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Optimizing Outcomes for Patients and Families affected by Congenital Heart Disease:

Psychosocial and Neurodevelopmental Screening and Intervention

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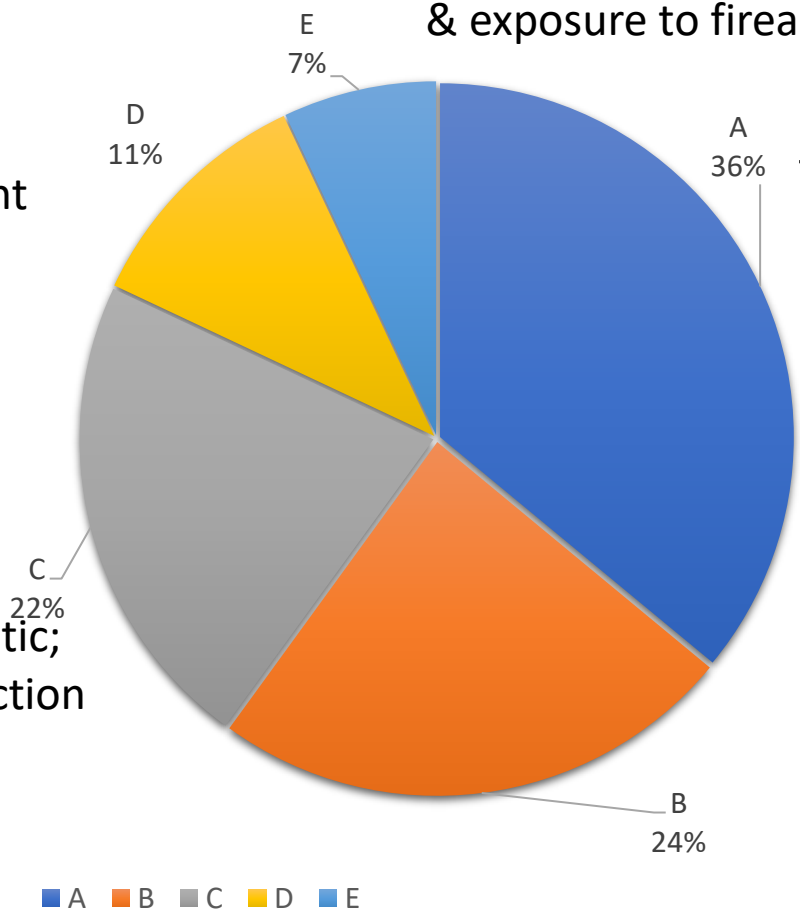
Why Specialized Psychosocial Health Services?

Determinants of Health

Physical environment: allergens, pollution, location & exposure to firearms

Medical care: health literacy;
access, quality, patient engagement



Individual behavior: sleep & diet patterns, physical activity, risk related behaviors; negative mood & affect, & psychological assets

Genetics/ biology: genetic; Body structure and function

Social circumstance: citizenship & social status, Culture/ tradition, discrimination, early childhood education & development

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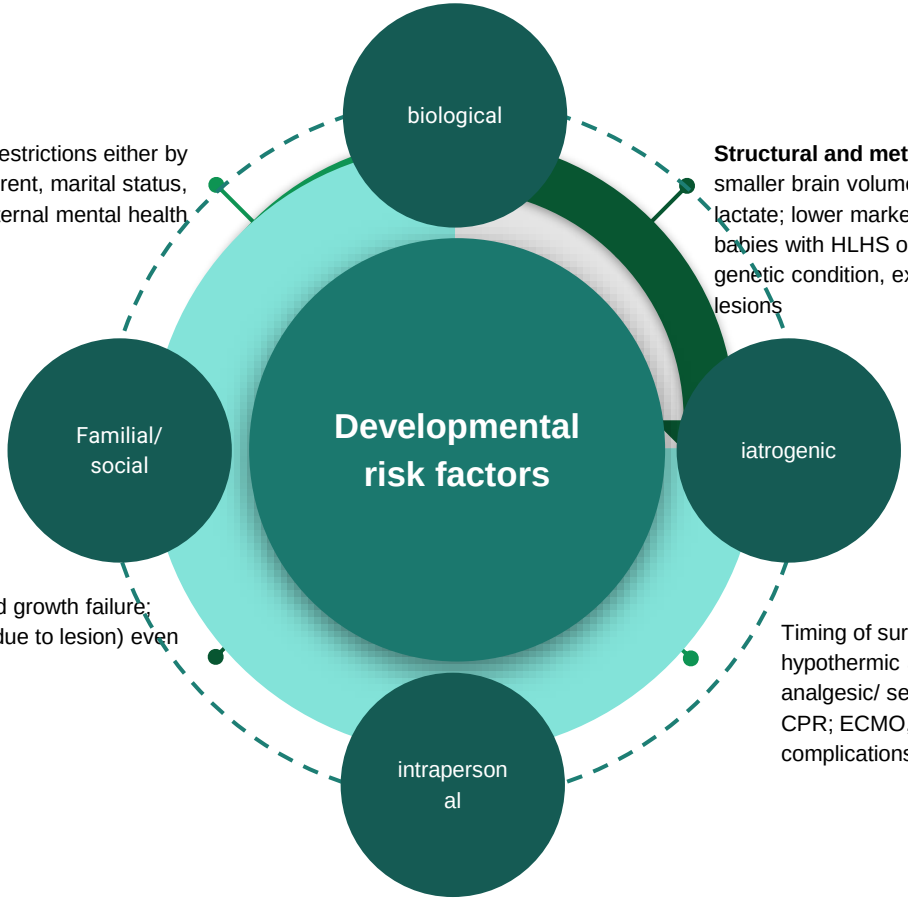


