

Resources for Children with Heart Disease

**Priyanka Doshi, Psy.D
Pediatric Psychologist
The Heart Institute
Children's Hospital Los Angeles**

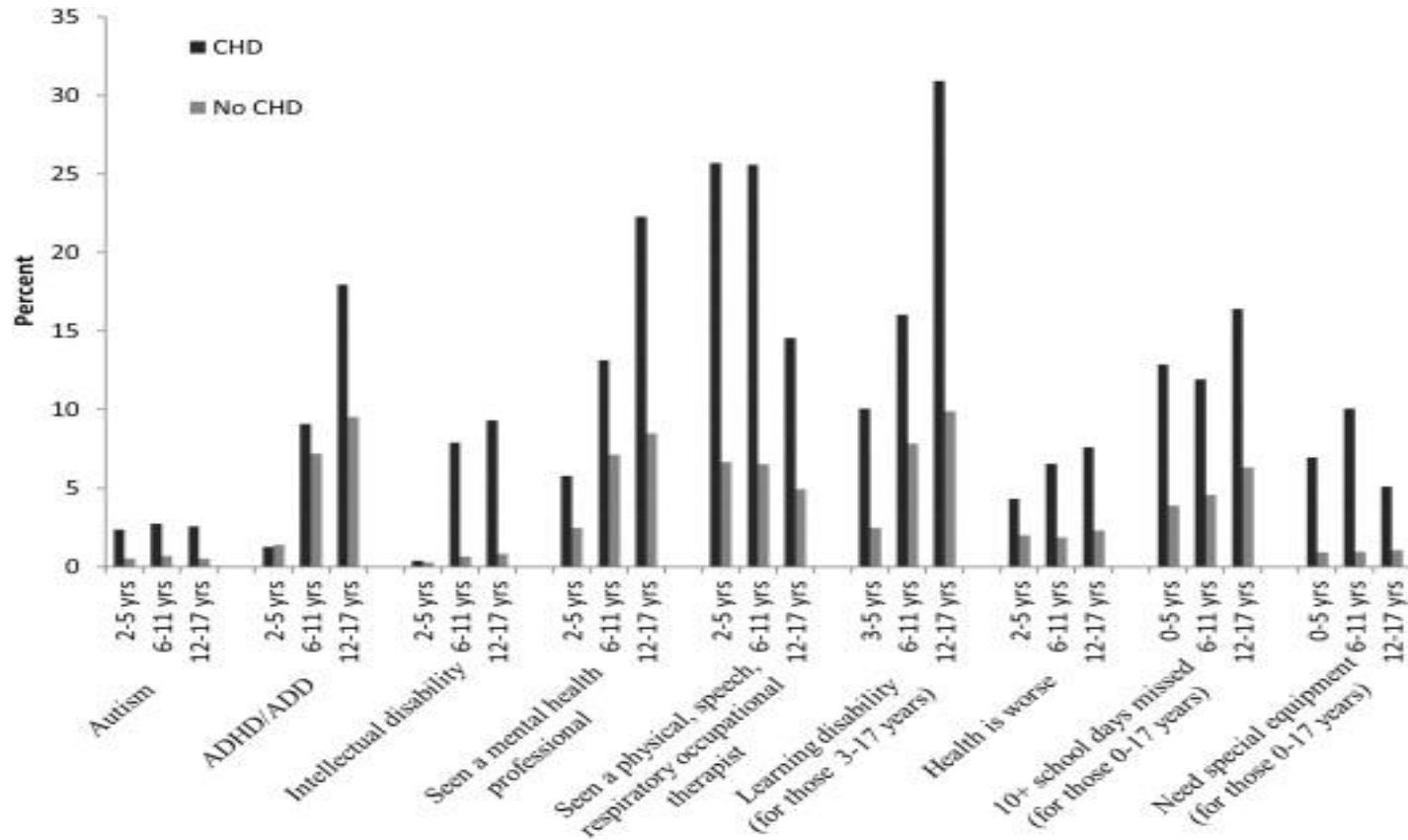
Agenda

- Resilience
- Helping a child deal with heart disease/limitations
 - Mental health strategies and finding therapy
- Cognitive/School Issues
- Parent Mental Health
- Transition to Adult Care: What should we know?
- Community Based Resources/Supports

