian	18/76 (23.7)	
Native American/Pacific Islander	3/34 (8.8)	
Other/multiracial	57/227 (24.1)	
Insurance		0.004
Public	319/1164 (27.4)	
Private	294/819 (35.9)	
Distance from hospital		<0.001
≤ 15 miles	135/357 (37.8)	
16–45 miles	142/439 (32.3)	
46–100 miles	97/359 (27.0)	
> 100 miles	61/367 (16.6)	
Antenatal diagnosis		<0.001
Yes	430/1142 (37.7)	
No	208/940 (22.1)	

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Barriers & Enablers to Care

"It's more than just a conversation about the heart": exploring barriers, enablers, and opportunities for improving the delivery and uptake of cardiac neurodevelopmental follow-up care

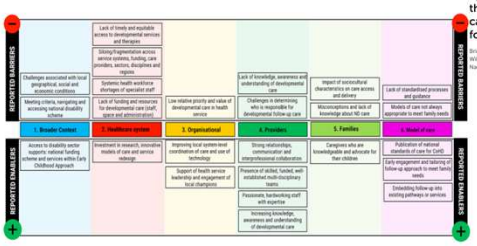


FIGURE 1
Perceived barriers and enablers to implementing and delivering neurodevelopmental care for children with CHD in Australia, grouped by colour-coded higher-order theme.

106

Integrating Telehealth Into Neurodevelopmental Assessment: A Model From the Cardiac Neurodevelopmental Outcome Collaborative

Opportunities to Integrate Telehealth within Neurodevelopmental Care*

Triage/Intake → Evaluation → Care/Management

107

"To move this field of research forward, we must strive to better understand the impact of neurodevelopmental and psychosocial intervention within the CHD population including adapting existing interventions for individuals with CHD.

- Cassidy et al., 2021

108

1 in 2 CHD patients are at risk of developing **mental health & neurodevelopmental disorders**

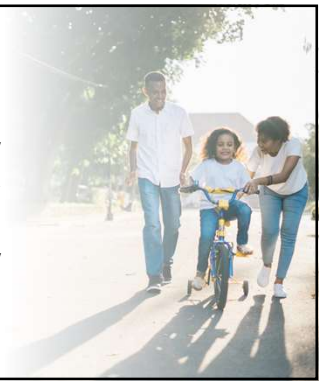
Yet **less than 10%** of children and/or their families receive mental health care

Williams 2017, 2018, & Vyas et al., 2021

109

"The relationship between CHD and child psychosocial behaviour does not occur in a vacuum"

Cassedy et al., 2023



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Supporting Parents

Cincinnati Children's Opens Nation's First Heart and Mind Wellbeing Center

Overall, evidence supports:

- Reduced maternal anxiety and distress
- Improved parenting confidence and coping
- More secure mother-infant attachment
- Improved infant feeding
- Improved family functioning
- Greater satisfaction with care
- Preliminary evidence of improved infant neurodevelopmental outcomes

Very few trials included fathers or caregivers from diverse socioeconomic or cultural backgrounds

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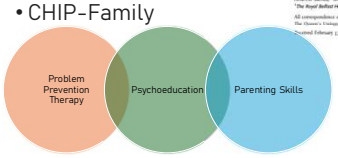
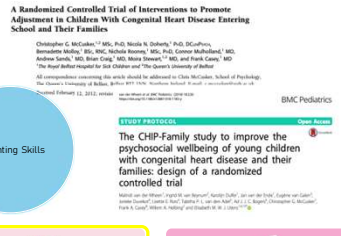
Supporting Families: Congenital Heart Disease Intervention Program

- CHIP-Infant
- CHIP-School
- CHIP-Family




A Randomized Controlled Trial of Interventions to Promote Adjustment in Children With Congenital Heart Disease Entering School and Their Families

BMC Pediatrics

STUDY PROTOCOL Open Access

The CHIP-Family study to improve the psychosocial wellbeing of young children with congenital heart disease and their families: design of a randomized controlled trial

112

Yoga Intervention in Congenital Heart Disease


Open access Protocol

BMJ Open A Parent–child yoga intervention for reducing attention deficits in children with congenital heart disease: the Yoga for Little Hearts Feasibility Study Protocol

Anne Gallagher, PhD, PI
Full Professor, UdeM
Neuropsychologist

113

Older Children & Adolescent Interventions

114

Pharmacological Interventions

- Stimulant and nonstimulant medications
- Generally safe to use in this population

Batra et al., 2012, Trairatvorakul et al., 2023

115

Cognitive Interventions

Review Article

Executive function deficits in congenital heart disease: why is intervention important?

