

I **HAVE** Chiari
(kee-AR-ee)

Taking Chiari to School: A Guide for Parents

Prepared by Suzanne Oró, RN, MSN-ed

This guide is dedicated to the parents of children with Chiari who tirelessly advocate for their children both in the school and community setting

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From Knowledge, Strength. Through Research, Hope.

This guide does not provide medical advice and is intended for general information purposes only. It is not a substitute for professional medical advice, diagnosis or treatment. Always seek the advice of your physician or other qualified health provider with any questions you may have regarding medication, medical conditions or treatment or before you begin a treatment program. Always speak to your healthcare provider if planning to make a change to your lifestyle or health habits. | Copyright 2012 C&S Patient Education Foundation.

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Introduction

Parent and School Relationship

Parents are important to their child's success in the school setting. Research studies on the effects of parent involvement upon student success reveal a significant effect upon the student's success and cognitive, emotional, and behavioral performance (Mo & Singh, 2008). This continues to be an important aspect of your child's success as he or she progress through middle school and high school, a time associated with the child's increasing independence and time away from the family.

A positive parent-school relationship is critical when a child has a disability or health condition like Chiari. A collaborative approach, working with school staff to promote your child's success, is in your child's best interest. As a parent, your positive involvement at school and your relationship with the school affects your child's cognitive, emotional, and behavioral performance at school. This guide is intended to provide you with information to assist you as you navigate the school environment and help your child with Chiari succeed.

Laws that Affect the Education of Students

The four primary laws that affect the education of children with disabilities or health impairments are the Individuals with Disabilities in Education Act commonly known as IDEA, The Americans with Disabilities Act known as ADA (ADAA, 2008), Section 504 of the Rehabilitation Act of 1973 referred to with 504-plans, and state laws.

IDEA

Individuals with Disabilities in Education Act

The Individuals with Disabilities in Education Act (IDEA) requires public schools to make available to all eligible children with disabilities a free appropriate public education (FAPE) in the least restrictive environment (LRE) appropriate to their individual needs. A qualifying disability under IDEA provides your child with access to an evaluation for an Individual Education Program more commonly known as an IEP. The IDEA definition of disability is strictly defined and based upon the need for specialized educational instruction (Zirkel, 2009).

ADA ADAA (2008)

Americans with Disabilities Act (Amended, 2008).

The Americans with Disabilities Act (ADA) underwent revision and amendment in 2008 resulting in the Americans with Disabilities Act Amendment (ADAA). Significant changes included an expanded scope of the definition of major life activities, no longer considers mitigating measures, except vision correction, clarifies that the disability must be viewed within the frame of the impact of disease if it were fully active and cannot be discounted if it is episodic or in remission (Sampson & Galemore, 2012, United States Department of Education, 2009).

Section 504 of the Rehabilitation Act of 1973

Section 504 of the Rehabilitation Act of 1973.

Section 504 of the Rehabilitation Act of 1973 states that qualified individuals with a disability will not be excluded from or discriminated against by any public institution or organization receiving federal funds. Section 504 of the Rehabilitation Act expands the definition of a disability into the following broad and simple definition: a disability is a mental or physical impairment that substantially limits one or more major life activities (United States Department of Education, 2009).