Resilience

- Resilience: “the process by which an individual harnesses internal, external, and learned resources to maintain well-being amidst a stressor.”
- Some studies have shown that young people with CHD demonstrate higher resilience than individuals without CHD.
- Modifiable Factors:
 - Exercise (as feasible, permitted)
 - Communication with other patients with CHD
 - Social Support (Attendance to camps and support groups)
- Nonmodifiable factors:
 - SES
 - # of Hospitalizations/Complexity of disease
 - Family structure

Impact of CHD



Common Psychosocial Concerns

- ~16% of children with CHD, ages 4-9, have anxiety and/or depression
- Kids with CHD have higher rates of ADHD, behavioral difficulties, and other medical and psychiatric comorbidities
 - ADHD: 5.1% in patients ages 4-17
- Adolescence: increase in medical complexity is correlated with increased risk for having psychiatric diagnosis and behavioral disorders
 - Adolescents with CHD have a higher prevalence of anxiety and/or depression than same aged, healthy counter parts

What can I do?

Younger Children:

- Predictability and Routine
- Play
- Be a safe haven
- Promote choices whenever possible
- Having open and honest discussions: don't give too much information, but don't try to hide the facts
- Validating Emotions

Adolescents:

- Active listening versus problem solving
- Involving the teen in conversations and decision making
- Giving them as normal a life as possible

All Ages:

- Give your child a chance to answer/ask questions before answering them
- Join support/community groups
- Finding the balance between independence and dependence
- Modeling talking about and coping with emotions

How Can I respond?

I'm scared

Invalidating: "calm down" or "you have nothing to be scared about."

Validating: I can see that you are really worried.

It sucks to have a heart condition

Invalidating: "You should be grateful for all you have."

Validating: This sucks and it's okay to feel this way. How can I support you?

I can't do what everyone else is doing

Invalidating: "At least you are alive" or "I know what that feels like" or "Yes you can, you just don't try."

Validating: It makes sense that you feel that way, I can see that it makes you upset."

General Interventions/Strategies:



Sleep Hygiene for Teens

- Incorporate Exercise Into Your Daily Routine
- Stop Using Technology An Hour Before Bed
- Maintain A Consistent Sleep Routine and Schedule
- Create a Sleep-Friendly Physical Environment
- Ensure the Bed is For Sleeping

@AMANDANSHARP.PHD



Things to be mindful about:

- Calling your kid strong for someone their age
- Saying “I know how you feel.”
- You can express your worries/feelings but not putting “adult worries on them” (e.g., how expensive this might be)
- Reacting versus responding
- Invalidation of emotions
- “Guilt Parenting”

Coping with physical limitations

- Creating space for grief and disappointment
- Validation + Empathy
- Positive Attitude
- Be patient
- Respecting Privacy
- Focus on Strengths
- Adapt Activities
- Open Communication



Mental Health Resources

Tips for Finding a Therapist

1. Call the member services phone number on the back of your insurance card and ask them to provide the names of therapists in your area that take your insurance. Specify the age of your child, and the type of therapy you are looking for; for instance, an 8-year-old who needs Cognitive Behavioral Therapy (CBT). If you have an HMO, you may need to work with your child's pediatrician or your insurance company to obtain authorization for services.
2. Go to the Psychology Today website ([psychologytoday.com/us/therapists](https://www.psychologytoday.com/us/therapists)), put in your city or zip code and narrow your search by the age of your child and the type of therapy you are looking for. You will be provided a list of therapists in your area. You can read about them, and then call them to a) determine if they are taking new patients, b) ask whether they take your insurance and c) confirm that they provide the type of therapy you are looking for and work with children your child's age.
3. If your child is a client of the Regional Center, ask your service coordinator if they have any suggestions for therapists.
4. Asking Social Worker/psychosocial support team in the hospital
5. Ask your child's pediatrician if they know of therapists in the community.
6. Ask your school psychologist if they know of therapists in the community.
7. An additional resource is <https://effectivechildtherapy.org/tips-tools/advice-for-selecting-a-psychologist/>.
8. Resources for specific therapies can be found below:
 - a. Parent Child Interaction Therapy- <http://www.pcit.org/>
 - b. Trauma-Cognitive Behavioral Therapy- <https://tfcbt.org>

