Global Genes®
Allies in Rare Disease

RARE TOOLKITS

The ABCs of Advocating in the Classroom

Most likely you have a need for the **ABCs of Advocating in the Classroom** toolkit because you or a loved one has a rare disease. As you prepare to use the tools in this kit, we want you to know that you are not alone. We are in this together. It is our hope that the personal stories, resources, tips, and suggestions for self-reflection in this guide will make the road to advocacy for your rare disease more manageable.

We know, all too well, that a lack of information and support for people living with rare diseases can lead to feelings of depression, anxiety, and isolation. This is common, but you are not alone. Fortunately, rare advocates see these challenges as opportunities to take control and many fill the void with support, knowledge, and advocacy.

While we believe you will benefit from reading all of the material in this toolkit, we don't want to overwhelm you. We've included a table of contents to make it convenient for you to find the information you are most interested in at this time. ■

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Paper and pen indicate an interactive exercise

Classroom Advocacy ABCs

Knowledge is power! It is not uncommon for children with disabilities to experience personal, social, and emotional difficulties that can affect their ability to learn, and eventually create obstacles for them as adults. Therefore, when It comes to advocating for the rights of a special needs child in a public school, private school, home-school, or medical facility, parents need a better than basic understanding of federal and state education laws.

One of the stated purposes of laws like the Individuals with Disabilities Education Act (IDEA) is: "...to ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living." ■

"Children are this country's most valuable asset and educating all children appropriately is vital to this country's long-term future. The statistics are clear--children who do not receive an appropriate education are much less likely to live independently and contribute productively to society."

SECRETARY OF EDUCATION
RICHARD W. RILEY, 1993-2001

Self-Check Interactive: Whada'ya Know?

Government regulations and legislation are often referred to by a numerical designation or an acronym. Use this list to see if you know the correct names of these terms.

1. 504 plan
   a. A mobile phone plan that offers five lines for the price of four.
   b. A plan for how a child will have access to learning at school.
   c. A plan to decide in 504 days how a child will have access to learning at school.

2. ADA
   a. American Dreamers' Act
   b. American Dentist Association
   c. Americans with Disabilities Act

3. IEP
   a. Individual education plan
   b. Initial education plan
   c. Individualized education program

4. PPT
   a. Parent placement team
   b. Party pooper team
   c. Planning placement team

5. IDEA
   a. Individuals with Debilitations Education Act
   b. Individuals with Disabilities Education Access
   c. Individuals with Disabilities Education Act

School House Rock : It's the Law

The animated bill in the "Schoolhouse Rock!" television series taught generations of American children how a bill becomes a law on Capitol Hill. Two bills that protect children and adults with disabilities over the course of a lifetime—from education to employment, are the Individuals with Disabilities Education Act (IDEA) and the Americans with Disabilities Act (ADA).

Individuals with Disabilities Education Act

On November 29, 1975, President Gerald Ford signed into law the Education for All Handicapped Children Act, which is now known as the Individuals with Disabilities Education Act (IDEA). The IDEA is hailed as a landmark civil rights measure, because it opened the doors of public schools to millions of children with disabilities. In 2004 Congress reauthorized the IDEA.

More recently, Congress amended the IDEA through Public Law 114-95: the Every Student Succeeds Act (ESSA). In the law, Congress states: "Disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society."

IDEA Facts to Know:

IDEA makes available a free appropriate public education (FAPE) to eligible children with disabilities throughout the nation and ensures special education and related services to those children.

IDEA governs how states and public agencies provide early intervention, special education, and related services to more than 6.5 million eligible infants, toddlers, children, and youth with disabilities.

IDEA Part C provides early intervention services to the families of infants and toddlers (birth through age two) with disabilities.

IDEA Part B provides special education and related services to children and youth ages three through 21. More than 62 percent of children with disabilities in the United States, due in large part to the IDEA, are in general education classrooms 80 percent or more of their school day.

Americans with Disabilities Act

In 1990 Congress passed the Americans with Disabilities Act (ADA). Congress stated the purpose of the Act was to, "...provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities."

More recently, on July 15, 2016, Congress enacted the ADA Amendments Act to clarify the meaning and interpretation of the ADA's definition of "disability" to ensure that the definition of disability would be broadly construed and applied without extensive analysis.

ADA Facts to Know:

ADA was enacted to establish that physical and mental disabilities in no way diminish a person's right to fully participate in all aspects of society.

ADA provides clear, strong, consistent, enforceable standards addressing discrimination against individuals with disabilities.

ADA ensures that the federal government plays a central role in enforcing the standards established in the Act on behalf of individuals with disabilities.

ADA allows for the sweep of congressional authority, including the power to enforce the 14th Amendment and to regulate commerce, in order to address the major areas of discrimination faced day-to-day by people with disabilities.

RARE Considerations

As defined by federal laws: "An individual with a disability means any person who: (i) has a mental or physical impairment that substantially limits one or more major life activity; (ii) has a record of such an impairment; or (iii) is regarded as having such an impairment." Without a doubt, many children with rare diseases match the legal definition of a disability, which qualifies them to be protected by federal laws in school and in society as a whole.

