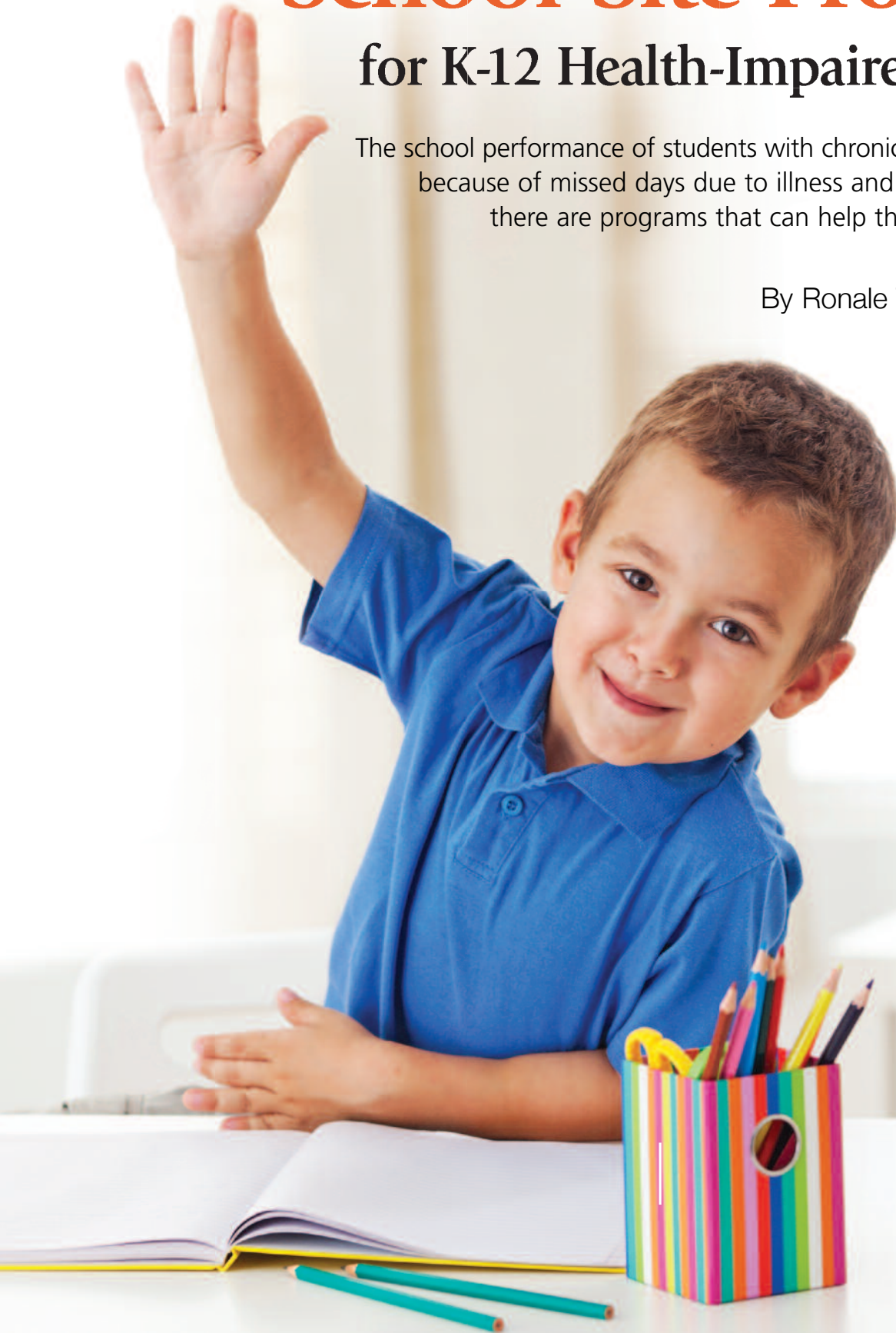


School Site Programs for K-12 Health-Impaired Students

The school performance of students with chronic illnesses often suffers because of missed days due to illness and treatments. However, there are programs that can help these students succeed.

By Ronale Tucker Rhodes, MS



Approximately 17 percent of all students under age 18 suffer from a chronic illness to the degree that it affects their performance in school.¹ Performance is hindered mainly because these kids miss numerous days of school due to sickness that requires them to go to the hospital, recover at home or attend regular medical appointments. As a result, they experience decreased academic performance, and they have difficulty completing work on time or taking part in exams, participating in some school activities (for example, physical education or excursions), and they often feel less confident and less motivated, which can affect self-esteem.² Fortunately, there are two laws designed to protect the educational rights of children with disabilities who wish to remain in school site educational programs.

