

As children grow, they achieve different developmental "milestones," like learning new words or how to walk. While each child reaches these milestones at their own pace, many children with congenital heart disease (CHD) have developmental delays.

These delays can be mild and affect learning and development. To confirm if your child has a delay, your child may need a neurodevelopmental evaluation. This is a set of tests to check different skills, like cognition (thinking), language, motor (physical movement), and social skills. If a child has developmental delays, it's important they get therapy early, preferably when they're a baby.

Below is a list of developmental delays often seen in children with CHD. These are areas you can watch for as your child grows. Ask your medical team or the Cardiac Neurodevelopmental Program if you have any questions or concerns.

Fine Motor: Hard time opening hands, extending the thumb and grasping; using one hand more than the other; hard time using a crayon or picking up small objects

Language: Hearing loss; poor hand-mouth coordination; delayed language skills and not using words

Behavior: Hard to calm down; hits; bites; throws things; unable to focus or sit still; always moving around

Nutrition & Feeding: Below average height and weight for age; needs extra calories; gags or chokes while eating; has a hard time with sucking, chewing and swallowing; has reflux (spits up) or allergies; needs tube feedings; has oral (mouth) aversions; is a picky eater

Gross Motor: Decreased motor tone and strength; difficulty with trouble holding head up, playing on tummy, rolling, crawling, pulling into standing up and walking

Social: Anxiety when separated from family or around strangers; doesn't make eye contact often; not very social or friendly; doesn't make facial expressions or imitate people often; has trouble playing by themselves or with others; very anxious in the hospital and around medical professionals

Cognitive: Very tired; not interested in exploring their surroundings; hard time problem solving; difficulty with completing puzzles, peg boards and shape sorters

Sleeping: Has a hard time following routines; has trouble falling or staying asleep; doesn't want to sleep in own bed; needs extra supports to sleep



Support for Family: Families are at high risk of stress, anxiety, and depression, which can lead to physical and mental health problems of their own.

Early Intervention (EI)

Many children with CHD need support once they leave the hospital, such as physical, occupational, feeding and speech therapy. There are many resources that can help, like Early Intervention, also called EI. EI provides family-centered services for infants and toddlers up to 3 years of age with a developmental delay or are at risk for developmental delays.

For children under the age of 3 who were admitted to the hospital for cardiac disease: We recommend that you contact your local EI program, even if your child is not showing a developmental delay. Your pediatrician can make a referral to EI for you or you can contact EI yourself. In Massachusetts, the main number for EI is (617) 624-6060.

For children over the age of 3 who need developmental support: Your child might be eligible for developmental therapies through the public school and an Individualized Education Program (IEP). Your pediatrician can help you with a referral or you can also reach out to your local public school system about services.

Resources

Touchpoints Birth to 3: Your Child's Emotional and Behavioral Development, by T. Berry Brazelton, MD

The New Language of Toys: Teaching Communication Skills to Children with Special Needs, by Sue Schwartz, PhD

It Takes Two to Talk: A Practical Guide for Parents of Children with Language Delays, by Ayala Manolson

The Incredible Years: A Trouble-Shooting Guide for Parents of Children Aged 2-8 Years, by Caroline Webster-Stratton, PhD

1-2-3 Magic: 3-Step Discipline for Calm, Effective, and Happy Parenting, by Tom Phelan, PhD

Discipline: the Brazelton Way, by T. Berry Brazelton, MD and Joshua Sparrow, MD

Just Take a Bite: Easy, Effective Answers to Food Aversions and Eating Challenges, by Lori Ernspenger, PhD

Sleeping Through the Night: How Infants, Toddlers and Their Parents Can Get a Good Night's Sleep, by Jodi A. Mindell, PhD and Tania Stegen-Hanson, OTR/L

Sleeping Like a Baby: A Sensitive and Sensible Approach to Solving Your Child's Sleep Problems, by Avi Sadeh, MD

Sleep: the Brazelton Way, by T. Berry Brazelton, MD and Joshua Sparrow, MD

Contact Us

For more information and appointments, contact our **Cardiac Neurodevelopmental Program** at (617) 355-3401



Boston Children's Hospital
Cardiac Neurodevelopmental
Program

**SUPPORTING THE DEVELOPMENT
OF YOUNG CHILDREN WITH**

Congenital Heart Disease



AGES 0-3 YEARS

Activities to support your child's development

Below are a few activities you can do to help your child's growth and development. You should also discuss supporting your child's development with your child's medical team.



Gross Motor

- Hold chest to chest
- Run after bubbles
- Slowly roll from back to belly
- Play on the playground
- Spend time on belly in crawl position
- Set up an obstacle course
- Walk on different surfaces
- Ball play (rolling, throwing, kicking)

Fine Motor

- Offer objects to feel with hands and fingers
- Build/stack blocks
- Offer your finger to grasp
- Use Play-Doh, clay and sand
- Offer objects to reach and grasp
- String pasta or cereal on pipe cleaners
- Present objects at your child's midline
- Play games with finger puppets

Social

- Read your child's cues (signs of stress are a wrinkled forehead, big eyes and looking away, and crying), and help your child to rest
- Participate in playgroups
- Give soothing and low stimulation if needed
- Play social games like peekaboo, and Itsy Bitsy Spider
- Encourage interaction with children and adults

Language

- Imitate your child's cooing, laughter and facial expressions
- Repeat and expand upon what your child says
- Sing songs and nursery rhymes
- Label objects in the environment
- Use speech that is clear and simple for your child to copy
- Talk to your child often
- Ask questions

Cognition

- Have your child's hearing and vision checked
- Play imitation games
- Play together
- Limit screen time
- Have your child play with brothers, sisters, and friends
- Play make-believe or pretend play
- Use mirrors
- Play with puzzles and shape sorters
- Hide toys and help find them

Behavior

- Use visual schedules
- Use positive discipline strategies:
 - Praise for positive behaviors
 - Ignoring bad behavior and use time-outs
 - Use "do this" instead of "stop" or "don't" commands
- Use behavior charts and low-cost rewards, like stickers
- Help your child identify and name emotions
- Show how you identify and control your own emotions

Nutrition & Feeding

- High-calorie diet, if recommended by medical team
- Introduce similar foods early in feeding, rather than a wide variety
- Environmental:
 - Hold infants for feedings
 - Help your child sit upright for feeding
 - Consistent schedule
 - Make feeding/mealtimes positive
- Play games with food, like touching, smearing, and smelling
- Oral motor development:
 - Practice sucking with a pacifier
 - Oral (mouth) muscle activities like sucking straws and blowing bubbles

Sleeping

- Set a firm and consistent nighttime routine
- Avoid screen time around bedtime
- Help your child to self-soothe
- Encourage use of comfort toys/loveys
- Use a sound machine
- For children under 12 months of age, follow safe sleep on a flat surface, with baby on their back
- Use a video monitor
- Use blackout curtains and a night-light

Preparing for Surgery

- Talk to a Child Life specialist before surgery and during the hospital stay
- Bring in familiar objects during hospital stays
- Create stories about medical checkups and procedures
- During a procedure:
 - Use distraction, like blowing bubbles
 - If possible, alternate which parent supports the child during procedures
- Encourage medical play at home with dolls, bears and pretend doctor kits
- Read books for children about medical procedures

Family Coping

- Eat healthy foods
- Attempt to set aside enough time to sleep
- Eat regular meals
- Seek help for yourself such as a mental health professional and/or parent support group
- Take time for yourself such as walks, fresh air, exercise, or reading