Invisible Disabilities

Invisible disabilities are physical or mental impairments that are not readily apparent to others. And while many special needs children have medical conditions that are apparent, such as paralysis or blindness, a child who has a rare disease may have hidden/invisible disabilities that are unique to his specific medical condition.

Part of advocating for your child with a rare disease may include informing school administrators that the IDEA and ADA establish a legal premise that ensures that children who have invisible disabilities are afforded the same rights and access to services as other children with disabilities.

Advocacy Tips!

Educate the educator about your child's rare disease diagnosis, including any invisible conditions the child has and how those conditions affect how the child learns.

Consult the "Students with Hidden Disabilities" pamphlet under Section 504 of the Rehabilitation Act of 1973, which specifically states: "Section 504 protects the rights not only of individuals with visible disabilities but also those with disabilities that may not be apparent."

Know that separate homeschooling, special classes, or other removal of children with disabilities from the regular educational environment occurs only if the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily. ■

Order in the Court!

There are circumstances when special needs classroom dilemmas are settled in courtrooms. Here are two landmark cases where the U.S. Supreme Court rendered the final judgment.

Court Cases

Irving Independent School District v. Tatro, is a court case in which the U.S. Supreme Court on July 5, 1984, ruled (9–0) that, under the Education for All Handicapped Children Act (EAHCA) of 1975, now known as the Individuals with Disabilities Education Act (IDEA), a school board in Texas, had to provide catheterization services during the school day to a student with spina bifida. This case is notable because it is the court's first attempt to define the distinction between "school health services" and "medical services."

The student, Amber Tatro, was born with spina bifida. The disease caused Tatro various health issues, including a bladder condition that required clean intermittent catheterization (CIC) every several hours. The CIC procedure was relatively simple and could be taught to a non-medical person in less than an hour.

In 1979, when Amber was three years old, the Irving Independent School District in Texas, created a special education program for her that did not include the CIC administration. When her parents asked the school to provide the service, the school refused. Subsequently, Amber's parents filed a lawsuit, claiming a violation of the EAHCA. They also cited the Rehabilitation Act of 1973, which bars a handicapped individual from being excluded from or denied the benefits of a program that receives federal funds.

A federal district court ultimately ruled in favor of the Tatros. The court determined that CIC administration did not require a physician; therefore it was not a medical service, but qualified as a related service. The court further held that the school had violated the Rehabilitation Act, which enabled it to award attorney fees to the Tatros. The ruling in this case set a standard for other cases. Fifteen years later it was cited in the Cedar Rapids Community School District v. Garret F. court case.

Cedar Rapids Community School District v. Garret F., is a court case in which the U.S. Supreme Court on March 3, 1999, ruled (7–2) that the 1990 Individuals with Disabilities Education Act (IDEA) requires school boards to provide continuous nursing services to disabled students who need them during the school day.

Garret F. was a student in Cedar Rapids, Iowa, who was a quadriplegic and required a ventilator. During the school day he needed a personal attendant to see to his health care needs. Those needs included urinary catheterization, suctioning of his tracheotomy tube, and observation for respiratory distress. Initially, from kindergarten through the fourth grade, Garret's family provided him with a personal attendant at school for his health care needs. When he was in the fifth grade, his mother asked the school board to provide his nursing services.

When the school board refused to provide the services, Garret's mother requested a hearing under the IDEA. An administrative law judge proceeded over the hearing and decided the school board was responsible for the nursing services. Following that decision, a federal trial court in Iowa affirmed and concluded that such services did not fall within the "medical services" exclusion clause of the IDEA's "related services" provision.

The case then moved to the Eighth Circuit Court of Appeals, which noted that the Supreme Court's earlier opinion in the Irving Independent School District v. Tatro case (1984) had established an unambiguous standard, whereby the services of a physician are exempted, but "services that can be provided in the school setting by a nurse or qualified layperson are not." Since Garret's services did not require a doctor, the Supreme Court upheld the lower court's decision.

Saved by the Bill!: K-12

Ideally, first day of school jitters is about new school clothes, new classmates, and new teachers—not issues of inequality. When enrolling a special needs child in school, it helps to remember your child has powerful "friends" (the Capitol Hill bill brothers: IDEA and ADA) that can help you advocate for your child's right to an impartial school experience.