The Laws

The first law that protects chronically ill kids' educational rights is Section 504 of the Rehabilitation Act of 1973. That Act was amended with the Americans with Disabilities Act Amendments Act of 2008 (ADAAA), effective Jan. 1, 2009, which broadened the interpretation of a disability. The second is Public Law 94-142 (Education of All Handicapped Children Act), which was passed by Congress in 1975 and has been revised many times over the years, with the latest revision published in 2006. That law is now codified as the Individuals with Disabilities Education Act (IDEA). Section 504 is not tied to any type of funding, which means schools are not provided any federal funds for the programs and services they must provide to comply. IDEA, however, is a grant statute and provides schools with additional, although limited, financial support. Both laws require school districts to provide children with a free appropriate public education (FAPE), meaning that accommodations and/or modifications must be made for children whose disabilities impede their ability to learn.³ It's important to note that Section 504 and IDEA do not apply to private schools. However, private schools are public accommodations under Title II of the Americans with Disabilities Act, which means students are entitled to reasonable accommodations in private schools, too.⁴

The Office for Civil Rights (OCR) in the U.S. Department of Education (ED) enforces Section 504 of the Rehabilitation Act, while the Office of Special Education and Rehabilitative Services (OSERS), also a component of the ED, administers IDEA. Section 504 is an anti-discrimination law enacted to "level the playing field" to eliminate impediments to full participation by persons with disabilities compared with

those without disabilities. As such, accommodations are made for educational opportunities that meet the needs of all students. IDEA, on the other hand, is remedial, often requiring the provision of programs and services in addition to those available to persons without disabilities. This means it focuses on the "unique" educational needs of the student. In short, Section 504 precludes hurdles to participation, whereas IDEA is similar to an affirmative action law that provides additional benefits for underrepresented groups such as those with disabilities.³

Children with a chronic illness may qualify for protection under Section 504 and/or IDEA. The definition of a disability is much broader under Section 504 than it is under IDEA. Section 504 protects children with a disability who 1) have a physical or mental impairment that substantially limits one or more major life activities; 2) have a record of such an impairment or 3) are regarded as having such an impairment. With the ADAAA's broadened interpretation of a disability, a major life activity includes the operation of a major bodily function, including but not limited to functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine and reproductive functions. Under IDEA, children are defined as having a disability if their educational performance is adversely affected due to the disability. There are 14 disability categories included in IDEA, including other health impairment under which children with a chronic health condition may qualify for services if the condition adversely affects their educational performance.⁵ What's critically important to chronically ill children is that under these laws, episodic illnesses — those that come and go — are disabling even when students are in remission if they would be disabling when active.⁴

The programs available to children with disabilities who qualify include a 504 plan under Section 504 of the Rehabilitation Act and an Individual Education Program (IEP), alternatively called an Individual Education Plan (IEP), under IDEA. See Table 1 for a list of differences between a 504 plan and an IEP.

Obtaining a 504 Plan

Children who do not qualify for an IEP may qualify for a 504 plan. To be eligible for a 504 plan, students do not need to receive special education services, and they will still remain in their regular classrooms. What the written plan entails is determined individually based on the nature of the disabling condition and what each child needs in order to have an equal opportunity to compete with those without disabilities.

Some examples of what accommodations are required to be provided to students with a chronic illness under a 504 plan include, but are not limited to, extended time on tests or assignments, peer assistance with note taking, frequent feedback, an extra set of textbooks for home use, computer-aided instruction, rearranging class schedules, taping lectures and individual contracts (see also Sample Accommodations for Chronically Ill Students Under a 504 Plan and IEP).⁶

To obtain a 504 plan, it must be proved that a student has a disability. A detailed letter from a doctor will often suffice; however, in some situations, schools request copies of medical records. The law does not require that school officials be able to obtain an unlimited release of medical records or that they be able to speak to a student's doctors whenever wanted. Once it is determined a student has a disability, a request for a 504 plan must be made to someone in authority at the school such as the principal, a guidance counselor or the coordinator of 504 plans for the district. Present at the meeting should be the student (depending on his or her age), the student's parent(s), the student's teachers and a school administrator.

The purpose of the meeting is to develop a plan of accommodation for the student. Parents, if appropriate, should have a list of things the student needs. For instance, if a child is repeatedly absent due to illness, the items needed may be copies of notes and/or handouts and homework assignments sent home each day, the ability of teachers to waive homework assignments if they are otherwise convinced the student has mastered the subject matter, and tutoring. With budget constraints, getting tutoring is often difficult. However, teachers may be willing to help a student via email or to spend extra time with a student, and that should be deemed an important supplement to tutoring that should be asked for. Once a plan is agreed upon and written, it requires yearly re-evaluations or periodic reviews.⁴

Under Section 504, the school cannot require parents of students with disabilities to pay the costs associated with necessary accommodations or services, but fees charged to all parents of the general student population may also be collected from parents of students with disabilities.³

Obtaining an IEP

An IEP trumps a 504 plan. Therefore, children who qualify for an IEP do not require a 504 plan. For students to qualify for an IEP, they must be found eligible for special education. IDEA defines the term "special education" as "specially

designed instruction, at no cost to the parents, to meet the unique needs of a child with a disability, including instruction conducted in the classroom, in the home, in hospitals and institutions, and in other settings, and instruction in physical education." Specially designed instruction means "adapting, as appropriate, to the needs of an eligible child under this part, the content, methodology or delivery of instruction to address the unique needs of the child that result from the child's disability and to ensure access of the child to the general curriculum, so that the child can meet the educational standards within the jurisdiction of the public agencies that apply to all children."⁷

How an IEP is obtained is similar to a 504 plan. However, there are differences. First, a full multifaceted evaluation is required using a variety of assessment tools and strategies to gather relevant functional and developmental information, including information provided by parents that may assist the team in determining whether the child has a disability and how it affects the child's educational program.⁸ Second, because the student is eligible for special education, the school district is required to assign a case manager (special education teacher) to the student. Third, how an IEP is written differs. The IEP document contains very specific language and parts such as goals and objectives that are not included in the 504 plan. Timelines for an IEP are also very specific, whereas there are no timelines written into the 504 plan. And, a minimum number of IEP participants and who they are, such as an administrator, general education teacher and special education teacher, are required, whereas there are no requirements stating who must attend the 504 plan meeting.⁸

After an IEP is finalized, it requires a re-evaluation every three years by the IEP team to determine if services are still needed to address the student's disability unless the parents and other members of the IEP team agree it is not necessary. Should a student require a change of placement, re-evaluation may not be required.⁹

Finally, under IDEA, all services included in a student's IEP must be provided at no expense to the student or the parents, including those that are charged to the general student population.³

Handling a Dispute

If parents believe their child has been discriminated against under Section 504 or ADA, or the school is not complying with an IEP, the parents have the right to file a complaint. For a 504 plan, a complaint should initially be filed with the school's or school district's Section 504

compliance officer. Should there not be such a position, that is a violation of Section 504. Unfortunately, there is no Section 504 requirement that says state education agencies must establish state complaint systems for Section 504 and ADA noncompliance allegations (as there is under IDEA). However, a complaint may also be filed with the OCR (usually the regional office).

The scope of Section 504 complaints with OCR is very broad. The complaint may be filed by any individual or organization, and it may address individual student, class or systemic issues. And, it must be filed within 180 days of the alleged discriminatory action, although the regional director is authorized to waive the time limit. The OCR will conduct an investigation of the complaint through data collection and written responses to questions, and it may conduct an onsite review. In individual complaints, an informal process known as early complaint resolution is available.

Once the complaint is reviewed, the OCR will issue a letter of finding either with a no-violation conclusion or

identifying violations and specifying corrective actions. If the school fails to implement the corrective actions, there may be an administrative hearing with the possibility that federal educational funds may be terminated.

It's important to note that the OCR states that its compliance monitoring generally focuses on whether a school district has followed the policy and procedural requirements of the law and regulations; it does not see its role as second-guessing substantive decisions. According to the OCR: "It is not the intention of the department except in extraordinary circumstances to review the result of individual placement and other educational decisions, so long as the school district complies with the 'process' requirements of [the identification and location, evaluation and due process procedures]."³

When a child has an IEP and the parents have concerns about their child's rate of progress, the appropriateness of the services provided to the child or the child's educational placement, these issues can be resolved either informally

Table 1. Differences in the Details of the Law Between the 504 Plan and the IEP

504 Plan	IEP
<ul style="list-style-type: none"> Offers all children with disabilities equal access to an education. In some cases, may include special education services, but for a child in a wheelchair it may mean a ramp or elevator to access the classroom 	<ul style="list-style-type: none"> Only for children who have a disability Only for children who require special education services Individualized program must meet each child's unique needs Must provide educational benefit
<ul style="list-style-type: none"> Documented in a written plan 	<ul style="list-style-type: none"> Document contains very specific language and parts such as goals and objectives that are not included in the 504 plan
<ul style="list-style-type: none"> No specific timelines 	<ul style="list-style-type: none"> Timelines are very specific and important
<ul style="list-style-type: none"> No requirements stating who must attend the plan meeting 	<ul style="list-style-type: none"> Specifies a minimum number of participants and who they are
<ul style="list-style-type: none"> Reports of noncompliance and the request for a hearing are made to the Office for Civil Rights 	<ul style="list-style-type: none"> Reports of noncompliance and the request for due process are made to the State Department of Education
<ul style="list-style-type: none"> Does not offer as many specific procedural safeguards 	<ul style="list-style-type: none"> Provides specific procedural safeguards, including but not limited to the right to request an independent assessment at public expense and a student to "stay put" until a dispute is resolved

Source: Education Center. 504 Plan vs. IEP. Accessed at www.ed-center.com/504

Sample Accommodations for a Chronically Ill Child Under a 504 Plan and IEP

In the classroom, the student may:

- Use the bathroom at any time, without delay.
- Keep a water bottle at the desk at all times.
- Keep hand sanitizer at the desk at all times.
- Alter the location of personal or classroom supplies for easier access or to minimize distraction.
- Have a preferential locker location that is centralized.
- Have preferential seating and be allowed to move seats if students around the student are ill.
- Go to the nurse's office when unwell, regardless of tests or lesson plans taking place.
- Have "stop the clock" breaks during state testing (only available under an IEP in some school districts) and classroom testing.
- Self-monitor energy levels, fatigue and pain to determine if he or she feels capable of participating in gym or other physical activities. Should be allowed to take breaks whenever he or she feels it is necessary, and rejoin the activity after the break.

The student will:

- Only miss class when necessary due to illness or medical appointments (every effort will be made to schedule appointments outside of school hours).
- Work toward handing in assignments on time and only request deadline extensions when his or her illness makes it necessary.
- Attend before- and/or after-school tutoring as needed to make up any missed work and assignments.

When away from class due to illness or medical appointments, teachers will:

- Make sure all PowerPoints, handouts, homework assignments and class materials are available, to the extent possible, for the student to complete the work from home.
- Reschedule tests and extend deadlines for submitting projects and homework assignments when the student requests the extension because of illness. The student will not be penalized for handing in work late or missing tests due to illness.

Additional provisions under an IEP:

- Provides the student with a case manager who is the point person who communicates between the student's family and his or her teachers regarding any absences and who meets with the student when he or she returns after an absence to help organize and prioritize missed assignments and tests.
- Provides the student with a private location and alternate time to perform any special procedures.
- Involves the school nurse, teachers and staff by establishing a health alert (the school provides training for every staff member involved with the student so that they are aware of the health issues and of proper procedures).
- Provides education and support for peers.
- Provides for modifications to recesses, physical education and transportation.

Source: Chronic Action. 504 Plans. Accessed at chronicaction.org/schools/504-plans/#Click_here_for_Sample_504_Plans_for_Students_with_Chronic_Illnesses.

or formally. It is advised that both sides first discuss their concerns and try to compromise. This can happen through an IEP review in which the parents and the IEP team discuss the parents' concerns and work toward an agreeable solution. Solutions can be temporary in which a particular plan of instruction is tried for a period of time. In those circumstances, after the trial period, the team reconvenes for an additional IEP review.

A second informal approach is an IEP facilitation. While this is not one of the dispute resolution options described in the law's procedural safeguards, its use is on the rise;

however, there is no requirement in IDEA for school systems to provide an IEP facilitation. An IEP facilitation includes an impartial facilitator who is not a member of the IEP team, but who is there to keep the team focused on developing the child's program while addressing conflicts as they arise. When disagreements arise, the facilitator can model effective communication and listening for team members, can encourage members to identify new options and, most important, will ensure the meeting remains focused on the child.

Some large school districts also have information dispute

- *Develops a healthcare and emergency plan.*
- *Arranges for trained personnel on school field trips.*
- *Allows for a modification to coursework (e.g., performing alternate assignments, working from home, turning in online work, etc.).*
- *Allows for a modification in the school day and the adjustment of class schedules.*
- *Allows for a modification of attendance policies.*
- *Allows for a modification of certain learning activities.*
- *Provides an extra set of textbooks for home.*
- *Provides note takers when the student is absent, or classroom aides as needed.*
- *Allows for separate testing locations and accommodations, such as providing the tests in segments.*
- *Provides additional support (e.g., a teacher who can go to the home, a special study hall period).*
- *Is a binding, legal document that is strictly adhered to by school staff (whereas under a 504, a parent must typically advocate the 504 plan with teachers).*

Notes:

- *Each 504 plan or IEP has to be customized to the student and the student's school district.*
- *Often, chronically ill children start with a 504 and find that it is not effective to the extent needed and then seek/obtain an IEP.*

resolutions (IDRs). An IDR is an optional, voluntary and informal process to resolve disputes regarding a child's IEP. Under IDR, the parents identify issues in dispute, and the district attempts to work with the parents to quickly and informally resolve the identified issues. Although the process is quick and informal, it may result in a formal, binding agreement between the district and the parents. This agreement will include a waiver of certain claims, including all special education claims the parents may have against the district up to the time of the agreement, meaning that the parents will no longer be able to file a

request for formal due process or state mediation for anything occurring prior to the agreement. Accordingly, parents should be sure they understand all of the terms of the agreement before signing. If the IDR process is unsuccessful, parents may still initiate formal proceedings.

Formal approaches include filing a state complaint, a resolution meeting, mediation and due process. A state complaint can be filed by an organization or individual, including those from another state. Complaints must be written directly to the state education agency (SEA) and must describe what requirement of IDEA the school has violated, among other specific things. A resolution meeting is then held between the parents and the SEA director, after which the SEA must either resolve the complaint or have a system in place in which complaints are filed with the school district. In the latter circumstance, complainants can have the district's decision reviewed by the SEA. When the SEA makes a ruling, the school system must be given the opportunity to respond to the complaint, including making a proposal to resolve the complaint. In most cases, the SEA must resolve the complaint within 60 calendar days and must issue a written decision. If the SEA finds the school system has failed, the SEA must address the failure and include corrective action.

Also, after a state complaint is filed, parents can opt for mediation. In mediation, parents and school personnel sit down with an impartial third person called a mediator to talk openly about the areas where they disagree and try to reach agreement. Mediation must be voluntary on the part of both parties; it must use a qualified and trained mediator who is selected by the state on a random, rotational or other impartial basis; all discussions must remain confidential; it can't be used to deny or delay parents' right to a due process hearing; and any agreement must be put in writing.

The final formal approach is due process. When due process is used, an impartial third person, called a hearing officer, decides how to resolve the problem. First, a due process complaint must be filed by providing a copy to the other party and forwarding a copy to the SEA. This includes the child's name, the address where the child resides, the name of the school the child is attending, a description of the conflict and a proposed resolution of the conflict. The information in the complaint must be kept confidential. Within 15 days of a complaint being filed, the SEA must convene a resolution meeting with the goal of giving the parties an opportunity to resolve the issues without holding a hearing. If the resolution doesn't

succeed, a due process hearing is held in which each party presents its views in a formal legal setting using witnesses, testimony, documents and legal arguments. Within 45 days of the resolution period expiring, a final decision must be reached. If the hearing officer's decision is not appealed, it is final.

For IEPs, each state also has specific ways for parents and schools to resolve differences. The state's guidelines can usually be obtained at the local department of special education. Parents may also wish to visit CADRE, the National Center on Dispute Resolution in Special Education, at www.directionservice.org/cadre.¹⁰

Other Resources

In addition to Section 504 and IDEA, there are other resources available for parents with chronically ill children. In some circumstances, it may be best for children to utilize the Home & Hospital Instruction Program, which serves students who incur a temporary disability that makes attendance in the regular day classes or alternative education program impossible or inadvisable. The district in which the home or residential health facility is located is responsible for instructing and educating pupils who must be hospitalized or remain at home due to a temporary but extended illness or disability. There is no provision in statute that specifically addresses instructional content; however, the goal of home or hospital instruction should be maintenance of the students' former level of performance while recovering. Once students' have recovered, they may return to the school to continue their education.¹¹

There also are other laws that parents should be aware of. The No Child Left Behind (NCLB) Act, Public Law 107-110, is the nation's latest general education law. The law, which focuses on accountability for results, and emphasizes doing what works based on scientific research, has increased parental options and increased local control and flexibility. Information about the NCLB Act is available at www.ed.gov/nclb.