Johanna Calderon, David C. Bellinger

THE JOURNAL OF PEDIATRICS • www.jpeds.com — ORIGINAL ARTICLES

Randomized Controlled Trial of Working Memory Intervention in Congenital Heart Disease

PEARSON COGMED

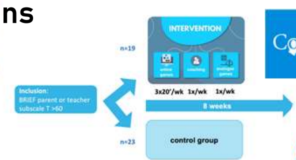
- Single-center, RCT, 60 adolescents (13-16 years) with CHD
- No improvement in working memory
- Improvements in inhibitory control, attention, and parent-reported cognitive regulatory skills
- The training did not enhance other areas of executive function or behavioral outcomes

116

Cognitive Interventions

BMJ Open **Multimodal personalised executive function intervention (E-Fit) for school-aged children with complex congenital heart disease: protocol for a randomised controlled feasibility study**

Mixed Complex CHD sample
Youth 10-12 years



CogniFit

BEAVER GANG

UNIVERSITY CHILDREN'S HOSPITAL ZURICH
Children's Research Center CRC

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Adolescence & Young Adulthood

- Mental Health & Resilience
- Self management & Transition
- Promotion of Health-Related Quality of Life
- Job Training, Vocational Rehabilitation & Education

Pt. Dr. Melissa Cousins, PhD

RESEARCH ARTICLE

Web-Based Mindfulness Intervention in Heart Disease: A Randomized Controlled Trial

Mindfulness training showed positive effects …a useful adjunct to current clinical therapy in patients with heart disease (Younge et al., 2015)

118

Gaps & Direction in Research

- Only emerging evidence-based interventions for other patient populations **adapted for CHD**
- Largely limited to North America and European countries
- Limited RCTs & no data on potential cost-effectiveness limited **real-world implementation**
- **Comparative effectiveness** of different intervention approaches and **mechanisms of action** unknown.
- Increasing recognition of the value of **shared decision-making**, **peer support**, and **technology**
- Few known to actively embed training and support in cultural humble practice delivery

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Case Example: From Heart to Home:

Promoting Mental Health Outcomes for Children with CHD through Positive Parenting (Interact-North)

SickKids

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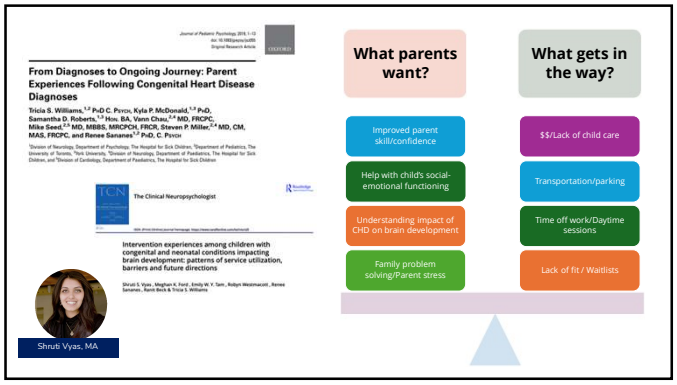
From Diagnoses to Ongoing Journey: Parent Experiences Following Congenital Heart Disease Diagnoses
The Clinical Neuropsychologist
Intervention experiences among children with congenital and neonatal conditions impacting brain development: patterns of service utilization, barriers and future directions
Shruti Vyas, MA
What parents want?
What gets in the way?
Improved parent skill/confidence
Help with child's social-emotional functioning
Understanding impact of CHD on brain development
Family problem solving/Parent stress
$$/Lack of child care
Transportation/parking
Time off work/Daytime sessions
Lack of fit / Waitlists

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I-InTERACT-North
A virtual therapy program empowering parents to promote resilience
Transdiagnostic feasibility trial of internet-based parenting intervention to reduce child behavioural difficulties associated with congenital and neonatal neurodevelopmental risk: introducing I-InTERACT-North
Brittany Burek, PhD
Meghan Ford, MA
Building I-INTERACT-North: Participatory Action Research Design of an Online Transdiagnostic Parent–Child Interaction Therapy Program to Optimize Congenital and Neurodevelopmental Risk