Planning Placement Teams

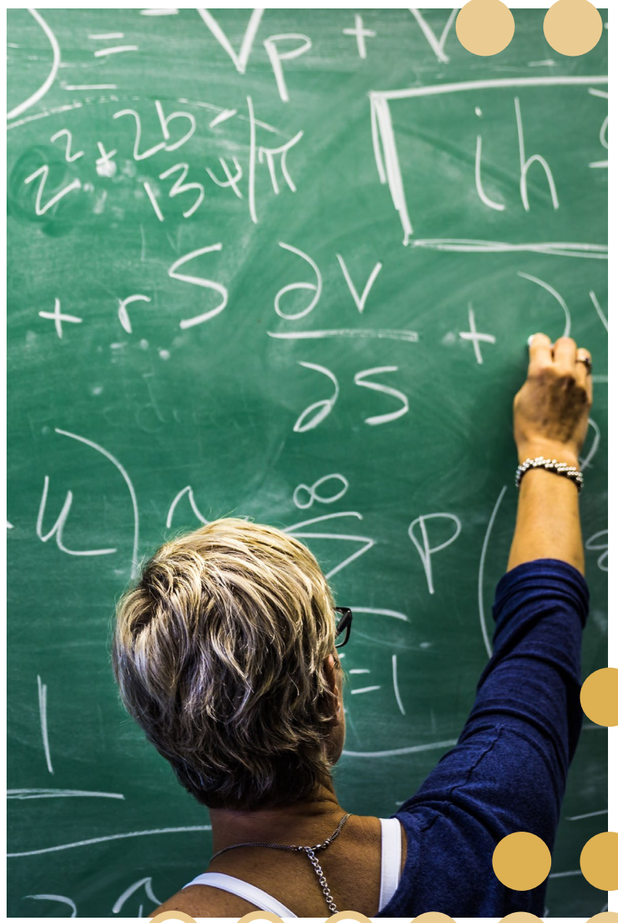
Long gone are the days of dreading you might be the last kid chosen for a dodge ball team; now you are the first and most valuable player (MVP) on your child's planning placement team (PPT). The PPT administers preliminary evaluation procedures to determine what the educational needs of a student with disabilities may be. Typically, there are designated staff members at a school who arrange Section 504 and Individualized Education Program (IEP) meetings for PPT members.

MVP notes about planning placement teams:

- Although the school handles the administrative functions of a PPT, parents have a right to request Section 504 and IEP meetings at any time during the school year (including the summer).
- PPT members may vary, but a parent of the child is always a member of the team. (See the Section 504 and IEP comparison chart for a specific list of team members.)
- The rules about who has to be on the Section 504 PPT are less specific than they are for an IEP.
- There are strict legal requirements about who participates in IEP meetings. With a few exceptions, the entire PPT must be present for IEP meetings.
- Parents should share with the PPT (1) the child's strengths (2) the child's aspirations (3) the child's likes and dislikes.
- Be prepared with medical documentation to educate the special education team about your child's rare disease.
- Schools have to abide by medical orders and medical care directives.
- Parents can appeal PPT Section 504 and IEP entitlement decisions.

Section 504 and IEPs

Starting with a diagnosis, there can be many unknowns about how a rare disease may affect a child's life. Although circumstances may differ, there are federal education laws that apply to all children in the U.S. school system. This chart is a comparison of the Department of Education Section 504 mandate and the individualized education program (IEP) that are often the focus of PPT meetings.



Comparisons	Section 504	IEP
Description	A plan based on equal opportunity for students with disabilities and how they will access learning at school.	An individualized plan for a child's special education program at school.
Purpose	Provides accommodations, services and changes to the educational environment to meet the needs of the child.	Provides individualized special education with modifications of the actual program or curriculum materials to meet the unique needs of the child.
Applicable Laws	Section 504 of the Rehabilitation Act of 1973: The federal civil rights law to stop discrimination against Americans with disabilities.	Individuals with Disabilities Education Act (IDEA): The federal special education law for children with disabilities.
Eligibility	1. A child with any disability (including learning or attention issues). 2. The disability must interfere with the child's ability to learn in a general education classroom. Section 504 has a broader definition of a disability than IDEA.	1. A child has one or more of the (currently) 13 specific disabilities listed in IDEA. 2. The disability must affect the child's educational performance and/or ability to learn and benefit from the general education curriculum, leading to the need for specialized instruction.
Oversight	Americans with Disabilities Act (ADA) Civil Rights Law	Individuals with Disabilities Education Act (IDEA) Education Law
Plan Creation Team	A team of people who are familiar with the child creates the 504 plan. This team understands the evaluation data and special services options; and might include: 1. A parent of the child 2. Teachers (general and special education) 3. The school principal	An IEP is created by a team of people that must include: 1. A parent of the child 2. At least one of the child's general education teachers and at least one special education teacher 3. School psychologist or other specialist who can interpret evaluation results 4. A district representative with authority over special education services 5. Whenever appropriate, the child with the disability
Plan Contents	A 504 plan generally includes: specific accommodations, supports or services for the child; the names of who will provide each service; and the name of the person responsible for ensuring the plan is implemented.	An IEP generally includes: disability listing; short-term goals; vision statement; progress impact; placement recommendation; transport needs; summer services; and behavior and/or social skills plan if applicable.
Parent Notice	The school has to notify parents about evaluation or any significant change in placement. The notice does not have to be in writing.	The school has to notify the parents in writing, prior to making a change to a child's services or placement. Notice is also required for any IEP meetings and evaluations.
Plan Reviews	A 504 plan is, generally, reviewed yearly and a reevaluation is done every three years or when needed. (Rules vary by state.)	The IEP has to be reviewed by the child's IEP team, at least once a year. The student must be reevaluated every three years to determine whether services are still needed.
Disputes	Parents have several options for resolving disagreements with the school: • Mediation • Alternative dispute resolution • Impartial hearing • Complaint to the Office of Civil Rights (OCR) • Lawsuit	Parents have several specific ways to resolve disputes (usually in this order): • Mediation • Due process complaint • Resolution session • Civil lawsuit • State complaint • Lawsuit
Costs	Although, states do not receive funding for eligible students, there are no costs for students to receive these services. But, the federal government can take funding away from schools and programs that don't comply with the law.	States receive additional funding for eligible students; but there are no costs for students to receive these services.