Types of Intervention

- Cognitive Behavior Therapy (CBT): A type of psychotherapy that helps people manage their thoughts and behaviors. It helps people recognize unhelpful thinking patterns and to reframe negative thoughts in a more logical way.
 - Depression, Anxiety
- Trauma-Focused Cognitive Behavior Therapy (TF-CBT): evidenced based therapy that is geared towards kids and teens who have experienced traumatic events.
 - Post-Traumatic Stress Disorder
- Behavior Management Training: A type of therapy that aims to change maladaptive or unwanted behaviors and uses principles such as positive/negative reinforcement, punishment, and extinction to increase positive behaviors.
 - PCIT (Parent Child Interaction Therapy): an evidenced-based, short-term treatment designed to help young children with highly disruptive behavior learn to control their frustration
 - CPP (Child Parent Psychotherapy): Therapy for young children from birth to 5 for children who have experienced at least one traumatic event and/or are experiencing mental health, attachment, or behavioral difficulties.
 - Behavior Difficulties (e.g., ADHD, noncompliance)
- Motivational Interviewing: a client-centered, evidence-based counseling approach that aims to help individuals explore and resolve ambivalence about making positive changes in their lives
 - Older kids: nonadherence
- Acceptance and Commitment Therapy: Acceptance and commitment therapy (ACT) is a type of mental health therapy that helps people understand and accept their thoughts and feelings. The goal is to adjust behaviors to better match values, and to live in the present moment.
 - Coping with a chronic medical condition

Books

- APA/Magination Press:
 - Helps you look up books by topic
- Meditation:
 - Moody Cow Meditates
- **Books for parents**
 - “Heart Defects in Children: What Every Parent Should Know,” by Cheryl J. Wild
 - “Heart of a Child,” by Catherine A. Neill, Edward B. Clark and Carleen Clark
 - “It’s My Heart,” by Children’s Heart Foundation
 - “The Heart of a Mother,” by Anna Marie Jaworski and Judy Norwood
- **Books for children with heart defects**
 - “Blue Lewis and Sasha the Great,” by Carol Donsky Newell
 - “Matty’s Heart,” by C.J. Hribal
 - “Nathan’s Special Heart,” by Jessica Ennis (available as a virtual book)
 - “Pump the Bear,” by Gisella Olivo Whittington

Mental Health Resources

- Apps:
 - Headspace for LA County
 - Insight Timer
 - The Breathing App
 - UCLA Mindful
 - Breathe, Think, Do with Sesame
 - Smiling Mind
 - GoNoodle
 - Cosmic Kids
 - Calm App

Cognitive/Academic Difficulties

- Children with moderate to severe forms of CHD are at most risk for deficits in various areas of cognitive and academic achievement.
- Findings across development:
 - Infancy: gross motor and oral-motor/feeding delays
 - Pre-school: motor and language functioning; lower IQ (especially after surgery)
 - School Age: More academic deficits compared to IQ
 - Adolescents: repeating grades, special education classes