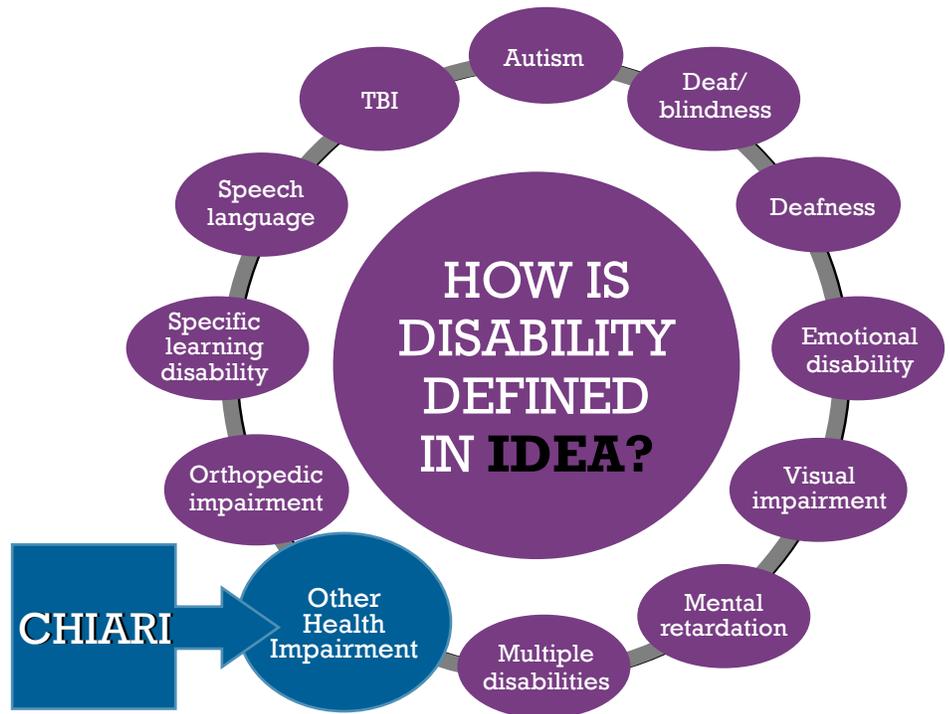
State Laws

State Laws

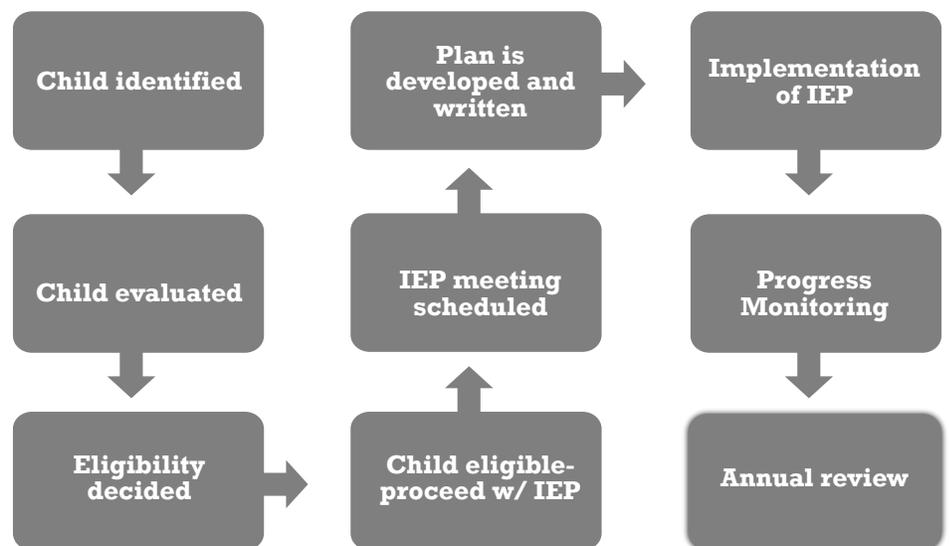
Individual states sets eligibility requirements and determine ages for services to children and youth with disabilities. Access to your states information can be located through your states Department of Education Office of Special Education. This information can be accessed through the National Dissemination Center for Children with Disabilities at <http://nichcy.org/state-organization-search-by-state>

What is an IEP?

An IEP is an individual education program. IEPs are for students with a qualifying disability under IDEA who require specialized instruction and services in the school setting to receive a free and appropriate public education in the least restrictive environment. The IEP, developed by a collaborative team, includes the school administrator, special services providers, general education teachers, special education teachers, the parents or guardians of the child, and the child. The IEP outlines the child's present assessment information and abilities, the targeted and intense interventions and specialized instruction the child will receive, the goals of the IEP, and the accommodations the child requires to promote success. The IEP involves progress monitoring during the implementation of the IEP to track the child's response to the interventions (National Dissemination Center for Children with Disabilities, 2010). The IEP is reviewed annually, upon parent request, during transitions to new schools, and if the child's progress or lack of progress warrants a review of the IEP. Not all children with Chiari qualify for an IEP.



DISABILITY IN IDEA requires the student have a qualifying disability listed above and experiences a lack of academic progress requiring specialized instruction or services. **SPED** is an educational acronym used in the school setting. SPED represents **s**pecial **e**ducation. When a child is identified in the school setting who may benefit from and qualifies for an IEP the law dictates a very specific process with timeframes for completion. The process includes procedural safeguards to protect the child's rights to FAPE in the LRE. Not all children with Chiari qualify for an IEP. Below is the SPED process under IDEA and outlined clearly by the National Dissemination Center for Children with Disabilities (2010).



SPED PROCESS UNDER IDEA

WHAT IS A 504 PLAN?