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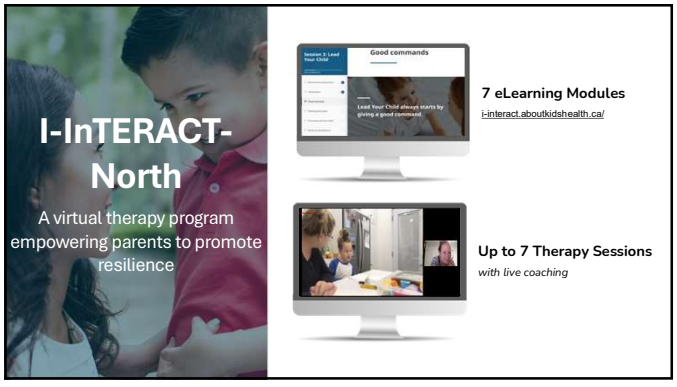
I-InTERACT-North
A virtual therapy program empowering parents to promote resilience
Good commands
7 eLearning Modules
i-interact.aboutkidshealth.ca/
Up to 7 Therapy Sessions
with live coaching

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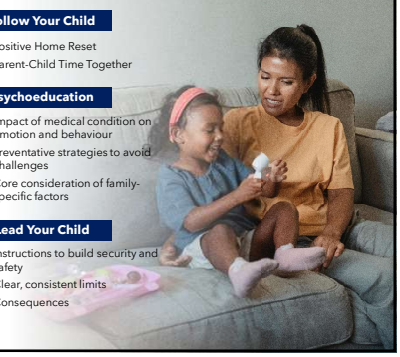
Session 1: Introduction
Session 2: Special play time
Session 3: Lead your child
Session 4: Setting child up for success
Session 5: Limit setting & consequences
Session 6: Home rules and family values
Session 7: Closing thoughts

Follow Your Child
- Positive Home Reset
- Parent-Child Time Together

Psychoeducation
- Impact of medical condition on emotion and behaviour
- Preventative strategies to avoid challenges
- Core consideration of family-specific factors

Lead Your Child
- Instructions to build security and safety
- Clear, consistent limits
- Consequences



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Step 1: Consult

Step 2: Brief Program

2 sessions & online modules

Step 3: Full Program

5 additional sessions & online modules

Journal of Pediatric Psychology, 2023, 00, 1–14
https://doi.org/10.1093/jpepsy/jsad032
Original Research Article

Stepping up to COVID-19: A Clinical Trial of a Telepsychology Positive Parenting Program Targeting Behavior Problems in Children With Neurological Risk

Angela Deotto,[1,2] PhD, Giulia F. Fabiano,[1] BSc, Beryl Y.T. Chung,[1,2] PhD, Shari L. Wade,[4,5] PhD, Evdokia Anagnostou,[6,7] MD, Jennifer Crosbie,[8,9] PhD, Elizabeth Kelley,[10] PsyD, Rob Nicolson,[11,12] MD, Brendan F. Andrade,[9,13] PsyD, Steven P. Miller,[14,15] MDCM, and Tricia S. Williams,[1,2,9] PsyD

Angela Deotto, PhD

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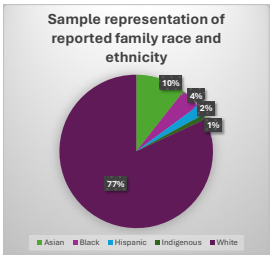
Embedding EDI-Informed Principles in Interact-North: Representation of I-North Families

Sample representation of reported family race and ethnicity



SickKids

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Interact-North EDI Training Curriculum

Dr. Naddley Désiré
PhD, C.Psych

Remember	Remember to engage in honest dialogue
Listen	Listen with compassion and empathy
Share	Share the space
Value	Value different perspectives
Reflect on	Reflect on moments of natural discomfort

SickKids

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EDI Considerations & Culturally Responsive Care

Culturally Humble Care Starts with...Introspection

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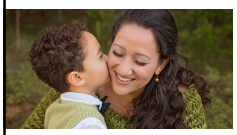

Big Picture Considerations

- Longstanding legacy of systemic racism in policing Black & Indigenous Communities of Color and Historically Marginalized Families
- Intersectionality of race & socioeconomic status
- Conceptualization of "good parenting"
- Parenting & Gender
  - Expectations/assumptions regarding women's
  - Majority of pediatric neuro/psychologists are also women
  - Limitation or Strength?