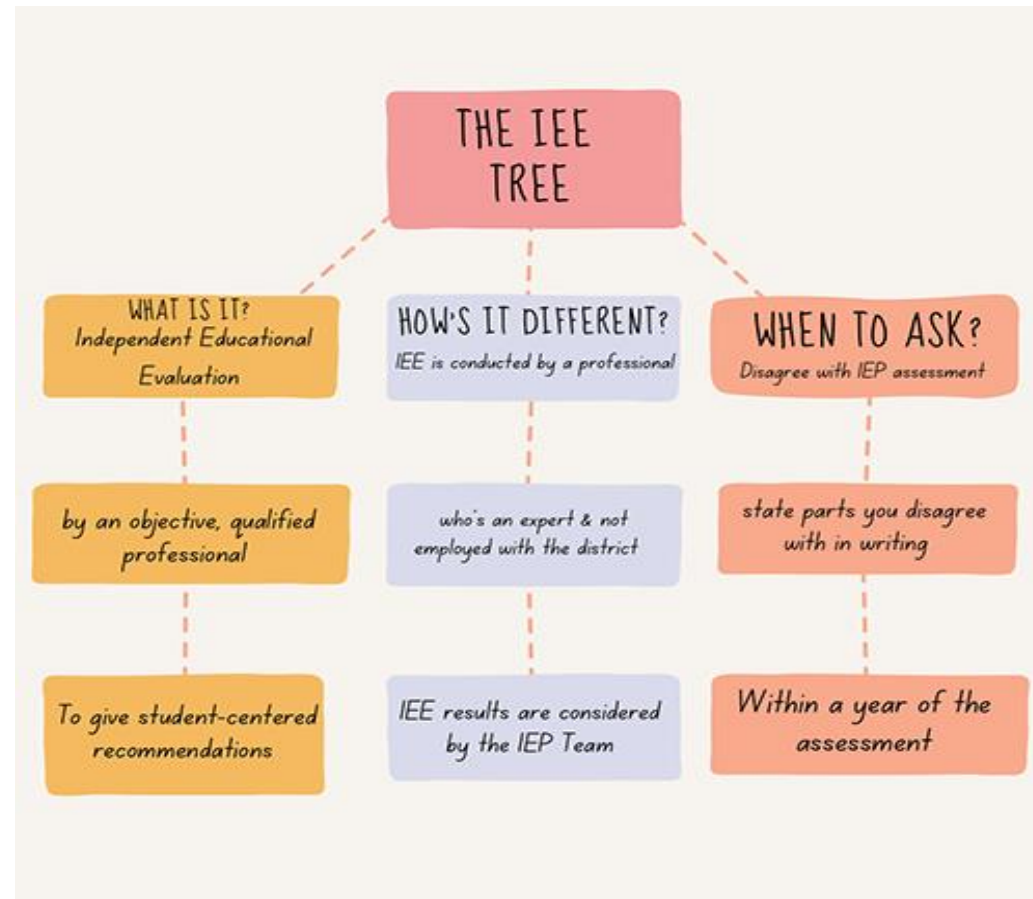
School Resources

IEP / 504 COMPARISON

Both are federally funded and free to families.

IEP	&	504 PLAN
Provides individualized special education and related services to meet a child's needs	What it does	Provides services and changes to the learning environment to allow the child to learn in the general education classroom
An IEP is reviewed at least once a year	How often is it reviewed	This is dependent on the state. It should be reviewed once a year
Present level of performance, goals, accommodations, modifications, services, placement	What is in it	Accommodations, supports, and who is in charge of the supports
Parent/caregiver, gen ed teacher, special education teacher, related service providers, district representative	Who is in the meeting	Parent/caregiver, general education teacher, school principal
A child with one or more of the 13 disability categories and the nature of the disability adversely impacts the child's education	Who is eligible	A child with any disability and the nature of their disability impacts the child's education in a general education classroom
A child is eligible to receive services through their IEP through high school	How long does it last	Colleges that receive federal funding should be able to provide accommodations similar to a 504 plan

