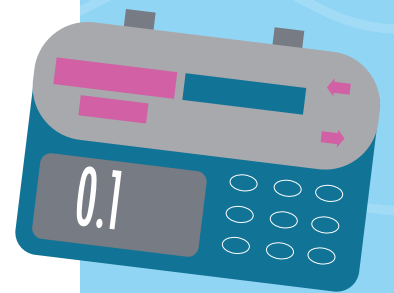
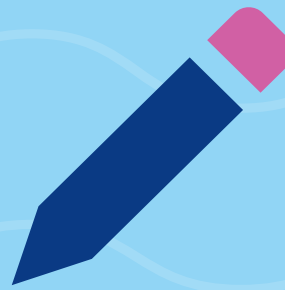


# Children with Intestinal Failure: Preparing for Matriculation

For caregivers



Where the world comes for answers



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## Can children with complex needs attend school? **Yes!**

Children with complex needs can attend school. The type of school and the setting of the classroom may vary depending on your child's needs. However, most children with complex needs can be found in a traditional classroom setting with peers by their side. The following handout outlines important information to consider when enrolling your child in school, such as:

- their educational rights
- specialized education plans
- support offered from Boston Children's Center for Advanced Intestinal Rehabilitation (CAIR) and Home Parenteral Nutrition (HPN) Program

## To begin, let's make sure you know your rights!

There are three major pieces of litigation that are important to know:

- 1) Individuals with Disabilities Education Act (IDEA): This education law requires public schools to meet the unique needs of eligible K–12 students with disabilities. Schools do this by providing services.
- 2) Section 504 of the Rehabilitation Act (Section 504): This civil rights law prohibits disability discrimination at schools that receive federal funding. Schools meet these requirements by removing barriers to learning.
- 3) Americans with Disabilities Act (ADA): This civil rights law prohibits disability discrimination by schools, employers, and anyone who offers goods and services to the public.

**What does this mean?** Your child has the right to a free education alongside their peers in the least restrictive setting\*.

*\*If you are not planning to use the public school system for any reason, some of these rights may change.*

## Who should be involved in the matriculation process?

- the school district
- the specific school your child is attending
- the school's special education team
- the school nursing team
- you and your child

## Can my child's medical team offer support?

Yes! We are able to support you throughout your child's matriculation into the school system. CAIR and HPN Program social workers are available to meet with you in clinic, via phone, or over Zoom to discuss this milestone. We are able to help prepare you and willing to join meetings with the school. These can be informal meetings, informational meetings, an IEP meeting, or 504 Plan meeting.

## What is an IEP?

- IEP stands for Individualized Education Program.
- The purpose of an IEP is to legally state a child's special education instruction, supports, and services that they need to thrive in school.
- IEPs are used in public schools from Pre-K through grade 12.
- IEPs are typically only recognized by public schools (this includes charter schools).
- The process begins with an evaluation that shows a student's strengths and challenges. Families and schools use the results to create a program of services and supports tailored to meet the student's needs.

## What is a 504 Plan?

- A 504 Plan is a formal plan that schools develop to provide children with disabilities the support they need. A 504 Plan covers any condition that limits daily activities in a major way.
- Typically, these are considered "accommodations." For example, a child might receive extended time on tests or the ability to leave the classroom for more frequent bathroom breaks.
- The most significant difference between an IEP and a 504 Plan is that there is no formal evaluation or testing needed for a 504 Plan. Instead, comprehensive documentation is often required. Additionally, 504 Plans do not need to be updated annually.



## How does my child's care team support them in starting school?

Contact the school at least six to nine months prior to the start of the incoming school year. This allows time for both the school and your child and family to understand and prepare for a successful school experience.

The school may need to:

- seek medical support for your child
- train staff in specific care that will happen during the school day
- determine what to do in case of a medical emergency

Our team can provide guidance, education, and support to the school staff.

We can also provide individualized school orders with care instructions needed for your child, including:

- timing of medications if needed during the school day
- enteral nutrition (continuous and/or bolus) schedule
- timing of parenteral nutrition and/or IV fluid infusions if needed during the school day
- how to react to urgent needs or emergencies that can happen during the school day

In addition to the written school orders, we will also provide the school staff with Boston Children's educational videos on:

- central venous catheter care
- mixing formula
- additional skills if needed

**Watch our videos here:**



**If the staff requires further training to ensure your child's safety and success at school, we can provide this via Zoom or in person on a case-by-case basis.**





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Contact us:

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