Charter School Choice: Section 504

A public charter school is a publicly funded school that is typically governed by a group or organization under a legislative contract (or charter) with the state, district, or other entity. The charter exempts the school from certain state or local rules and regulations. But, students with disabilities who attend charter schools (and those seeking to attend them) have the same Section 504 rights as other students with disabilities who attend public schools.

Among other things, these rights for students with disabilities include:

- A free appropriate public education (FAPE), which under Section 504 is regular or special education and related aids and services designed to meet the individual educational needs of a student with a disability as adequately as the needs of nondisabled students are met.
- Equal treatment and nondiscrimination in nonacademic and extracurricular activities such as counseling services and sports; and accessibility (such as entrance ramps for people who use wheelchairs).
- Section 504 requires charter schools to provide the opportunity for students with disabilities to apply to a charter school on an equal basis as students without disabilities.
- Section 504 FAPE requirements for placements are separate from requirements related to admission procedures. Section 504 provides that a charter school's admission criteria may not exclude or discriminate against individuals on the basis of disability, and that a school may not discriminate in its admissions process.
- During the admissions process, a charter school generally may not ask a prospective student if he or she has a disability. Limited exceptions include that, if a school is chartered to serve students with a specific disability, the school may ask prospective students if they have that disability.
- When a student with a disability is admitted to and enrolls in a charter school, the student is entitled to FAPE under Section 504. After enrollment, a charter school may ask if a student has a disability, which includes, e.g., whether a student has an individualized education program (IEP) or Section 504 plan.
- A charter school may not counsel out, i.e., try to convince a student (or parents) that the student should not attend (or continue to attend) the school because the student has a disability.
- A school's charter is reviewed periodically by the entity that granted the charter. A school's charter status can be revoked if guidelines on curriculum, management, and government mandates are not followed or if accountability standards are not met.

Advocacy Tips!

- Guidelines for who is required to attend Section 504 meetings can vary by state. Parents should check with their state's Department of Education website for specific information.
- In some states meetings to discuss these special education mandates are called: Planning and Placement Team (PPT) meetings; Committee on Special Education (CSE) meetings; or Admission, Review and Dismissal (ARD) meetings.
- Parents have "stay put" rights to keep services in place while there's an unresolved IEP dispute.

"IEPs and 504 plans are the most common school dilemma parents in the rare community need help with. A child with a rare disease may have complex medical needs, but is not cognitively challenged. Often special education teams are not experienced with rare disease disorders, so they question the child's need for an IEP; even though most children with rare diseases qualify for them."

JESSICA SHRIVER, MA THEOLOGY, MS BIOMEDICAL ETHICS, PATIENT AND FAMILY ADVOCACY, MEDICAL ETHICIST, RARE NEW ENGLAND

Health Plan

Depending on the disability, a child may need healthcare services administered during the school day. When this is the case, an individual health plan (IHP) can be written as a related service provided by an IEP or as an accommodation under a Section 504 plan. Schools are obligated to provide the necessary health services to a child at school, at no cost to the parents.

Under the Child Find policy, it is generally the responsibility of the school nurse to identify whether or not a child's health needs affects daily functioning and/or the ability to access the school's curriculum. An IHP developed for the child by the school nurse should include input and approval from the child's primary care physician and/or other health providers.

Child Find policy and procedure, a state must ensure: (i) all children (including homeless and wards of the state) with disabilities in public or private schools, regardless of the severity of their disability, and who are in need of special education and related services, are identified, located, and evaluated; (ii) and a practical method is developed and implemented to determine which children are currently receiving needed special education and related services.

The health plan team should consider:

- The medical needs the child has at school and how these needs will be met on a daily basis.
- The nature and complexity of the healthcare need (such as suctioning, ventilator support or tube feeding).
- The level of nursing or assistive personnel necessary to ensure the health and safety of the child.
- If the child will need frequent and/or potential emergency assistance from the school nurse or other health provider.
- The IHP will often require frequent updating as changes in the child's medical condition and needs occur.
- The type of healthcare assistance needed beyond the classroom (during physical education, on the school bus, for behavioral situations, on field trips, and for extracurricular activities).
- The IHP should include instructions about how to respond to a child's medical need if there is a fire drill, loss of power, a school lockdown, and the child's access to emergency exits.
- The need for additional staff support and emergency response time by the school nursing and/or local ambulance service should be planned for.

(See the Resource Guide at the end of this toolkit for more information on school nurse services.)

Additional related service includes speech-language pathology and audiology services (including hearing aids), interpreting services, psychological services, physical and occupational therapy, recreation (including therapeutic recreation), early identification and assessment of disabilities in children, counseling services, rehabilitation counseling, orientation and mobility services, and medical services for diagnostic or evaluation purposes.

The Medicaid School Program can reimburse participating schools for related services provided to Medicaid-eligible students. Services must be identified in the IEP and can include nursing, occupational therapy, physical therapy, speech therapy, specialized medical transportation and medical equipment and supplies for use only in school. ■

Meeting of the Minds: School System

All grown up with a child of your own to advocate for, now is the time to apply a trick teachers use to help children understand the meaning of the words principal and principle: "When referring to the principal of the school the word is spelled princi-p-a-l because he/she is your pal."

That is to say, it may minimize your school meeting jitters to think of the principal, teachers, nurse, and other school administrators as pals who want what is best for your child.

PPT Meetings: The Parent's Role:

Contact the PPT meeting school coordinator and ask this person if your child's medical records and other documents should be sent to the school prior to the meeting.

Share information about your child's skills, abilities, and needs at the meeting.

Provide the PPT with: recent medical evaluations; prior school evaluations (504 plans, IEPs, IHPs); private evaluations; doctor's letters about educational accommodations and modifications; hidden disability diagnosis; report cards; and progress reports.

Share the concerns you checked off in this toolkit's Self-check Interactive: Parental Concerns exercise with the team.

Assist the team in creating the 504 plan.

Take notes or have another person accompany you to the meeting to takes notes.

Ask for clarification or additional information as needed throughout the meeting.

Ask your child's primary physician to contact the PPT directly about obtaining the health services and staffing necessary to support your child's special needs at school.

PPT Meetings: The School's Role:

Schedule PPT meetings with the parents and other required team members.

Review information collected by the school (standardized tests, documents provided by parents, and other sources) about the student prior to meetings.

Ensure that the parent understands the proceedings of the meeting.

Consider information from the parents and medical personnel when making a decision concerning the child's program.

Provide parents with detailed decisions the team makes about a child's special education needs and/or related services.

Expert Tips!

- A positive attitude is one of the most important things you can take into a PPT meeting.
- Pursuant to Child Find legislation, it is up to the school district to continue to evaluate the child in all areas of the suspected disability.
- If a parent disagrees with the school districts evaluation, they may have a right to a private evaluation at the district's expense.
- Pursuant to Family Education Rights and Privacy Act (FERPA) parents have a right to a complete copy of all relevant school records regarding a child which includes: emails, data, progress reports, rated IEPs, notes, and other related documents.
- Keeping track of what progress the child has made or not made can be very helpful in advocating for needed changes and needed additional services.

"Listen to your child and find the best private experts possible to clearly identify the exact nature of your child's strengths and weaknesses, so an appropriate program can be developed to enable your child to access their education and be as successful as possible." Piper A. Paul, Cohn & Paul, PLLC, of Counsel to Goldman, Gruder & Woods, LLC

Dispute Resolution

In the span of years from kindergarten to college, there may be times when the school system is not adhering to the law regarding your child's special needs rights. If school administrators are denying services to your child, being negligent, or challenging the law, it helps to know what you can do to address the problem.

One option for a resolution is the Office for Civil Rights (OCR). Shown here is the directive on how to file a complaint with the OCR.

The Office for Civil Rights

The Office for Civil Rights (OCR) investigates discrimination complaints against institutions and agencies that receive funds from the U.S. Department of Education and against public educational entities and libraries that are subject to the provisions of Title II of the Americans with Disabilities Act.

The OCR complaint form asks the filer of the complaint to identify the institution or agency that engaged in the alleged discrimination. If the OCR cannot accept the filer's complaint, they will attempt to refer it to the appropriate agency and will notify the filer of that fact.

The OCR enforces:

Section 504 of the Rehabilitation Act of 1973, which prohibits discrimination on the basis of disability.

Title II of the Americans with Disabilities Act of 1990, which prohibits discrimination on the basis of disability.

"Our Mission is to ensure equal access to education and to promote educational excellence throughout the nation."

U.S. DEPARTMENT OF EDUCATION,
OFFICE FOR CIVIL RIGHTS

(See the Resource Guide at the end of this toolkit for an example, courtesy of the state of Illinois, of an OCR complaint form.)

Legal remedies are another option parents have to address critical issues with the school system. Listed are expert tips to consider about taking legal action against a school:

- If the school's staff makes false claims about the legitimacy of your child's disability and/or they contact the Department of Child and Family Services (DCFS) about your child, seek legal counsel.
- When you get an "oh-oh" feeling about an issue with your child and the school, seek legal counsel.
- The assistance of an experienced attorney can be a worthwhile investment in your child's future. An attorney can work behind the scenes and guide you on ways to avoid and resolve conflicts with the school system.
- An experienced attorney can protect your child's rights without making the issue litigious.
- If you're considering taking legal action, don't tell the school! When the time is right, let your attorney contact the school. ▪

"In the U.S., the federal role in education is limited. Because of the 10th Amendment, most education policy is decided at the state and local levels. So, if you have a question about a policy or issue, you may want to check with the relevant organization in your state or school district."