The Family Educational Rights and Privacy Act (FERPA), a federal law that protects the privacy of student education records, applies to all schools that receive funds under any program administered by the U.S. Secretary of Education. FERPA gives parents certain rights with respect to their child's education records. These rights transfer to the student when he or she reaches the age of 18 or attends a school beyond the high school level. Information about FERPA is available at www.ed.gov/policy/gen/guid/fpco/ferpa/index.html.⁵

Setting Students Up for Success

It's critical for parents to utilize the school site programs to ensure their chronically ill children succeed in school. School districts want their students to succeed, and they work with each and every one to ensure they get the modifications and/or accommodations they need. But, which program is best for a child depends on his or her unique academic needs. According to Erin Vanderwood, program specialist/pupil services at Riverside Unified School District, Riverside, Calif., "The team actually discusses at what level support is needed. If a student has a medical condition that requires him or her to have some kind of special education services, like a resource teacher or a special classroom, then an IEP is needed. However, if it's determined that the student doesn't need extra help, just accommodations, then a 504 plan is needed. The 504 keeps a student in the least restrictive environment." ■

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Arianna's Need for an IEP

Arianna Kazemi was diagnosed at age 2 with primary immunodeficiency. When she was in kindergarten, the teacher called Arianna's mother, Annaben, to tell her that Arianna was sleeping at her desk every day. "She said, 'I don't think this is normal,' and she was concerned," explains Annaben. In addition to being overly tired, Arianna was getting a lot of colds and picking up every illness. It was then that Arianna was retested and began treatment with intravenous immune globulin, which made a difference, but because it was such a shift in Arianna's routine, she needed special accommodations. So Arianna was placed on a 504 plan.



Arianna had a 504 plan throughout elementary and middle school. "The elementary school was very accommodating," says Annaben. She had preferential seating, which meant if someone was sick, she was able to switch desks to be seated farther away. Because she was prescribed so many antibiotics, Arianna was allowed to get up and go to the bathroom or get a drink when she wanted. And, she could go to the front office, where they had a cot that Arianna could lie on to rest. "The teacher in kindergarten started washing Arianna's desk every day," says Annaben. "And, the school secretary would call me to let me know what was going on and to ask if what Arianna was doing was OK. In first grade, the teacher washed all the desks."

But, in middle school with six or seven teachers, Annaben started to find it harder to obtain accommodations for Arianna. So, in eighth grade, before transferring to high school in another district, Annaben decided to fill out the necessary paperwork to obtain an IEP for Arianna. Unfortunately, in the fall, when Arianna started high school, the IEP was met with resistance. "They felt a 504 would suffice because she wasn't behind in her academics," explains Annaben. "But, we were bumping into a lot of problems like 15 days of missed school in the first quarter." Arianna had always been a straight-A student, yet with so many missed school days, she had a B in physical

education, which was precluding her from being on the dance team (even though Arianna's PE teacher expressed that she was her best dancer). She also was in advanced English, and that teacher wouldn't allow Arianna the extra time to make up work. "The 504 plan just didn't carry enough weight," says Annaben. "She was a straight-A student, but they didn't understand the stress she

was under to keep up those grades."

What Arianna really needed was a flexible schedule to allow her to complete her work. "An IEP is a legally binding document that would force the situation," explains Annaben. So, she fought for an IEP and obtained one with the help of a letter from Arianna's immunologist. As part of the IEP, they requested a free block period at the beginning or end of the day so if Arianna was tired, she could go in later or come home early. But, the school denied that. "Even with an IEP, we couldn't adjust her schedule. She had to be a regular student with the same attendance policy," says Annaben. That was when Annaben discovered Arianna could instead be enrolled in independent study. "Now, if she misses school, she can make it up in a different way," explains Annaben. "If she's not feeling well on Tuesday, she can go in on Thursday and make up the hours. Or, she can do it online." The IEP also provided Arianna with a case manager who advocates for her. According to Annaben, a case manager often helps because he or she can approach the situation in a more neutral manner, whereas a parent might often get frustrated. "Many parents aren't knowledgeable when they go in to ask for things, or they don't know how to get what they want to help their child, so it becomes very adversarial," says Annaben.

With the IEP, Arianna has managed to stay a straight-A student and her stress level is greatly reduced. "I get a lot more rest and am more energized," says Arianna. "I feel like I can finish something without having to take a nap or get an incomplete."