IEE: Independent Educational Evaluation

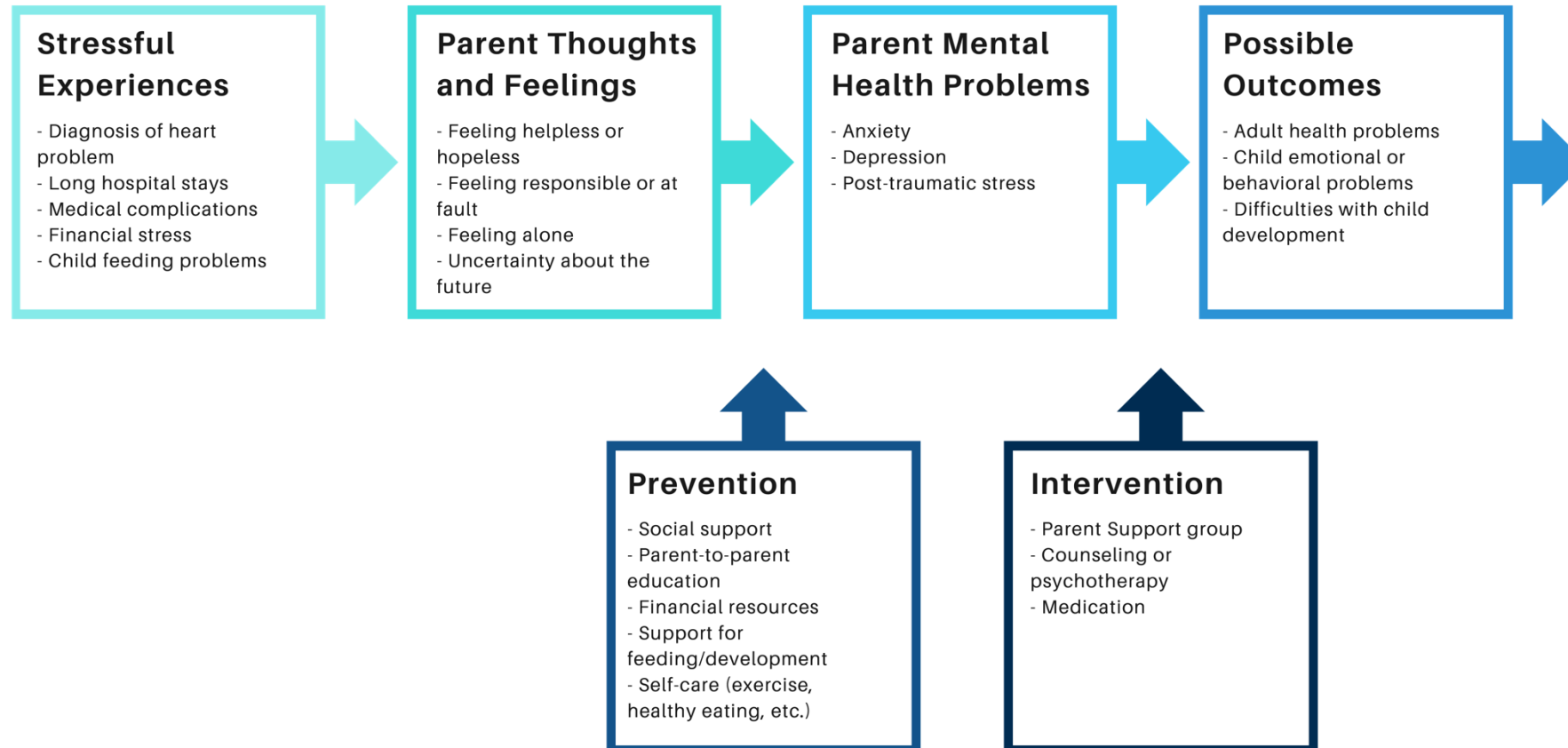


Neuropsychological Testing

- Neuropsychological testing is a diagnostic tool that measures how well your brain works. It assesses cognitive skills like attention, memory, and problem-solving, as well as mood and behavior. Identify strengths and weaknesses, and help with differential diagnoses



Parent Mental Health



Transition

- General Consensus: start talking about transition between 12-13 years old
- Key Considerations for transition:
 - Individual:
 - Knowledge of medical condition & medical management
 - Family:
 - Gradual versus rapid approach
 - Shift from provision of direct support of monitoring for daily activities to emotional support or discrete support for infrequent events (e.g., refilling prescriptions).
 - CEO's (childhood)→managers (middle childhood)→supervisors (adolescence)→consultants (young adulthood).
- Interventions
 - Self-management skill building
 - Goal Setting
 - Time Management
 - Problem-solving
- Resources: www.gottransition.org

Community Resources

- Mended Hearts
 - Mendedhearts.org
- Sisters by Heart
 - www.sistersbyheart.org
- Conquering CHD
 - Conqueringchd.org
- Kids with Heart
 - Kidswithheart.org
- Band-aids and Blackboards for teens •
 - <http://www.lehman.cuny.edu/faculty/jfleitas/bandaides/contteen.html>

Questions/Comments?
Ideas for Future Topics?