

Educational Advocacy: The ABCs of IEPs and 504 Plans

For children, the educational years play a critical part in their growth into successful, happy adults. While faced with challenges that their classmates may not experience, most children with neuromuscular diseases — with proper preparation and relatively simple accommodations — grow up to have careers, families and contributing roles in their communities. That's why MDA offers support and information to assist parents of children with neuromuscular disease in preparing and advocating for the best education possible.

In talking to adults with neuromuscular diseases who grew up and went on to college, graduate school and thriving careers, several key themes are prevalent:

- They were frequently asked what they wanted to be when they grew up.
- Their parents expected them to pursue the same postsecondary education as their nonaffected siblings.
- Their teachers held them to high academic standards.
- From an early age, they were included in their annual academic planning meetings (IEP and 504 plans).
- Self-advocacy skills were incorporated into academic plans.
- They joined clubs and extracurricular groups, and built support networks.

Ensuring your child's school experience is as rigorous and supportive as possible is sometimes easier said than done, but MDA stands ready to be your advocacy partner, providing tools and support.



Communicating with teachers and school staff

Maintaining communication: Frequent meetings and open communication among teachers, school personnel, students and their families help ensure the school is providing an accessible, rigorous and nurturing academic environment. This is especially important when medication, therapies and medical interventions impact classroom performance or attendance.

Teacher presentations: Your local MDA staff can speak at faculty meetings or trainings, with a focus on explaining the disease and highlighting your child's strengths.

Communicating with students and peer groups

Children and peers are naturally curious about each other and will likely have questions about anything that causes a classmate to seem different, whether that be eyeglasses, a cast from a playground injury, or accommodations and orthopedic equipment used by a classmate with a neuromuscular disease. Providing peers with information that allows them to feel helpful and empowered — as well as any information that demystifies any perceived differences — will foster an inclusive environment that focuses on the children's strengths and commonalities.

Student presentations: Many families choose to be proactive about questions from classmates. Your local MDA staff can conduct classroom presentations or an assembly for an entire grade level. These

presentations help build a sense of community by showing students how to be helpful while underscoring all of the wonderful traits your child and his/her peers share in common. This can be especially helpful when new mobility equipment and school accommodations are introduced. Presentation outlines and recommendations for disease-specific school accommodations also are available from your local MDA office.

Presentation topics can include:

- Basic information about your child's diagnosis (it's equally as important to talk about what the disease does and does not affect);
- How does someone get a muscle disease?
 - Emphasize that a muscle disease is not contagious.
 - Ask students to define "contagious," and give examples of some illnesses/diseases that are contagious (e.g., common cold, flu, chicken pox).
 - Talk about examples of traits that are inherited — which like muscle disease — are a part of the recipe that you are born with and are not contagious. Examples include: eye color, hair color, height.
- Discuss how to be a good friend and encourage students to identify their strengths and good personal qualities that they bring to a friendship. Guide them to identify personal weaknesses and how to ask for help with those shortcomings.

Classroom community/fostering friendships: If the student misses a lot of class time, it is important to maintain social connections. Suggested ways of accomplishing this include:

- having classmates write letters to one another during an absence;
- having the student "skype" in during class time; and
- creating blog projects where students keep an online journal about their experiences with one another in a secured community.

IEP (Individual Education Program)

What is an IEP?

An Individualized Educational Plan (IEP) is the blueprint for the education of a child with a disability. IEPs address physical assistance, academic adaptations and technological equipment.

The IEP is a legally binding document that outlines the services that have been determined to be necessary to support your child in thriving within the school setting in the least restrictive environment. By law, IEP meetings must be held at least once a year, but parents, teachers or administrators may call for one at any time.

The IEP is a powerful document for students and parents. It means that you — the person who best knows your child's physical, intellectual and emotional needs — enters into a partnership with the school to ensure that the academic day is structured around your child's needs, and that the school is accountable to you and your child.

The IEP process also allows you to take full advantage of the school's expertise and resources. For the process to be effective, all parties need to be realistic and open to different possibilities.

The IEP team may include:

- Parents
- Personal/private advocate
- General and special education teachers

- Principal
- School district administrator
- Adaptive physical education teacher
- Specialists
- Therapists
- Student (if appropriate) **

With the parent's and school's approval, some IEP members may be excused from attending if their area won't be discussed or modified at that time.

*** Note: Many families opt to include their child in IEP meetings when appropriate. This often begins around fifth grade, or when they deem that their child is emotionally mature enough to observe and participate in the process. This allows students to learn how to be effective self-advocates, appreciate their options when it comes to making adaptations and accommodations to their schedule and physical environment, and develop an understanding of who the members of their academic and advocacy team are and how they can help the students achieve their goals. Additionally, it may be beneficial to create several questions that the student could be responsible for asking in order to initiate verbal involvement in the meeting.*

What's IDEA 2004?

The Individuals with Disabilities Education Act is the federal law guaranteeing children with disabilities access to a public education. The original special education law enacted in 1975 was renamed IDEA in 1990 and was most recently reauthorized by Congress in 2004. Among IDEA 2004's notable changes is the requirement that IEPs consider "functional" as well as "academic" goals. This ensures that qualifying students with neuromuscular diseases who are keeping up academically but who have physical impairments will receive special education services, including occupational and physical therapy. Notably, students are required to receive these services in the least restrictive environment deemed appropriate for each individual student. In other words, the school district legally must provide an educational program suited to your child's specific needs, in a setting that's as inclusive as possible.

What's a 504 Plan?

Named after Section 504 of the federal Rehabilitation Act, 504 plans are less formalized educational plans than IEPs, but they still are designed to ensure equal access to education for students with disabilities.

Some students with muscle diseases have IEPs (Individualized Education Plans) and some have 504 plans. As the accompanying diagram shows, there's a lot of overlap between the two plans. The key is for parents to be aware of the pros and cons of each, to stay in constant communication with your child's school, and to keep a close eye on how well the plan is meeting your child's specific needs at school.

While IEP teams must follow strict procedures, guidelines and timelines, Section 504 only requires that schools notify parents that their child has been identified, evaluated and placed under a 504 plan.

For example, in order for a child to receive services, every detail must be written into the IEP and parents must sign off on any changes. On the other hand, a 504 plan doesn't have to be in writing, and schools aren't required to involve the parents in the process in any way. This puts the responsibility on parents to keep the lines of communication open. