



CHDResources.org

Congenital Heart Defects (CHD) And Neurodevelopmental Issues

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.

Most can be helped with appropriate testing, intervention, accommodations and/or services. Needs may arise as an infant, toddler, school-aged child, or as an adult. There are resources and ways to get help no matter the age of the person with CHD.

Since neurodevelopmental outcomes have only recently been researched by the medical community, parents need to know how to identify problems, and how to get their child appropriate help in a timely manner to maximize their child’s potential.

This handout will help you:

1) UNDERSTAND:

- What are neurodevelopmental delays or disorders and how they related to those with congenital heart defects (CHD).
- Why children with CHD are at greater risk for these issues.
- How to watch for these delays or disabilities, and how to talk with your physician about your concerns.

2) GET HELP:

- Get appropriate help from Early Intervention (for ages birth to age 3 or 5 depending upon your state).
- Get help from the school system when your child transitions from Early Intervention, or later in their school-aged years if issues develop or become more pronounced.
- Find sample forms, handouts and more information.

What is a “developmental delay” or a “developmental 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.

For some children, even with interventions, the issue will continue. This is more accurately termed a “disorder” or “disability” - but it can still often be helped through adequate accommodations or therapies. For example, a child with fine motor skills disability may always have trouble with handwriting, but receiving Occupational Therapy services, and using accommodations such as a keyboard to type papers will help the child to successfully complete writing tasks required at school or work. (An accommodation is any tool that can be used to help someone achieve a certain task.)

Knowing what delays/disabilities 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. It is also important to note that some delays or disabilities are not apparent until the child is older. This is especially true for learning disabilities and executive functioning issues, which are explained below.

Why do some children with CHD have neurodevelopmental delays/disabilities?

Children with CHD are at greater risk of developmental delays/disabilities. “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.

There are many possible reasons that children with CHD are at greater risk of delays. Current research indicates that any of these factors, or a combination of factors may be responsible:

- Genetics and genetic disorders (some which may be identified)
- Delayed brain development
- Malnutrition due to problems with feeding.
- The effects of being on a heart/lung bypass machine or deep hyperthermic circulatory arrest (DHCA) during surgeries due to lack of oxygen
- Extended stays in the ICU
- Lower oxygen levels (cyanosis) over an extended period of time
- Other factors

Some studies have shown that babies with severe congenital heart conditions, such as Hypoplastic Left Heart Syndrome (HLHS) often have brains that are similar to brains of premature babies, even when they are born full term. This indicates that even before the surgeries or other environmental factors, some children born with serious heart defects may be at higher risk of developmental delays or disabilities.

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

Several researchers are studying the effects of congenital heart defects on learning and behavior. 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, and share with your physician

How do I know if my child is developing normally?

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. 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 so you can compare your child's development with typical developing peers.

What types of delays or disabilities are there?

Delays or disabilities can occur in the following areas (see examples below):

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

The table below offers 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 issues such as learning disabilities may not become apparent until the child is school-aged.

Potential neurodevelopmental issues:

Developmental Skill	Description	Examples	How this can “adversely affect educational performance”*
Physical			
Fine motor skills	Involves small muscle movements involving the fingers, hands, toes, mouth	Gripping, writing, feeding, speaking	Hard to handwrite, take notes, communicate, eat
Gross motor skills	Involves large muscle movements	Crawling, walking, running, jumping	Hard to play sports, get around the campus, sit in a chair
Cognitive			
Learning disability	A specific learning disability occurs when a child has trouble with reading, writing, math, or other areas that is unexpected due to their overall cognitive abilities.	Dyslexia is an example of a reading disorder that affects people of average to above average intelligence. It interferes with the way to brain functions, impeding the quick, automatic reading ability that most others acquire. Other learning disabilities can occur in listening, math, or in the ability to write (put thoughts on paper) and in other areas.	Creates difficulties in learning age and grade appropriate materials.
Visual-spatial or visual motor integration	“Eye-hand coordination” This is a complex cognitive ability that requires us to visualize something, process that information, then use our motor skills into a	Copying words, a picture or a paragraph onto paper.	Difficulty writing notes, performing some assignments

	physical response.		
Inattention	An inability to focus on tasks.	Has trouble paying attention in class, inability to concentrate on a book or homework.	Difficulty following directions, difficulty completing tasks.
Executive functioning	Usually involves planning, organizing, and completing tasks/projects that require multiple steps	Writing an essay, predicting how much time a school project will take, organizing and prioritizing homework, understanding and remembering all of the steps involved with an activity.	Difficulty following through with homework or assignments, making plans with friends
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)	Difficulties with math calculations, writing down thoughts
Behavioral			
Hyperactivity	An inability to sit still	Constant physical movement	Difficult to sit in class
Impulsivity	Acting without thinking through the consequences	Blurting out verbally, not taking turns, hitting others, eloping (leaving without permission.)	Difficult to pay attention, impedes social skills.
Speech/Language			
Communication	Receptive (receiving information)	May not understand others' words or actions.	Hard to listen to teacher instructions, difficulties with social interactions.
Communication	Expressive (how the child expresses him/herself.)	Has trouble expressing thoughts or feelings.	Trouble with self-advocacy – expressing wants and needs. Difficulty with relationships.
Social/Emotional			
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	Social skills relate to education since children need to work with others on projects.

		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.	
Anxiety	Fear, worry, nervousness	Exaggerated worry over tests, homework, friends, irrational fears/phobias	

*Special education laws are meant to prepare children for life after school, and function in the outside world. So, "education" encompasses much more than just academics. Schools are also responsible for "functional" skills that are routine activities of everyday living such as behavioral, communication and social skills.

