



Developmental Delays, Learning Difficulties/Disabilities and Behavioral Issues in Children with Congenital Heart Defects (CHD)

What parents need to know:

Some children with congenital heart disease (CHD) may have neurodevelopmental delays or disorders. The term “neurodevelopmental disorder” refers to the brain’s development and how it relates to learning, behavior, social interaction, and memory issues. Not all children with CHD will experience neurodevelopmental problems, and the majority of those who do, do not have severe disabilities. ([See AHA Scientific Statement](#)). Most can be helped with appropriate testing and intervention or services. Parents need to know how to identify problems, and how to get their child help in a timely manner to maximize their child’s potential.

This handout will help you:

- Learn what types of neurodevelopmental delays or disorders are associated with CHD that can affect learning, memory, behavior and social interactions.
- Understand why children with CHD are at greater risk for these issues.
- Understand what types of testing you can get for your child.
- Discuss the connection between CHD and these issues with your physicians.
- Get appropriate help from Early Intervention (for ages birth to 3).
- Communicate with the school to help them understand how the CHD may impact learning and/or behavior and receive appropriate accommodations or services. (A link to a separate handout with an overview of 504 plans and IEPs, a sample 504 plan, a sample Health Summary form, and a Physical Restrictions form is provided.)

What are “developmental delays”?

According to the [National Dissemination Center for Children with Disabilities](#) (NICHCY), delays can occur in the following areas:

- Physical development (fine motor skills, gross motor skills)
- Cognitive development (intellectual abilities)
- Communication development (speech and language)
- Social or emotional development (social skills, emotional control)
- Adaptive development (self-care skills)

What is normal development for babies and young children?

Babies and children usually follow a pattern of development at certain ages, but this can vary widely from child to child. Make sure you understand what is typical for your child’s age, and if you have any concerns, talk to your child’s pediatrician and/or pediatric cardiologist.

The National Dissemination Center for Children with Disabilities (NICHCY) website states:

Don't be surprised if the pediatrician tells you not to worry, to be patient, to give your child more time to develop. Often, that's what parents hear, especially in the early stages of investigating their child's seeming delays. And it's often true. Children develop at different rates; the pediatrician is well aware that many children show sudden bursts in development rather than slow, steady growth.

Since children with CHD are at greater risk of delays, it is important to monitor them closely. Waiting too long for further evaluation may make it more difficult or take longer to help the child get back on track. So, remind your physician that children with CHD are at greater risk and be assertive if you think your child needs further testing now rather than later. See the Resources section for information on developmental milestones.

Why do some children with CHD have neurodevelopmental delays?

Children with CHD are at greater risk of developmental delays. "Greater risk" means that a higher percentage of children with CHD show developmental issues than children without CHD. This does not mean that every child with CHD will have developmental delays. However, they should be monitored closely throughout infancy, preschool and school years to detect any problems that may occur and to get the child appropriate help. Even those with "corrected" CHD may be at risk for some of these issues. (See the [American Heart Association scientific statement](#).)

The reasons that children with CHD are at greater risk of delays is not entirely known, and may be a complex interaction between genetics, the effects of being on a heart/lung bypass machine during surgeries, extended stays in the ICU, lower oxygen levels or other factors. (See the [video/article by Dr. Gil Wernovsky](#).)

What are some of the problems children with congenital heart defects have during infancy, preschool years and school years?

The American Heart Association published a scientific statement in 2012 that reviews studies on children with CHD and documents the types of issues that are most common. Most importantly, it gives guidelines for which tests should be performed at each age level to identify (or rule out) cognitive, learning or behavioral difficulties or disabilities. This detailed article is meant for physicians who care for children with CHD, but parents can also refer to this article for testing guidelines and to see what types of delays/disabilities are most common. (See the [American Heart Association scientific statement](#))

Below is a table with some basic explanations and examples of developmental issues children with CHD may face. Some delays can be identified during infancy (i.e. problems rolling over) but some do not show up until the child is school-aged (such as

executive function skills.) This is why constant monitoring of children with CHD is important.