DEPARTMENT OF EDUCATION, ED.GOV

(See the Resource Guide at the end of this toolkit for more information on education policy and the 10th Amendment.)

Self-check Interactive: Parental Concerns

From assisting with homework to concerns about bullying, issues at school rank high on the stress meter for many parents. For parents of special needs children, these issues and other concerns about school can be multiplied 10-fold (remember to carry the one). Identifying and prioritizing your concerns can make it easier to discuss them with your child's planning placement team. The school advocacy experts who contributed to this toolkit say the items listed here, are some of the most common concerns they hear from parents.

Rate the items on this list from 1 to 10; number 1 being your greatest concern and number 10 being your least concern. Please add other concerns you may have to the end of this list and rate them accordingly.

- ☐ News about discrimination or negative incidents with schools and special needs children
- ☐ The process for transferring a child's services and documentation to another school
- ☐ Negative experiences other parents had with the school system and special needs children
- ☐ The school has not met Child Find guidelines in evaluating the child as required by law
- ☐ The school will not make the necessary accommodations/modifications for their child
- ☐ The nature of the child's disability or hidden illness being understood by school staff
- ☐ Lack of confidence in the abilities of the school's staff (teachers, nurses, aides)
- ☐ Section 504, IEP, and related services issues
- ☐ PPT pushing for homeschooling
- ☐ Knowing how to handle unresolved or reoccurring issues with the school
- ☐ _____
- ☐ _____
- ☐ _____
- ☐ _____

Transition Time: Self-Advocacy

By law, the IEP must address student transition services requirements beginning no later than the first IEP to be in effect when the child turns 16 or younger (if determined appropriate); and the child must be included in IEP meetings.

Role Model

Before she retired, special education teacher, Pat Hensley used role-play scenarios to teach her special needs students how to advocate for themselves in the classroom. Her strategies have been modified here for parents to use at home:

1. List what the child would say in requesting an educational accommodation from a general education teacher.
2. Practice with your child how to verbalize the request to the teacher.
3. Video the role-play so the child can see how he looks and sounds making the request. (This step is really important because children are often unaware of their tone of voice or body language in these situations.)
4. Explain to the child that it is important to make the request in a non-aggressive manner.
5. Work with the child on how to effectively communicate his needs and concerns in different school scenarios (a request to see the blackboard versus needing medical assistance).

(Pat Hensley is Nationally Board Certified as an Exceptional Needs Specialist and is on the National Board of Directors for the Council for Exceptional Children. The original article "Teaching Self-advocacy in the Special Ed Classroom can be read at teachingmonster.com.)

A child who has been encouraged to communicate their concerns and medical needs to healthcare professionals can also develop the confidence to self-advocate at school. But, as your child transitions to self-advocacy remind her that, at any age, it is still very important to let you know if there are problems at school.

Ultimately, children who are cognitively able to self-advocate benefit from being actively involved in their PPT meetings. The experience they receive from having input in these academic team meetings is a path to self-advocacy in college, the workplace, and public life. ▪

The Final Chapter: College

Years of courage, advocacy and patience have helped you navigate your child from toddler to teen through the local school system. As you and your child prepare for this final chapter of education, it is important to know what legal protections exist for college students with disabilities.

While students with disabilities are entitled to comprehensive supports under the FAPE requirements of IDEA or Section 504, if applicable, while in high school, they are no longer entitled to FAPE under IDEA or Section 504 if they graduate with a regular high school diploma. Therefore, a postsecondary student with a disability is not entitled to the same services and supports that the student received in high school.

To assist children with disabilities to achieve their post-school and career goals, Congress enacted two key statutes that address the provision of transition services: the Individuals with Disabilities Education Act (IDEA) and the Rehabilitation Act of 1973 (Rehabilitation Act), as amended by Title IV of the Workforce Innovation and Opportunity Act (WIOA).

Transition Services

Transition services mandates a coordinated set of activities for a student with a disability to be designed within a results-oriented process that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from school to:

- Postsecondary education; vocational education; continuing and adult education
- Integrated employment (including supported employment)
- Post-school activities
- Adult services
- Independent living or community participation

The coordinated set of activities is based on each student's needs. And it should take into account the student's strengths, preferences and interests; and include instruction, related services, community experiences, the development of employment and other post-school adult living objectives. Also, if appropriate, the acquisition of daily living skills and a functional, vocational evaluation should be included.

Section 504

Under the Section 504 regulation, a recipient that operates a public elementary or secondary school, or an adult education program has a number of responsibilities toward qualified handicapped persons with visible and hidden disabilities in its jurisdiction including:

- Ensure that a student with a handicap is educated with nonhandicapped students to the maximum extent appropriate to the needs of the handicapped person.
- Establish nondiscriminatory evaluation and placement procedures to avoid an inappropriate education, due to misclassification or misplacement of students.
- Establish procedural safeguards to enable parents and guardians to participate meaningfully in decisions regarding the evaluation and placement of their child.
- Afford handicapped children an equal opportunity to participate in nonacademic and extracurricular services and activities.