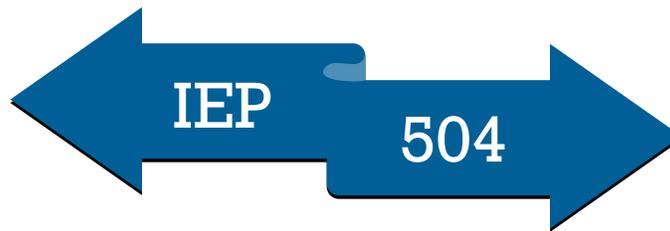
A 504-plan is legal document for students with disabilities who do not require specialized academic instruction; however, these students need the assurance that they will receive equal access to a free and appropriate public education (FAPE) and services (Sampson & Galemore, 2012). Section 504 of the Rehabilitation Act expands the definition of a disability into the following broad and simple definition: **a disability is a mental or physical impairment that substantially limits one or more major life activities** (United States Department of Education, 2009). This expansive and broad definition increases the number of children with a disability who qualify for accommodations in the school setting.

Children with Chiari may have specific accommodations dependent upon personal needs, extent of disability, and the disability’s effects on the school environment; however, a child with Chiari who is asymptomatic and has no restrictions may not require a 504-plan. The Olathe Public School District in Kansas developed a list of warning signs indicating a possible need for a 504-plan including frequent or excessive absences, frequent visits to the school nurse, medical reports indicating a serious health concern, low level of self-care ability of a student, the need for multiple staff members to be aware of a students health condition, and mental health concerns including threats of suicide (Sampson & Galemore, 2012).

The 504-plan is shared with education professionals in the school setting who need to know of the accommodations required for the specific student. Students with 504-plans do not require specialized instruction or monitoring. A 504-plan, like the IEP, should be updated annually to ensure that the student receives the most appropriate accommodations for his or her specific circumstances. The goal of the 504-plan is to “level the playing field” (Sampson & Galemore, 2012).

The 504-plan follows your child to post-secondary educational settings. Students with existing 504-plans in K-12 education are required to begin transition planning to prepare for post-secondary education where the responsibility for disability disclosure shifts to the student. This transition planning must begin at age of 16 years and should include weaning the student from accommodations not permitted in higher education (Shaw, 2009).

HOW DO I KNOW THE MOST APPROPRIATE PLAN?



This is a confusing question for parents to address when they are confronted with their child's Chiari diagnosis. The plan or program that your child may qualify for is determined by the different definitions of disability found in both IDEA and Section 504. Additionally, the child's academic progress, or lack of progress will assist in determining the most appropriate plan. This is a question best addressed by the collaborative team including parents, school administration, special service providers, classroom teachers, and the school nurse.

There are two primary types of educational programs, general education programs and special education programs. General education programs are based upon national education standards to meet the need of the majority of the population. Special education programs involve targeted and intensive interventions for the child who is not making progress academically or requires services in the school setting. A child with an IEP is involved in the special education program and the child with a 504-plan is enrolled in general education with accommodations.

Where will my child fit in?

If your child has an IEP or 504-plan, he or she is not alone. According to the National Center on Educational Statistics in the year 2010 approximately 50 million students were enrolled in public schools. Of these students approximately 12-15% of students were enrolled in a special education program. Data from 2004 estimates 1.2% of students had 504-plans (Zirkel, 2009); however, schools report increasing trends in the development and implementation of 504-plans after the 2008 amendment of the Americans with Disabilities Act expanding the definition of disability (Sampson & Galemore, 2012). Every child with Chiari will have different needs in the school setting. The assessment and placement process must be individualized for each child and completed with input from the collaborative team.

What is an Individual Health Plan (IHP)?

Chiari malformation type 1 (CM1) Individual Health Plan

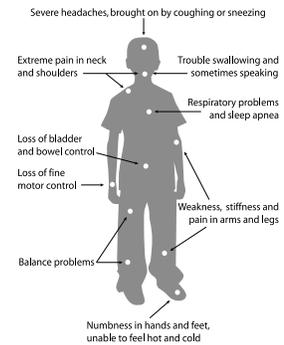


I HAVE Chiari

The Chiari Malformation Type One (CM1) is the dropping of the cerebellar tonsils of the brain (not the tonsils in your throat) into the opening from the brain to the spinal canal.

Normally, only the spinal cord passes through this opening called the foramen magnum.

The most common presenting symptom in children is pain reported by the child as a headache or neck and shoulder pain. Circle symptoms that apply to this student.