Potential neurodevelopmental issues:

Developmental Skill	Description	Examples
Fine motor skills	Involves small muscle movements involving the fingers, hands, toes, mouth	Gripping, writing, feeding, speaking
Gross motor skills	Involves large muscle movements	Crawling, walking, running, jumping
visual-spatial or visual motor integration	Coordinating what the child sees into a physical response	Copying words, a picture or a paragraph (fine motor skills) or kicking a ball
Inattention	An inability to focus on tasks	Has trouble paying attention in class, inability to concentrate on a book or homework
Hyperactivity	An inability to sit still	Constant physical movement
Executive functioning	Usually involves planning, organizing, completing tasks/projects that require multiple steps	Planning a trip, writing a term paper, predicting how much time a school project will take, understanding and remembering all of the steps involved with an activity
Working memory	Ability to keep several things in mind at once	Remembering a phone number before writing it down, remembering a sequence of instructions (do A, then B, then C)
Behavioral issues such as impulsivity	Impulsivity	Acting without thinking through the consequences, blurting out verbally without taking turns
Social skills	Accurately understanding what others say and do, understanding how their actions affect others	Children with social problems may not understand social cues (i.e. if someone is irritated or upset). They may not see a correlation between their behavior and others' responses (i.e they talk loudly and others don't want to play with them.) They may be socially immature and prefer to play with younger children rather than their peers.

Please see www.LDOnline.org or www.NCLD.org for more detailed explanations and definitions of these issues.

Are learning difficulties/disabilities and behavior issues related?

Problems with neurodevelopment can lead to many different, but often overlapping issues. A child with a behavior problem (difficulty paying attention, or who is impulsive) may also have a learning disability. Therefore, it is important for parents to watch for behavioral issues as well as learning problems (trouble with reading, writing, math or language) and trouble with social issues. Any of these problems could be due to neurodevelopmental issues, and can be identified by appropriate testing.

What is a delay vs. a disorder?

If a child is not reaching certain milestones then the child may be experiencing a “developmental delay.” This may be a temporary issue that will resolve on its own or with interventions (such as physical therapy, speech therapy or other services.) “Delay” implies that the milestone will eventually be achieved, but for some children, even with interventions, the issue will continue. This is more accurately termed a “disorder” - but can still often be helped through adequate accommodations or therapies. (For example, a child with fine motor skills problems may always have trouble with handwriting, but accommodations such as using a keyboard and typing papers will help the child to successfully complete writing tasks required at school or work.) Knowing what delays/disorders your child may have enables you as the parent to get the services the child needs (if any) and to understand what accommodations can help your child be successful in school and beyond.

How do I help my child?

Watch for any of the issues outlined above. Children with any of these problems may experience more difficulties with school work or have difficulties with social interactions and making friends. The important thing for parents to understand is that if children with CHD exhibit any of these issues, getting the appropriate testing and intervention in a timely manner is vital. It can help your child succeed academically and socially and improve your child’s overall self-esteem and well-being. If you think your child has problems in any of these areas, contact your pediatrician and/or request testing from your child’s school. See the references below for information on 504 plans, and Individualized Health Plans (IEP’s) that can help your child get the appropriate help.

References/Resources:

Definitions of developmental delays and where to find Early Intervention services in your area (for children ages birth to 3):

National Dissemination Center for Children with Disabilities (NICHCY)
<http://nichcy.org/disability/specific/dd>

Developmental milestones:

American Academy of Pediatrics (Parent website) - www.healthychildren.org
Search “milestone” and age (baby, toddler, preschool)
National Dissemination Center for Children with Disabilities (NICHCY),

Age birth to 12 months: <http://nichcy.org/disability/milestones>
Centers for Disease Control and Prevention
Age 2 months to 5 years:
<http://www.cdc.gov/ncbddd/actearly/milestones/index.html>

Neurodevelopmental issues and appropriate testing at different age levels:
Marino BS, Lipkin PH, Newburger JW. et al. Neurodevelopmental outcomes in children with congenital heart disease: evaluation and management: a scientific statement from the American Heart Association. Circulation. 2012;126:1143–1172. <http://circ.ahajournals.org/content/126/9/1143.long#ref-50>

Incidence of neurodevelopmental issues by Dr. Gil Wernovsky:
<http://www.medscape.com/viewarticle/748351>

Definitions and examples of learning disabilities, and info on 504 plans and IEP's:
LDOnline: www.LDOnline.org
National Center for Learning Disabilities: www.nclld.org/

Parents' legal rights, information on 504 Plans and IEP's:
Wrights Law website: www.wrightslaw.com

Communicating with the school regarding your child's CHD: Handouts including an overview of 504 plans and IEPs, a sample 504 plan, a sample Health Summary form (a "cheat-sheet" for substitutes and other caregivers), and a Physical Activities form for the physician to fill out to clarify any restrictions.
<http://chdresources.homestead.com/Handoutsandforms.html>