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Positive Parenting Approaches & EDI

- **Parental warmth, nurturance & predictability consistent positive predictors across race, culture and socioeconomic status**
  - Parenting behaviors measured in most studies are representative of middle-class North American families
  - Varying values (i.e., compliance, parent respect),
  - Varying views of mental health, causes of children's behaviour and help-seeking

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EDI Considerations & Culturally Responsive Care

Interact-North Current Practices:

- **Participation:**
  - Creating safe space to foster trust from the outset
  - Flexible, virtual scheduling, interpreter services, questionnaires with demonstrated utility among BIPOC parents (i.e., ECBI), tablets
  - Active involvement of Family Advisory Committee
  - ***EDI should be considered at each step***, across sessions (i.e., SPT, Time out, goals of program, time commitment, positive reinforcement)

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EDI Considerations & Culturally Responsive Care

EDI & Culturally Humble Care: Considerations within the Interact-North Program

Culturally responsive care is predicated on ***Safety and Inclusion***:

Inclusive Language

- Use adequate pronouns
- Be mindful of Terms: Mother/Father vs Caregiver; Parent training vs coaching
- House Rules v Home Values

Acknowledging and Appreciating racial and cultural differences in parenting styles

Invite opportunity for discussion

- I would like to learn more about your experiences and your culture so that I can support you more effectively in a culturally responsive way. Is that okay? How has your culture shaped your parenting style? How has it shaped the way you interact with your child?

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EDI Considerations & Culturally Responsive Care

EDI & Culturally Responsive Care Considerations within the Interact-North Program

Culturally responsive care is predicated on ***Safety and Inclusion***:

Neurodiversity & Mental Health

- Are there psychosocial stressors or mental health concerns that may impact a family's ability to fully participate?
  - History of repetitive micro/macro-aggressions
  - Repeated exposure to invalidating experiences within the healthcare system
- Caregiver's own mental health
  - Embracing and supporting neurodiversity vs focus on promoting families/children to become "more neurotypical"
  - Inclusion also means acknowledging and validating the diverse, lived experiences of neurodiverse caregivers

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Feedback from Trainees

- Trainee feedback regarding EDI-embedded training was **positive**.
- Specific appreciation of EDI content related to:
  - self-reflection regarding **positionality** and implicit biases,
  - differentiating cultural competence from cultural **humility**
  - instruction on specific practices to be integrated into I-N promoting cultural humility.

SickKids

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Feedback from Trainees

*"It **encouraged me to reflect on my biases and assumptions** and approach clinical care by creating a safe and inclusive space for all patients".*

*" It gave me an appreciation for the concept of **cultural humility as opposed to cultural competence**".*

SickKids

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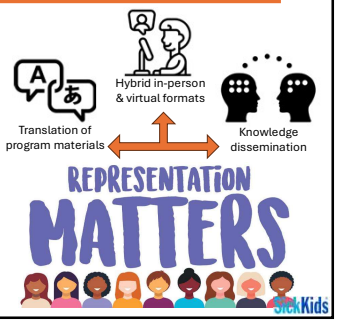
Patient & Family Voices

Parents reported that the program and therapist ***adequately*** incorporated their family's cultural heritage to guide treatment

Focus groups identified future EDI opportunities for larger scale implementation including:



I-InTERACT-North

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Stepped-Care Online Parent Support following Congenital Heart Disease: A Randomized Control Trial

Objectives

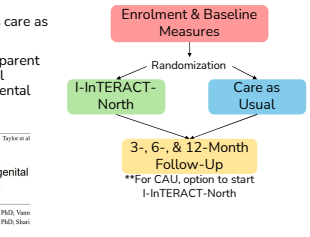
1. Determine efficacy of I-InTERACT-North vs care as usual in families of children with CHD
2. Assess feasibility and acceptability among parent and clinical partners to inform future clinical implementation in Cardiac Neurodevelopmental follow up programs

JMIR RESEARCH PROTOCOLS Taylor et al

Protocol

Stepped-Care Web-Based Parent Support Following Congenital Heart Disease: Protocol for a Randomized Controlled Trial

Marie Taylor[1], BA; Bianca Christina Bondi[1], PhD; Brendan F Andrade[2,3], PhD; Stephanie H Au-Young[4], PhD; Vann Chau[4], MD; Ashley Dangucuan[1], PhD; Naddley Désiré[1], PhD; Ting Guo[1], PhD; Dragana Ostojic-Aitkens[1], PhD; Shari Wade[5,6], PhD; Steven Miller[7], MD; Tricia Samantha Williams[1,8], PhD