An individual health plan (IHP) is a document prepared for students that outlines how health conditions are managed in the school setting. The development of the individual health plan is a collaborative effort that includes families, school nurses, school staff, and health care providers and is reviewed annually by this collaborative team. An IHP is not an educational plan like an IEP or 504-plan; however, it may be included in the IEP and 504 as a supporting document for the provision of accommodations (NASN, 2008).

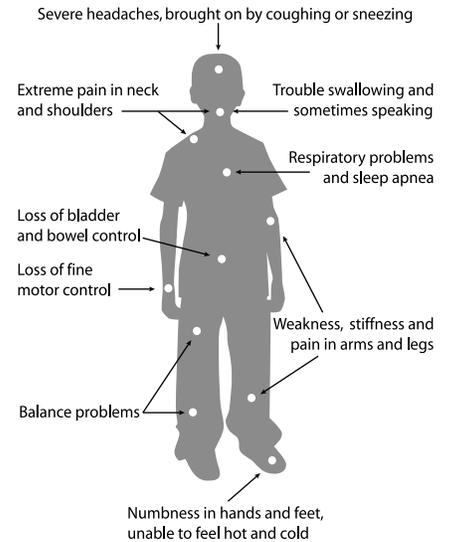
The child's need for an IHP is based on required nursing care. The IHP will include doctor's orders that are implemented in the school setting, medication administration, communication with the parent, and staff direction on proper response to the child's presenting symptoms in both chronic and emergency situations. Also noted on the IHP is the special training of school personnel to assist the child with timely and appropriate interventions. A school nurse may not always be present in the school to respond to the child's needs. Therefore a health aide or secretary will undergo training, known as delegation, to safely implement interventions for the child (NASN, 2008). Pictured above is a draft of a standardized IHP developed for the CM1. It includes a definition of CM1 and symptoms. Data fields allow for the customization of the plan for the child. Children with CM1 will have different symptoms, different needs, and their IHP will require customization to reflect this.

Chiari malformation type 1 (CM1) Individual Health Plan



I HAVE Chiari

The Chiari Malformation Type One (CM1) is the dropping of the cerebellar tonsils of the brain (not the tonsils in your throat) into the opening from the brain to the spinal canal. Normally, only the spinal cord passes through this opening called the foramen magnum. The most common presenting symptom in children is pain reported by the child as a headache or neck and shoulder pain. Circle symptoms that apply to this student.



Health Concern: _____

Student name: _____	Parent or Guardian: _____
Grade/ Student ID #: _____	Contact information: _____
Academic year: _____	Emergency Contact: _____
Teacher: _____	Doctor: _____
Allergies: _____	Other health conditions: _____

Nursing Assessment: _____

Expected Outcome: _____

Intervention: _____	Staff Persons Involved: nurse, delegated staff, staff working w/ child
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Implementation: _____

Evaluation Plan: _____

Items needed: _____	Persons Responsible: _____	Deadline: _____
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Nursing Assessment:

Expected Outcome:

Intervention:

Staff Persons Involved: nurse, delegated staff, staff working w/ child

[Redacted area for Intervention]

[Redacted area for Staff Persons Involved]

Implementation:

[Redacted area for Implementation]

Conclusions:

[Redacted area for Conclusions]

Items:

[Redacted area for Items]

Persons Responsible:

[Redacted area for Persons Responsible]

Deadline:

[Redacted area for Deadline]

Nursing Assessment:

Expected Outcome:

Intervention:

Staff Persons Involved: nurse, delegated staff, staff working w/ child

[Redacted area for Intervention]

[Redacted area for Staff Persons Involved]

Implementation:

[Redacted area for Implementation]

Conclusions:

[Redacted area for Conclusions]

Items:

[Redacted area for Items]

Persons Responsible:

[Redacted area for Persons Responsible]

Deadline:

[Redacted area for Deadline]

I give permission for the information on this care plan to be shared with the listed health care provider of my child and adult staff at the school that will be working with my child. This plan will remain in force for 1 year from approval date. It is the responsibility of the parent to notify the school nurse whenever there is a change in the health status of the child. Signed parent permission allows the school nurse or delegated staff to contact the health care provider as necessary and authorizes staff members to seek emergency medical assistance for my child

Signature of Parent/Guardian Date

Signature of School Nurse Date

Resources for parents

Following are four resources for parents to obtain information on education law, assistive technologies, and pediatric Chiari.