SES, family functioning, restrictions either by medical team or anxious parent, marital status, parental style and maternal mental health

Structural and metabolic abnormalities
smaller brain volumes; and slower brain growth; elevated brain lactate; lower markers of brain maturity and neural health. Ex term babies with HLHS or d-TGA similar to healthy 35-week newborns genetic condition, extracardiac anomaly, lower birth weight, specific lesions

Take away:
Disease and surgical factors must be considered in the wider, systemic context

Feeding intolerance and growth failure; persistent hypoxemia (due to lesion) even after surgery

Timing of surgery, Ph management, minimization of deep hypothermic arrest, balancing pain management with analgesic/ sedation exposure (especially under age 3); CPB; CPR; ECMO, hemodynamic instability; strokes; complications*

CHD & Psychosocial Functioning

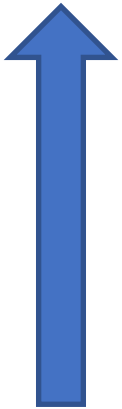
Neuropsychological Functioning

- ≤ 75% of children, at risk/ deficits in at least one neuropsychological functioning area
- ~75% of infants and toddlers demonstrate delays and deficits mostly in motor delays
- Regardless of lesion all children with CHD are at risk for motor delays by age 4
- In childhood and adolescence delays noted in:
  - language, executive functioning, visual perception, and inattention and impulsiveness and in deficits in domains requiring integration such as visual-spatial processing, developing complex narratives
- Adults with CHD have an increased risk for executive dysfunction

Educational Functioning

- ≈ 50% of students with cCHD at-risk attentional/ hyperactivity issues
- Lower EF skills (differences observed depending on lesion)
- 1.24 x more likely to not meet reading or math standards
- 20% of students with more complex CHD repeat a grade
- Milder forms of CHD still require some type of remedial support
- Special education (SpED) service involvement:
  - 50% more likely to receive SpEd
  - Higher rates of involvement in all types of SpED services
  - Likelihood of receiving SpEd services increases with severity of diagnosis
- Historically underserved in school system

Psychosocial Functioning

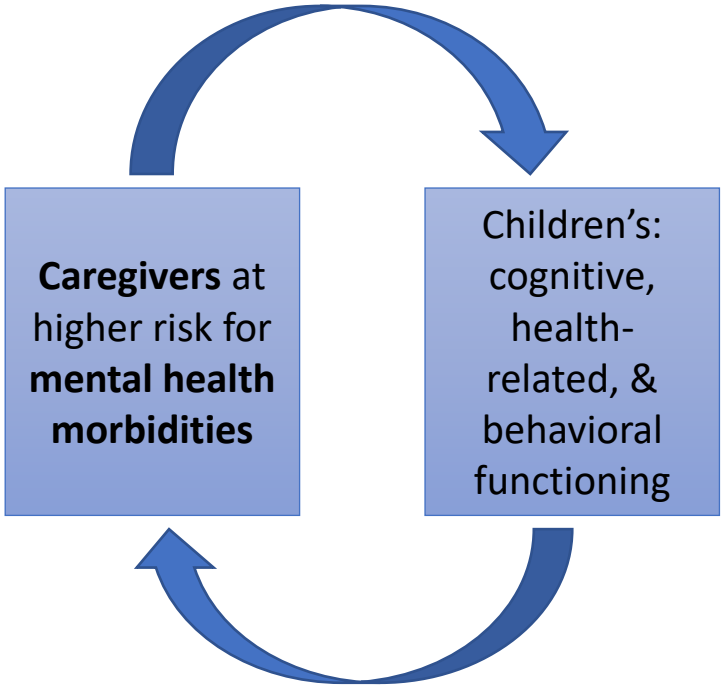


Irritability/ lethargy
Externalizing behaviors
Internalizing behaviors
Social challenges
Psychosomatic symptoms
Difficult temperament