Section 504 does not specifically require that eligible students receive transition services as defined in IDEA. However, implementation of an IEP developed in accordance with the IDEA is one means of meeting the Section 504 FAPE standard.

Summary of Performance

The Summary of Performance (SOP) directive mandates that a student with a disability receiving services under Part B of the IDEA who either graduates from high school with a regular high school diploma or exceeds the age of eligibility for FAPE under state law. The school must provide the student with a summary of his or her academic achievement and functional performance. The SOP must include recommendations on how to assist the student in meeting his or her postsecondary goals.

Major Declaration

Starting with the student's interests, strengths and weakness is a practical conversation to have with a college bound child. And because of your special needs child's ongoing experiences of medical diagnosis, PPT meetings and IEPs he or she is likely better prepared to participate in the college planning process than a child without disabilities.

Before choosing a college do your homework:

- Meet with your child's high school academic counselor to discuss the child's desired field of study; and then research schools that have a good academic rating in that field.
- Ask the parents of other children with disabilities who are in college about the schools their children attend.
- Arrange to take a campus tour and meet with an admissions counselor, academic advisor, financial aid advisor, campus healthcare services representative, campus housing/dorm resident advisor, and the disability support services (DDS) administrator. DDS can provide answers about disability related concerns and needs, and may also provide advocacy support after your child enrolls in school. ■

Academic Adjustment Request

Unlike high school, a postsecondary school is not required to provide FAPE, but they are required to provide appropriate academic adjustments as necessary. Academic adjustments ensure that postsecondary schools do not discriminate on the basis of disability.

It should be noted, a student is not required to inform a school about his disability; but if the student wants to make an academic adjustment request, he will have to declare the disability. In their publications providing general information, postsecondary schools usually include information on the procedures and contacts for requesting an academic adjustment.

Making an academic adjustment request:

- Unlike your school district, a postsecondary school is not required to identify your child as having a disability or to assess the child's needs.
- The student must inform the school that he has a disability and needs an academic adjustment.
- The school may require the student to provide documentation prepared by an appropriate professional, such as a medical doctor, psychologist, or other qualified diagnostician showing a current disability.
- The appropriate academic adjustment must be determined based on the disability and individual needs.
- Academic adjustments may include auxiliary aids (hearing devices) and services, as well as modifications to academic requirements as necessary to ensure equal educational opportunity.
- In providing an academic adjustment, a postsecondary school is not required to lower or substantially modify essential requirements.
- Contact the school's Section 504 Coordinator, ADA Coordinator, or Disability Services Coordinator for more information about the school's academic adjustments requirements.

Your ABCs: Always Be Championing

Many decades ago Congress passed laws that are the foundation of the United State's commitment to providing children with disabilities educational opportunities to learn and develop their talents. Today, because of these laws, classrooms are more inclusive and the future of children with disabilities is promising.

An education affords children with special needs, as it does all citizens, a chance to contribute to their communities and to society as a whole. Use the information in this toolkit on the ABCs of classroom advocacy to always be championing your child's legal right to an education.

Welcome to Something Bigger!

You are a part of something bigger—The rare community! Building connections within your specific disease community is absolutely the most vital part of your efforts. Members will tell you that the depth of the connection they feel with others in their rare disease community is hard to describe. There is an innate sense of closeness and empathy that comes with a rare disease diagnosis.

Like we said in the beginning you are not alone. You are part of an estimated 30 million Americans and 350 million people worldwide that are affected by a rare disease. While the diseases and the symptoms may be different, people in the rare community often share the same challenges and fight for the same changes. This is a powerful thing! Rare is everywhere and is frankly not-so-rare.

"It's not in the stars to hold our destiny, but in ourselves."

- WILLIAM SHAKESPEARE

Glossary of Terms

504 Plan is a blueprint or plan for how a child will have access to learning at school.

ADA (Americans with Disabilities Act) gives civil rights protections to individuals with disabilities that are like those provided to individuals on the basis of race, sex, national origin, and religion. It guarantees equal opportunity for individuals with disabilities in employment, public accommodations, transportation, state and local government services, and telecommunications.

ESSA (Every Student Succeeds Act) is legislation signed by President Obama on December 10, 2015. This bipartisan measure reauthorizes the 50-year-old Elementary and Secondary Education Act (ESEA), the nation's national education law and longstanding commitment to equal opportunity for all students.

FAPE (free appropriate public education) refers to special education and its related services.

FERPA (Family Educational Rights and Privacy Act) is a federal law that protects the privacy of a student's education records. Parents or eligible students have the right to inspect and review the student's education records maintained by the school.

IDEA (Individuals with Disabilities Education Act) is a law that makes available a free appropriate public education to eligible children with disabilities throughout the nation and ensures special education and related services to those children.

IEP (individualized education program) is a written statement for each child with a disability that is developed, reviewed, and revised in accordance with section 614(d) of the IDEA.

IHP (individual health plan) may be developed by the school nurse as part of the IEP or a Section 504 plan to specifically address your child's medical needs in the school setting.

