



Overview of Services for Children with CHD

*Early Intervention (IFSP), 504 Plans,
Individual Health Plans (IHPs) and
Individualized Education Plans (IEPs)*

Infants with congenital heart defects (CHD) may experience developmental delays and need help with feeding issues and/or muscle coordination and strength. Sometimes these issues resolve by age 2 or 3, and sometimes children will continue to need services throughout the preschool and school-aged years.

Some children with CHD will benefit from educational help at school due to developmental or learning difficulties or disabilities. To learn what developmental delays or learning disabilities are sometimes associated with CHD, please see our [handout on developmental delays and learning/behavioral issues](#) for more information.)

Many children with CHD will not need educational services or therapies, but have health issues that need to be communicated effectively to the schools and caregivers to ensure the child's physical safety. This brief guide is meant to serve as an overview of how to seek services for your child if needed, and communicating your child's health needs to the school administrators, teachers, and staff.

Potential plans by age

Age	Agency	Potential Plans
Birth to age 3	Early Intervention services, (often through county Regional Centers)	Individual Family Service Plan (IFSP)
Ages 3 to Kindergarten	Public school district	IEP
Kindergarten – 12 th grade	Public school district	IEP, 504 plan, IHP
College	Need to self-identify	504 plan

Early Intervention (ages birth to age 3):

Infants with CHD often need help with feeding issues, and/or fine and gross motor skills. Through Early Intervention, these young children can receive free physical therapy, occupational therapy, speech therapy (for speech and feeding issues) and other

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services. Talk with your child's pediatrician to see if your child may qualify for these services. You will need to contact the [Early Intervention services in your area](#) to schedule an evaluation. If the child qualifies, an Individual Family Service Plan (IFSP) will be created to provide appropriate services and monitor your child's progress.

Preschoolers (age 3-5)

Once children reach the age of 3, services transition to the public school system. Because the criteria for services at this point is different, many children who received Early Intervention services will not qualify for services. Those who do may receive free preschool services and/or therapies such as speech, occupational therapy or physical therapy.

School aged children (K-12)

With children spending the majority of their day at school, it is important that school administrators and teachers understand the child's medical, academic and social needs. Some children with CHD may need minor accommodations while others may have more complex conditions or special educational needs, so parents need to clearly communicate these issues to the school in a simple, effective manner.

The following information is a brief outline of the types of documents you may use to communicate with the school. Some parents choose to communicate verbally, but please know that having information in writing helps protect you and your child, and makes it easier for the correct information to be given to ALL of the appropriate people at school including – teachers, aides, substitutes, office staff, recess aides, parent volunteers who chaperone field trips and/or others.

It is up to you to decide what information you want the school to know, and who at the school you wish to share that information with. Schools are required to keep information confidential and only communicate to those directly involved, so make sure to give the administrators and teachers permission in writing to share with others, if you deem it necessary or beneficial to your child.

Types of plans to consider for your child:

- Individualized Education Plans (IEP)
- 504 Plan
- Individual Health Plan (IHP)

What is an IEP?

An IEP stands for "Individualized Education Plan." This is a plan that is created for children that have a disability that affects academic performance. It falls under the federal law - Individuals with Disabilities Education Act (IDEA) – which is designed to ensure that qualified children with disabilities receive educational services.

Parents must request testing to see if a child qualifies for any type of educational services such as speech therapy, or academic help with the resource teacher. An IEP is the most stringent document with strict legal rules and guidelines for the schools to follow. Federal funding for the school can be denied if these rules are not followed exactly. To have your child tested, request testing IN WRITING to the school. Sometimes this request needs to go to the principal or the school psychologist. See the [AHA Scientific Statement](#) for specific testing guidelines for children with CHD.

Requesting an IEP:

- Testing is not automatic. You need to request this testing from the school or district IN WRITING. Find out to whom the request should go (principal, school psychologist, etc.)
- Once you request the testing, the school has a certain amount of time to perform the testing and determine eligibility. The timelines vary from state to state, but are often 60 days from the time of the request for testing to complete the testing. This can be 60 calendar days, 60 business days (does not include weekends), or even 60 school days – which means a huge delay over the summer months or holiday breaks. An IEP meeting will then be held to go over the testing results. So, it may be several months between when you request the testing, eligibility is determined, and when services can actually start.

Eligibility:

- Understand the criteria used by your public school district to determine if your child would qualify for services. There are 2 main methods of eligibility: Discrepancy model or Response To Intervention.
 - Discrepancy model – Some schools require that a discrepancy exist between the child’s IQ and academic performance. The benefit of this model is that it is primarily objective – if there is a certain difference between these scores, the child automatically qualifies. However, this large difference in scores can mean that the child is up to 2 years or more behind academically, making it difficult to get the child caught up.
 - Response to Intervention (RTI) model - Sometimes schools want to try other interventions before testing the child. For example, a child who is having difficulty reading may be put in an afterschool reading class. While this may help some children, this approach essentially uses a “trial and error” method. Without prior testing, there is no way to know if the interventions implemented will have any effect. Testing may be postponed until many methods are attempted, which can waste precious time in getting the appropriate help.

Even if your child qualifies for an IEP, the services offered to your child may not be adequate. For example, your child may be very behind in math, and will be pulled out by the resource teacher once a week with a group for some extra time. Consider if that would be enough to achieve the goals, and consider if the child would miss out

on any instruction or other activities when “pulled-out” for services. Some parents prefer to pay for outside tutoring rather than have the child “pulled out” which can make some children feel self-conscious.