QoL (self and caregiver report)
Educational exposure
Self-esteem
Physical functioning
Sibling adjustment
Social cognition

- Limited educational success
- Limited employability

Caregiver Functioning and Patient Psychosocial Outcomes



Caregivers Mediate Outcomes

The good news is…

“Fire melts butter and hardens steel”

Rethink CHD

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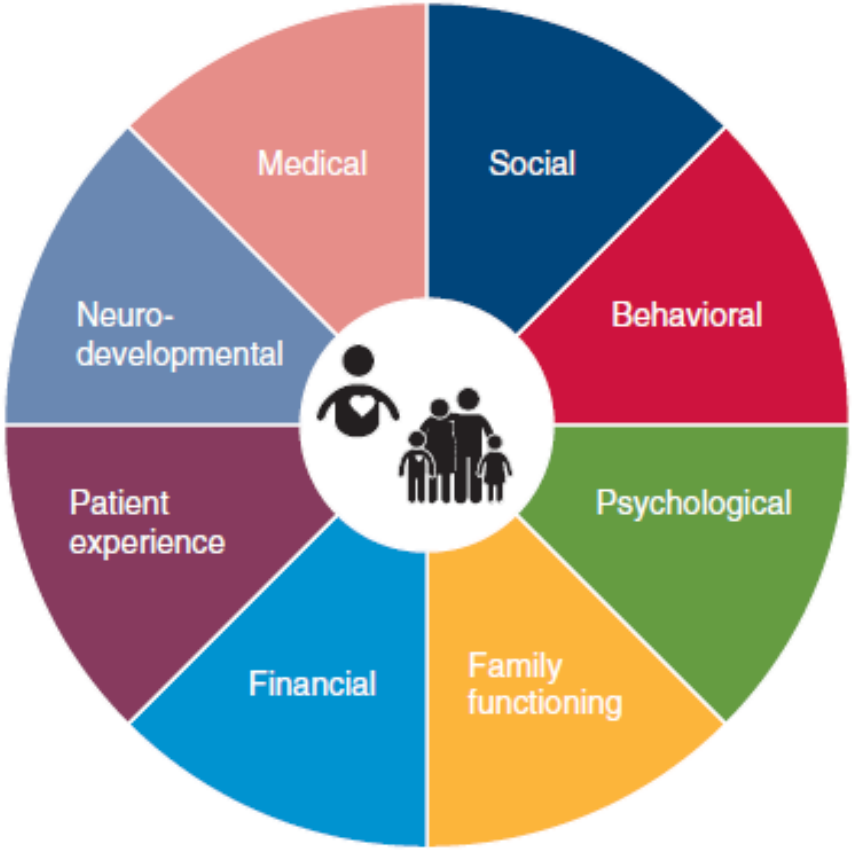

Medical
Social
Neuro-
developmental
Behavioral
Patient
experience
Psychological
Financial
Family
functioning

Assets or Modifiable Risk Factors

Psychosocial:

- Increased social support
- Improved coping strategies
- Regulating the impact of stress on the family
- Parental coping & attachment
- Help with family adjustment
- Trust in physician

Medical:

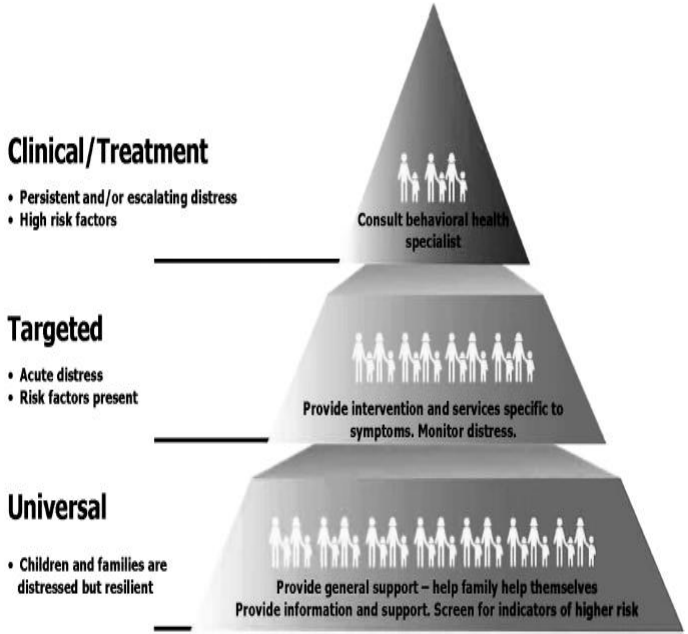
- Preoperative
- Intraoperative:
- Postoperative:
  - achieve balance between untreated pain and risk of analgesics/ sedation;
  - shorten hospital length of stay as much as safely possible;
  - feeding intolerance and growth failure

Public Health Approach

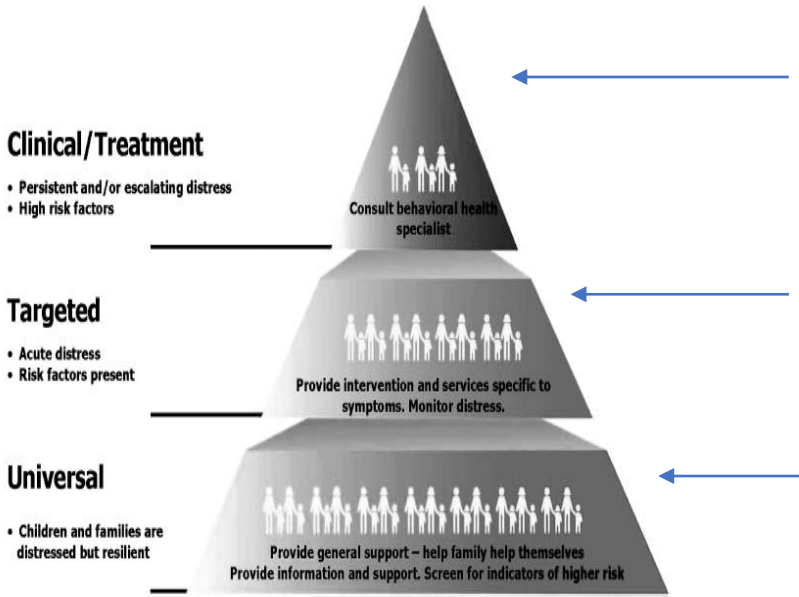
The Pediatric Psychology Preventative Health Model (PPPHM):

Moves from a siloed approach of psychosocial service delivery

To a horizontal approach, where providers are able to work to the top of their license.



The PPPHM in Practice



Tier 3: 15%; Psychology, Psychiatry, SW, School Advocate, Medical team (CLS)

Tier 2: 25- 33% Psychology, SW, School Advocate, CLS, Medical team (Psychiatry)

Tier 1: 50-66% Medical team, CLS, SW, nurse educator, (School Advocate)