Individual Representative "individual's representative" and "applicant's representative" mean a parent, a family member, a guardian, an advocate, or an authorized representative of an individual or applicant, respectively.

LEA (local education agency) is a public board of education or other public authority legally constituted within a state for either administrative control or direction of, or to perform a service function for public elementary schools or secondary schools in a city, county, township, school district, or other political subdivision of a state.

LRE (least restrictive environment) means to the maximum extent appropriate: children with disabilities in public schools, private institutions or other care facilities, are educated with children who are not disabled.

OSEP (Office of Special Education Programs) is dedicated to improving results for infants, toddlers, children and youth with disabilities (birth through 21) by providing leadership and financial support to assist states and local districts.

OSERS (Office of Special Education and Rehabilitation Services) supports programs that serve millions of children, youth and adults with disabilities. OSERS is committed to improving results and outcomes for people with disabilities of all ages.

PPT (planning placement team) performs preliminary evaluation procedures to determine what the educational needs of a student with disabilities may be.

Related Services are transportation and such developmental, corrective, and other supportive services required to assist a child with a disability. It also includes school health services, school nurse services, social work services in schools, and parent counseling and training.

Special Education means (at no cost to the parents) specially designed instruction to meet the unique needs of a child with a disability.

Student With a Disability for purposes of Section 504 is an individual who is participating in an educational program, including secondary education, non-traditional secondary education and postsecondary education, who meet the age requirements of the definition.

Resource Guide

The 14th Amendment

Section 1.

All persons born or naturalized in the United States, and subject to the jurisdiction thereof, are citizens of the United States and of the state wherein they reside. No state shall make or enforce any law which shall abridge the privileges or immunities of citizens of the United States; nor shall any state deprive any person of life, liberty, or property, without due process of law; nor deny to any person within its jurisdiction the equal protection of the laws.

The 10th Amendment

The 10th Amendment (1791) of the U.S. Constitution (1787) states: "The powers not delegated to the United States by the Constitution, nor prohibited by it to the States, are reserved to the States respectively, or to the people." Therefore, the general authority to create and administer public schools is reserved for the states. There is no national school system nor are there national framework laws that prescribe curricula or control most other aspects of education. The federal government, although playing an important role in education, does not establish or license schools or govern educational institutions at any level.

How to File a 504 Complaint in Illinois

If a parent has a disagreement with the district's 504 plan, a parent may inquire whether the district offers parents the opportunitytoparticipatein"504 hearing." A 504 hearing is a much less formal process than a due process hearing and may be only an opportunity to discuss the complaint with a school administrator. A school district is not required to make a 504 hearing process available to parents.

Regardless, a parent who has a complaint about a 504 issue may still file a complaint with Office for Civil Rights (OCR) of the US Department of Education. If you wish to file a 504 complaint in Illinois, you may direct a written complaint to the following address:

U.S. Department of Education Office for Civil Rights
111 N. Canal St., Suite 1053
Chicago, IL 60606-7204

Your complaint should be as detailed as necessary to describe the issues you are experiencing and the facts about the situation. OCR will conduct the necessary investigation and, if there is a violation of Section 504, order the school district to take the necessary action to correct the situation.

[See the link at the end of the Resource Guide to the U.S. Department of Education, OCR Discrimination Complaint Form, Consent Form, and Complaint Processing Procedures website for more info on how to file a complaint in your state.]

School Nurse Services

The individual health plan (IHP) should detail the nursing services your child will require at school. The options for nursing care range from using an on-site school nurse for intermittent needs to assigning a one-to-one nurse for the entire school day. Some school districts may use Licensed Practical Nurses (LPN) or aides who are supervised by a Registered Nurse (RN).

When planning for nursing in school it is important to consider:

Type of skilled medical needs
Level and frequency of skilled medical needs
Proximity of the nurse to the child
Type of nursing skill and/or licensure required to provide the care
How providing the required care impacts student participation in a typical school schedule

There are times when a family can use the same nurse before, during and after school. In this situation, the before and after school nursing care is often paid for under a financial assistance program such as a home care benefit, a public waiver program or by private insurance.

However, it is becoming more common for school districts to hire their own nursing staff to cut costs. As a result, families are finding it difficult to find nurses who are willing to work a split shift before and after school. Therefore, some families are choosing home instruction on their child's IEP to avoid this dilemma.

A Transition Guide to Postsecondary Education and Employment for Students and Youth with Disabilities: bit.ly/SchoolTransitionGuide

Americans with Disabilities Act (ADA): www.ada.gov

Department of Education: www.ed.gov

GARD: rarediseases.info.nih.gov

National Association of School Nurses: schoolnursenet.nasn.org/home

Office of Special Education Programs: bit.ly/SpecialEdPrograms

Office of Special Education and Rehabilitative Services: bit.ly/SpecialEdRehabServices

United States Dept. of Education Office for Civil Rights: Discrimination Complaint Form
bit.ly/DiscriminationComplaintForm

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Global Genes is invested in collecting and then sharing best practices and lessons learned as well as devoted to celebrating successes of the rare disease community.

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