CONQUER CHIARI®

RESEARCH CENTER

CONQUER CHIARI®

From Knowledge, Strength. Through Research, Hope.

Taking Chiari to School:

What is an IEP?

An IEP is an individual education program. IEPs are for students with a qualifying disability under IDEA (see below) 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 —

A Guide for Parents

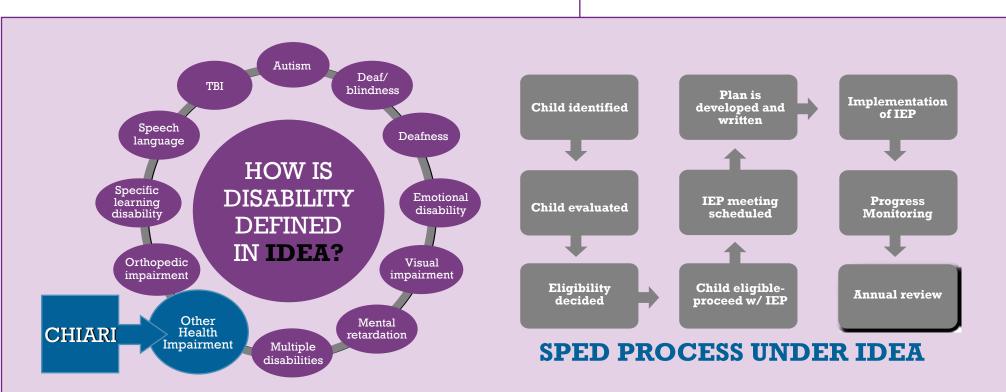
This guide is dedicated to the parents of children with Chiari who tirelessly advocate for their children both in the school and community setting.

Laws that Affect the Education of Students

There are four primary laws that affect the education of children with disabilities or health impairments

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*).



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 special education. 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 Free Appropriate Public Education in the Least Restrictive Environment. 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).

How do I find the plan for me?-

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 needs of the majority of the population. Special education programs

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 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

Individual states set eligibility requirements and determine ages for services to children and youth with disabilities. Access to your state's information can be located through your state's 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

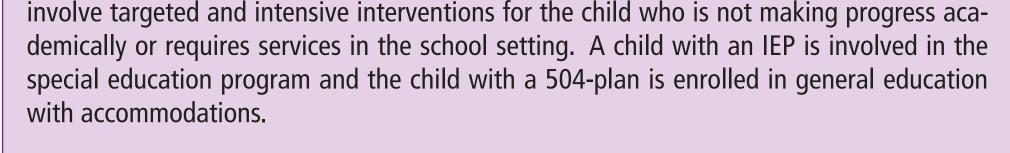
What Is A 504 Plan?

• Student does not require specialized instruction

• Student has

Accommodations

- Plan ensures equal access to education
- Reviewed annually
- Student specific
- Shared with those who need to know





The C&S Patient Education Foundation is a 501(c)(3) non-profit organization dedicated to improving the experiences and outcomes of Chiari and syringomyelia patients through education, awareness, and research.