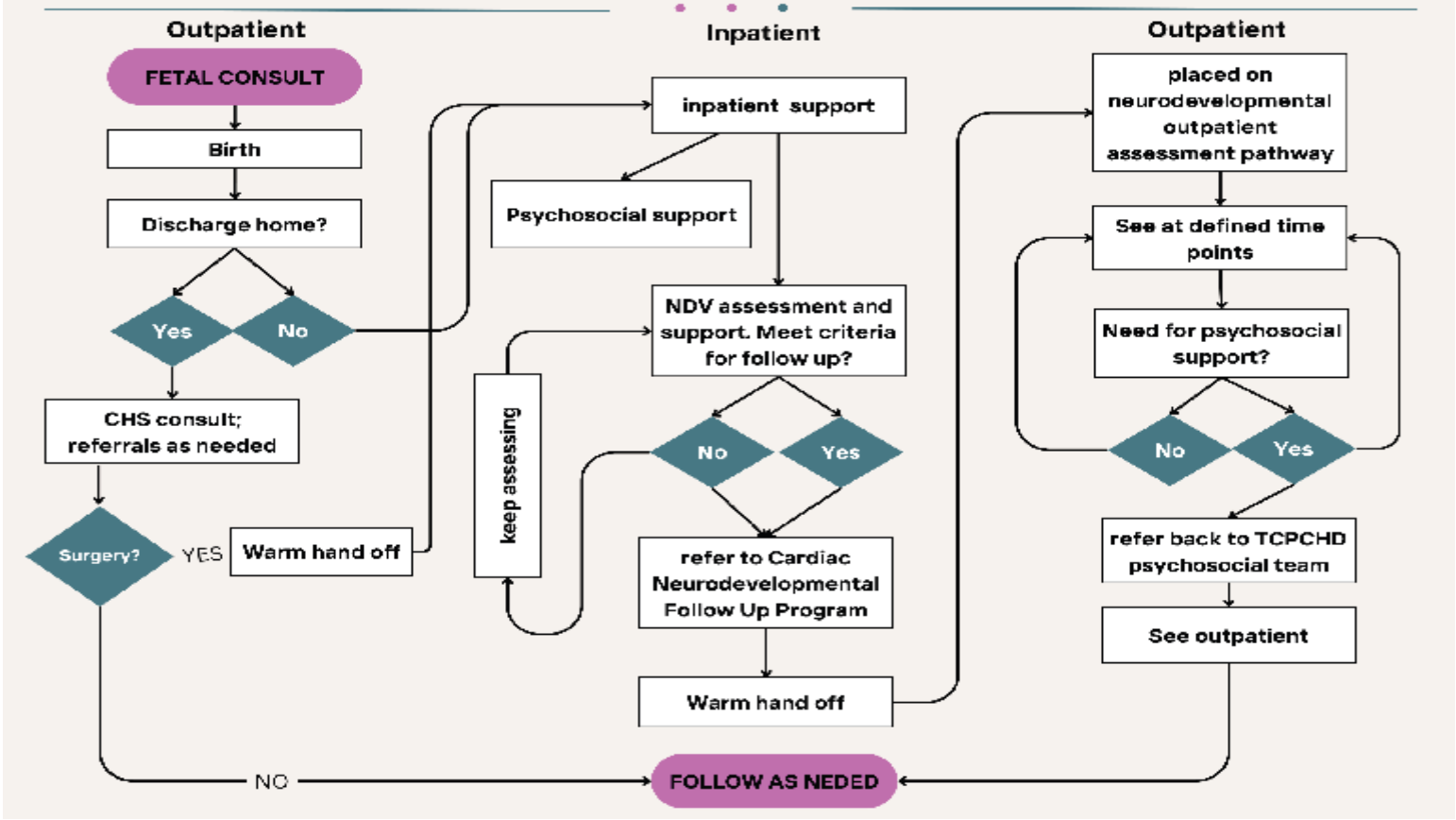
Accessing Services

Psychosocial Health Services Within TCPCHD

Texas Center For Pediatric and Congenital Heart Disease (TCPCHD) psychosocial team:
4 social workers
3 child life specialist
1 psychologist

Partnered neurosciences Cardiac Neurodevelopmental Follow Up Clinic, developmental neurologist, neuropsychologist, NP

TCPCHD: Comprehensive Neuro-Psycho-Social Support Across the Lifespan



PPPHM: Areas Screened & Assessed

Domain	Measure
Structure/ Resources	Psychosocial Assessment Tool (PAT), fetal PAT (fPAT)
Social Support	PAT, fPAT
Patient functioning	PAT, PedsQL, Ages and Stages Questionnaire (ASQ), fPAT, Depression, Anxiety, Stress Scales 21 (DASS21) [adult patients],
Sibling Functioning/ other children	PAT, fPAT
Caregiver & partner functioning	PAT, & DASS21, fPAT
Family functioning & family beliefs	PAT, fPAT

Fetal Consult

- Introduce team
- Discuss neurodevelopmental outcomes
- Psychoeducation on resources
- Administer measures
- Warm hand off to other services

Birth to Outpatient Surgical Consult

- Follow as required for surgery
- Conduct assessment outlines above
- SW and psychology front facing
- Warm hand off to inpatient

Inpatient: Psychosocial Services

- Child Life and Social Work front facing
- Refer to psychology as needed

Heart Program Psychosocial Consult Guidelines

Note: Surveillance, screening & assessment will help determine appropriate providers using th tiered model to intervention (Tier model based on the PPPHM)