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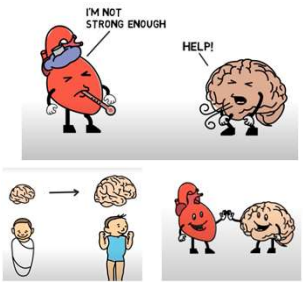
Customization to Congenital Heart Disease



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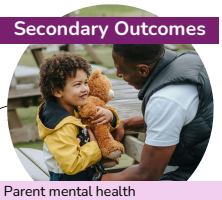
Primary Outcomes

- Feasibility, reach, adherence
- Positive parenting skills
- Child behaviour problems & intensity

Secondary Outcomes



- Parent mental health
- Parent & child quality of life
- Program acceptability
- Program implementation (TIR)
- Service utilization & economic impact

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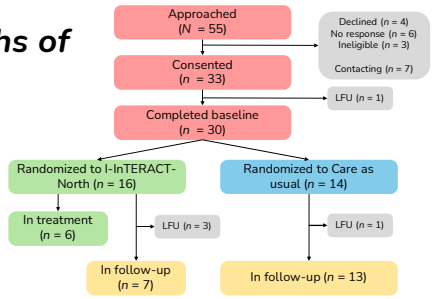
First 9 Months of Recruitment

(Feb– Nov 2024)



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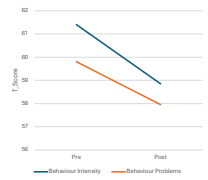
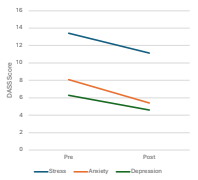
Preliminary Evidence of I-InTERACT-North Efficacy and Acceptability in CHD

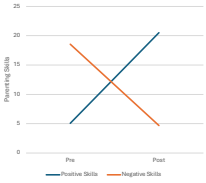
N = 20 children (60% male, M_{age}=5.43, SD_{age}=1.41) with CHD who participated in an I-InTERACT-North trial



Improvement in child behaviour

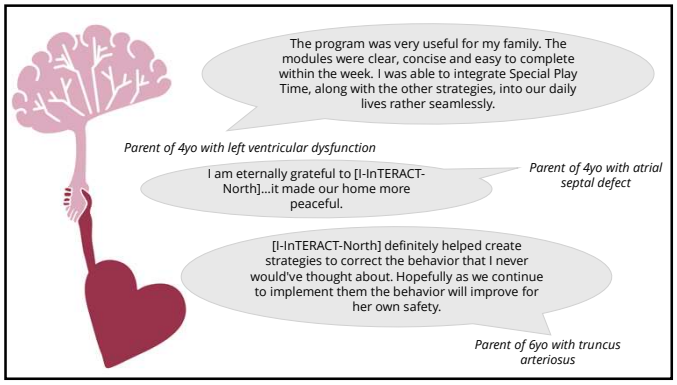


Improvement in parent mental health



Improvement in parenting skills

141



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I-InTERACT-North

Parent Testimonials

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The NeuroOutcomes Lab

SickKids | AboutKidsHealth.ca | I-InTERACT-North

539 Families offered the I-InTERACT-North program since 2019

1.5	12	31	1178
Days	**Weeks**	**Therapists**	**Sessions**
Mean time from referral to first contact with parents	Mean time from intake to first contact with I-InTERACT-North therapist	Trained since 2019	Total number of therapy hours provided focusing on family stress and positive parenting strategies

Thank you to the Garry Hurvitz Centre for Brain and Mental Health for the support that makes I-InTERACT-North possible.

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Investing in the next generation

SickKids

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Concluding Call to Action: Neuropsychological Clinical Precision & Research in CHD

- Unique expertise in brain-behaviour relationships & common outcomes
- Increasing professional accountability for competencies in intervention and advocacy for CHD children, youth & families
- Increasing precision and range of service and research to optimize brain health across lifespan

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Acknowledgements

NeuroOutcomes Lab
&
Therapists

RCT & Implementation
Team & Partners

FAC & Families

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Thank you for Attending

Getting to the *Heart* of the Matter:

Translational Neuropsychological Service Pathways in Congenital Heart Disease

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