Are learning difficulties/disabilities and behavior issues related?

Problems with neurodevelopment can lead to many different, but often overlapping issues. For example, a child with a behavior problem (difficulty paying attention, or who is impulsive) may also have a learning disability. In some cases, the learning disability or social skills problem makes the child frustrated or bored, and can lead to behavioral issues. 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.

How can I help my child?

1) Watch for signs

Continue to watch for any of the issues outlined above, as different delays or disabilities may appear throughout childhood and adolescence. 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, behaviorally and socially and improve your child's overall self-esteem and well-being.

2) Check with your physician

If you think your child has problems in any of these areas, contact your pediatrician first to see if your child is lagging behind in milestones. Remember, that any delay should be taken seriously because of the high risk associated with CHD.

3) Know your child

Understand your child's medical condition and any issues that put him or her at greater risk for developmental delays or disabilities.

4) Know the laws

Learn about Early Intervention, school health plans, 504 plans and Individual Education Plans (IEPs). The laws can be confusing, and you may get conflicting information from the school about what is best for your child.

- A Health Plan is an informal plan, and there is no legal accountability if it is not followed by the school or district.
- A 504 plan is for students who need accommodations and/or certain services. Violations of 504 plans are accountable to the American's with Disabilities Act.
- An Individualized Education Plan (IEP) is for students who qualify for special education and related services. Special education offers the most legal protections under the Individuals With Disabilities Education Act (IDEA.) When requested by a parent, the school is obligated to assess in all areas of suspected disability since these issues greatly impact a child's education. Examples are physical issues, social/emotional issues, behavioral issues, executive planning, etc.

5) Consider getting a neuropsychological assessment

A neuropsychologist is a psychologist with experience in medical and neurological issues. In some circumstances, you may be able to get the school district to pay for it, or your insurance may cover it, or you may need to pay for it out of pocket. This type of assessment by someone familiar with congenital heart defects may help to explain the connections between the heart condition and any learning or behavioral issues.

6) Keep up on the information

Look through the resources given below to read more information on the areas that may affect your child. Neurological development in patients with CHD is a relatively new area of study, so not all physicians will have experience with this or understand how CHD relates to the issues outlined above. In addition, physicians do not always understand how the school system works, so it is up to parents to learn about how CHD can affect their child overall, and also learn about the school system in order help your child reach his/her maximum potential. There is a lot to know, and there are lots of resources and specialists that can help you. See the Resources and References below for good, reliable resources.

References and Resources

Neurodevelopmental Outcomes in those with Congenital Heart Disease

["Neurodevelopmental Outcomes of Children with Congenital Heart Disease"](#) (Video – Aug 2017)

Description: “In this video, Dr. Jane Newburger, Associate Cardiologist-in-Chief at Boston Children's Hospital and Commonwealth Professor of Pediatrics at Harvard Medical School, shares her expert's perspective on the current state of understanding of neurodevelopment in children with congenital heart disease.”

Comment: This is a detailed overview of the research that has been done on neurodevelopmental issues that affect those with CHD. Dr. Newburger does a wonderful job at explaining the risk factors, how these issues affect patients and what the medical profession is doing to prevent or reduce these issues. The video is about 46 minutes long. Here are some of the main areas discussed at certain points of the video if you want to skip to the part that is most applicable to you:

- First 25 minutes – Research and known risk factors for CHD patients in neurodevelopmental delays (lesser brain maturation at birth, malnutrition/feeding issues, cardiac arrest, arrhythmias, length of hospital stay, oxygen levels)
- @ 25 minutes – Types of Neurodevelopmental delays seen in those with CHD
- @ 29 minutes – Single Ventricle patients
- @ 32 minutes – Fontan adolescent patients
- @ 38 minutes – Adults with CHD and the future

Neurodevelopmental issues and appropriate testing at different age levels: (Detailed study written for physicians)

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.

Developmental milestones:

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

Centers for Disease Control Milestone Checklists:
https://www.cdc.gov/ncbddd/actearly/pdf/checklists/all_checklists.pdf

Parents' legal rights, information on learning disabilities, 504 Plans and IEP's:

LDOnline: www.LDOnline.org
Good descriptions of learning issues and disabilities

National Center for Learning Disabilities: www.nclld.org/
Learning and attention issues.

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Parent Center Hub - <http://www.parentcenterhub.org/>
Find a Parent Center near you that offers free information

Individuals with Disabilities Education Act (IDEA) – special education law
<https://www2.ed.gov/policy/speced/guid/idea/idea2004.html>

Section 504 of the Rehabilitation Act of 1973
<https://www2.ed.gov/about/offices/list/ocr/504faq.html>

Wrights Law website: www.wrightslaw.com
This is a wealth of information for parents which explains your rights, how to work with the school, how to document issues, etc.

Council of Parents, Attorneys and Advocates (COPAA) – www.copaa.org
This organization works to educate those interested in special education. It has the only year-long, national advocacy training program to teach parents and others about special education law, and how to advocate for yourself and others. Parents can find good, reliable information as well as lists of advocates and attorneys in your area.

CHD Resources - chdresources.homestead.com/Handoutsandforms.html

- An overview of 504 plans and IEPs
- A sample 504 plan
- A sample Health Summary form (a “cheat-sheet” for substitutes and other caregivers)
- A Physical Activities form for the physician to fill out to clarify any restrictions.

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