Patient & Sibling Concerns	*Who to Consult*
*Adaptation and health promotion after new diagnosis – ***child*** *Medical adherence issues – ***child*** *Adjustment problems related to diagnosis, hospitalization, recovery (e.g. anxiety, depression/mood problems, behavioral reactions – ***child*** *Behavior problem: complex, multiple behaviors interfering with care – ***child*** *Physical appearance/functional changes- cognitive, behavioral, and emotional adaptation/coping – ***child*** *Developmental screening and surveillance – ***child*** *Non-pharmacological pain management (chronic pain) – ***child*** *Psychiatric & psychological symptom clarification: normal v abnormal, diagnosis – ***child*** *Interventions specific to behavioral health or psychiatric diagnoses during hospitalization – ***child*** *Suicide/risk- Assessment and discharge plan (within 24 hours of medical clearance) – ***child***	Psychology
*Medical/procedural play pre- and post- intervention: IV insertion, stitches, MRI, sedation – ***child*** *Short term, immediate intervention: pre-surgical anxiety, abrupt breakthrough pain – ***child*** *Normalization play – routine – ***child*** *Non-pharmacological pain management/procedural pain – ***child*** *Daily goals/routines while inpatient- ***child*** *Pill swallowing – first line intervention – ***child*** *Behavior problem: singular behavior interfering with care such as refusal to eat, medication refusal, ambulation – ***child*** *Developmentally appropriate activities – ***child*** *Cardiology related resources – ***child***	Child Life
*Adaptation and health promotion after new diagnosis – ***sibling*** *Adjustment problems related to diagnosis, hospitalization, recovery process: concerns of anxiety, depression/mood problems, behavioral reactions – ***sibling*** *Behavior problems – ***sibling*** *Developmentally appropriate activities – ***sibling*** *Other ***sibling*** issues: coping, sibling programming/resources	Child Life
*School issues: homebound assessment, initiating or adjusting IEP/504 for medical diagnosis, school visits & letters – ***child*** *Discharge planning needs/coordination of care – ***child*** *Child abuse and neglect: suspected or evaluation needed – ***child*** *Suicide/risk- Facilitation of discharge plan after medical clearance (day treatment, inpatient psychiatric hospitalization) – ***child***	Social Work

Inpatient: Neurodevelopmental Services

- Monday/Wednesday Lightning Rounds
- Tuesday Full Neurodevelopment Rounds
  - Any patient on unit > 2 weeks
  - Personalized developmental care plans
  - Generic developmental care plans available for all
  - Neurology, Cardiac Critical Care, PT/OT/ST, Psychosocial Team
- Thursday Bedside Rounds on Follow-Up Patients
  - Follow up for pending imaging and weaning of medications
- Warm hand off

Risk Criteria for Outpatient Follow Up

1. Neonates/ infants requiring open heart surgery
2. Single ventricle diagnosis
3. Children with a cyanotic heart lesion* regardless of operation status
4. Prolonged hospitalization
5. Other (any combination of CHD and following comorbidities):
    a. Prematurity (<37 wks)
    b. Developmental delay recognized in infancy
    c. Suspected genetic abnormality or syndrome associated with DD
    d. Genetic/ chromosomal abnormality finding (unknown effects of development)
    e. Hx of mechanical support (ECMO or VAD)
    f. Heart transplantation
    g. Cardiopulmonary resuscitation at any point
    h. Perioperative seizures related to CHD surgery
    i. Any abnormality on neuroimaging (Strokes, Periventricular leukomalacia)
    j. Microcephaly as identified by radiologist
6. Other conditions

Outpatient Neurodevelopmental Testing Timelines

Follow up with Cardiac Neurodevelopmental Follow Up Clinic (CNFC) timeline:

- Neurology
  - 6 months
  - 12 months
- Multidisciplinary Clinic (neurology and neuropsychology)
  - 18 months
- Neuropsychology
  - 3 years
  - 4 to 5 years
  - 8 to 9 years
  - PRN at 10-11, 13-14, 17-18
- *Patients may be seen at other time points as needed if there are additional/new concerns.

Referral back to PS team for therapeutic services

Psychosocial Follow up

- Outpatient therapy with psychologists
- Seen by PS team members through multidisciplinary clinics:
  - ACHD
  - AAOCA
  - Heart Failure/ Heart Transplant/ VAD
  - Preventative cardiology
  - IMPACT

CHD and Primary Care

Supporting Children & Families

- Assess access to services through their cardiac center
- Encourage to follow through with any rehabilitation services offered
- Encourage follow up with Neuropsychological testing in childhood and adolescence
- Assess family functioning:
  - Offer support to siblings or parents
- Offer ADHD and autism testing
- Parent training support
- Help advocate at the school level
- Cardiac medication in daily life

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