Parent Technical Assistance Centers

Parent Assistance Resource Centers

Provides parents access to extensive resources and workshops, evidence-based information, and technical assistance to improve the lives of families with disabilities. Centers are available in all states and to find the one nearest you visit:

<http://www.parentcenternetwork.org/parentcenterlisting.html>

National Dissemination Center for Children with Disabilities

National Dissemination Center for Children with Disabilities.

Serves as the national clearinghouse for children with disabilities from birth to 21 years. Provides access to easy to read information on education laws, access to state specific information, and referral to local organizations.

Visit: <http://nichcy.org/>

Conquer Pediatric Chiari

Conquer Pediatric Chiari is a section within Conquer Chiari,

also known as the C&S Patient Education Foundation. Fact sheets, access to social networking with other Chiari families, and opportunities to become actively involved with the organization are available at:

<http://www.conquerchiari.org/pediatric/pediatric-index.html>

Technology

Technology. Is there an APP for this?

Emerging technologies are assisting parents as they struggle to keep up with the navigating the complexities of the educational environment with a child with a disability. For more information on an application to assist with IEP information visit:

<http://itunes.apple.com/au/app/myiepmeeting/id479474205?mt=8>

Documentation for the School

An essential aspect of the relationship with the school is appropriate and timely communication and documentation regarding your child's needs. A 504-plan, IEP, and IHP will require doctor verification of the Chiari Malformation Type One (CM1) diagnosis from your child's physician. A doctor verification letter should come from your child's physician on their letterhead and contain the following information:

- Diagnosis with definition
- Associated comorbidities (other illness or associated conditions)
- Current treatment recommendations and physician orders
- Activity restrictions
- Doctor's contact information

This information should be given to the school administrator, copied to the school nurse, and will become a part of your child's permanent academic record. Following is a sample letter of introduction to the building administrator to begin the development of the collaborative relationship that benefits your child's success.

Date

Dear [name of school Administrator](#),

My child [child's name](#) is diagnosed with the Chiari Malformation Type One. The Chiari Malformation Type One (CM1) is the dropping of the cerebellar tonsils of the brain (not the tonsils in your throat) into the opening from the brain to the spinal canal. Normally, only the spinal cord passes through this opening called the foramen magnum. [Childs name](#) experiences the following symptoms that may affect his activities of daily living and performance in the school setting. [List symptoms](#).

I write to request a meeting with you to discuss my child's health condition and the accommodations [he/she](#) may need in the school setting to promote [his/her](#) school success and safety. Please feel free to contact me at [phone number](#) to set up a meeting.

I look forward to developing a long-term collaborative relationship with the school to promote my child's school success. Many thanks for your kind attention to my request.

Sincerely,
[Parent name](#)
[Contact information](#)

Glossary of Educational Acronyms

The language of education and what it means for your child's success.

ADAA 2008(ADA)

AMERICANS WITH DISABILITIES ACT AMENDED 2008

“a disability is a mental or physical impairment that substantially limits one or more major life activities”
(U.S. D.O.E., 2009)

FAPE

FREE AND APPROPRIATE PUBLIC EDUCATION

This specific terminology is from the Individuals with Disabilities in Education Act (IDEA) describing your child's educational rights.

FERPA

FAMILY EDUCATIONAL RIGHTS TO PRIVACY ACT

School health records that contain private health information are academic records under FERPA. HIPPA does not apply to schools except in school-based health centers.

IEP

INDIVIDUAL EDUCATION PROGRAM

An educational program written by a collaborative team providing intense and targeted interventions and specialized services to children with qualifying disabilities under IDEA.

LRE

LEAST RESTRICTIVE ENVIRONMENT

IDEA requires student access to classroom instruction with their non-disabled peers to the greatest extent possible in the least restrictive environment.

IDEA

INDIVIDUALS WITH DISABILITIES IN EDUCATION ACT

IDEA requires public school to provide a free and appropriate public education in the least restrictive environment.

IHP

INDIVIDUAL HEALTH PLAN

A customized individual health plan provides instructions for management of student health conditions in the school setting during both chronic and emergency situations.

504

SECTION 504 OF THE REHABILITATION ACT OF 1973

A 504-plan is a legal document outlining a student's specific accessibility requirements through the provision of accommodations.

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Parent Checklist

- Willingness to Collaborate
- Doctor Verification Letter
- Letter of Introduction to Building Administrator
- Information for Individual Health Plan
- Positive Attitude

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