Other things to know about IEPs

- You can have your child tested through a private psychologist (at your expense), however, schools may not accept these tests. They often want to use their own results. If you do private testing, you can share this with the school, which will remain in your child’s record, or you may choose to keep those results private.
- Private schools do not have to follow IEPs, because they are only enforced for schools which receive federal funding. (However, some private schools offer resource teachers and help children with special needs.)
- If your child attends a private school, your child can be tested for an IEP through the public school district. This is often a good idea to have in place in case your child attends public school in the future.
- If your child receives an IEP – think carefully before ever stopping services. Once an IEP is discontinued, it can be nearly impossible to reinstate it. Even if you have an IEP and are at a private school, keep the IEP in place (with the public school district) in case your child ever returns to private school.
- The older the child gets (junior high and high school) the harder it is to receive an IEP. If you have concerns about your child, try to get the testing done early in elementary school.
- You do not need a separate 504 plan if you have an IEP. The accommodations will be listed under the IEP.

What is a 504 Plan?

Section 504 is a federal law designed to protect the rights of individuals with disabilities in programs and activities that receive federal funds from the U.S. Department of Education. A 504 plan helps ensure that children are not excluded from activities due to their disability. A 504 plan may be used when an IEP is not necessary (the child does not need educational services), but the child needs certain accommodations. Parents need to meet with the school officials to get a written plan in place which includes a plan for alerting substitute teachers to the plan and any necessary accommodations.

The definition of a disability is quite long and complex. According to the US Dept of Education, “The determination of whether a student has a physical or mental impairment that substantially limits a major life activity must be made on the basis of an individual inquiry.” This means that the child must 1) have an impairment and 2) that impairment “substantially limits a major life activity.”

1. Several conditions are given as examples of “physical or mental impairment.” Some that may be applicable to those with CHD include: neurological; respiratory, cardiovascular; intellectual disability, or specific learning disabilities.

(Please see [U.S. Department of Education](#) for the whole list of potential impairments.)

2. Some examples of “major life activities” which may be pertinent to those with CHD include: breathing, learning, concentrating, thinking, and communicating as well as “major bodily functions” such as the immune system, neurological, brain, respiratory, or circulatory systems. (See the [U.S. Department of Education](#) for the whole list of “major life activities.”)

Things to know about 504 plans:

- A child with a disability (see definition above) does not have to illustrate any problems with educational performance. A 504 is merely to create “a level playing field” by providing accommodations, and does not provide any educational services to the child.
- A medical diagnosis is NOT sufficient for a 504 plan. The medical condition MUST substantially limit one or more “major life activities.” (see above)
- Private schools also need to comply with 504 plans, because it is a federal protection for those with disabilities. Enforcement is not related to federal funding of the school, as are IEP’s.
- The use of [Assistive Technology \(AT\)](#) can help students of any age (without giving an “unfair advantage.”) Many types of AT tools exist: keyboarding instead of handwriting, using software that reads text to the student, using talking calculators, and tape-recording classes or lectures are just a few examples. Take some time to research what devices or tools may help make your child’s academic experience more productive and positive.

Examples of accommodations for children with CHD may include:

(See our [Sample 504 Plan](#) for more examples.)

- being allowed to walk instead of run during physical education
- being allowed to rest if tired after physical activity
- having access to shade and water at all times
- having a second set of books at home so he or she does not have to carry heavy books back and forth to school
- allowing for more absences due to medical condition
- the use of [Assistive Technology \(AT\)](#) devices or tools.

What is an Individual Health Plan (IHP)?

An IHP is a health plan created by the school for a child with medical needs (allergies, asthma). This would include treatments such as medications, and emergency procedures for a child with a life-threatening condition. This is the least restrictive type of plan and does not necessarily include accommodations for a child with disabilities. Determine if your child needs accommodations, and if so, request a 504 plan instead.

College

IEPs are not applicable at the college level, however, those with disabilities under Section 504 may still receive accommodations. The definition of disability and requirements for services for those attending college are different than for children in elementary, junior and high school. However, college students may still receive “appropriate academic adjustments and auxiliary aids and services” in order to create an equal opportunity for the student with a disability. Auxiliary aids and services may include [Assistive Technology \(AT\)](#). See the [U.S. Department of Education](#) to see how students with disabilities can receive the necessary help.

References/Resources:

NICHCY:

- Early Intervention by state – <http://nichcy.org/state-organization-search-by-state>
- (For birth to age 3. Select “agency” and state, search for “Early Intervention”)
- Services of Preschoolers (ages 3-5) - <http://nichcy.org/schoolage/preschoolers>
- Developmental disabilities and milestones - <http://nichcy.org/disability/specific/dd>

U.S. Department of Education:

IEP Guide for parents: www.ed.gov/parents/needs/speced/iepguide/index.html

504 Plans: www.ed.gov/about/offices/list/ocr/504faq.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>

Definitions and examples of learning disabilities, 504 plans and IEP’s:

LDOnline: www.LDOnline.org

National Center for Learning Disabilities: www.nclld.org

Legal rights of parents, detailed information on 504 Plans and IEP’s:

Wrights Law website: www.wrightslaw.com

CHDResources.org handouts/forms:

<http://chdresources.homestead.com/Handoutsandforms.html>

- Developmental, behavioral and learning issues in children with CHD
- Sample 504 plan

- Sample Health Summary form (a “cheat-sheet” for substitutes and other caregivers)
- Physical Activities form for the physician to fill out to clarify any restrictions

College resources for those with disabilities:

Wrights law: <http://www.wrightslaw.com/flyers/college.504.pdf>

LDOonline: <http://www.ldonline.org/article/6082>

Assistive Technology (AT) – tools to help students with disabilities

LDOonline - <http://www.ldonline.org/article/33074/>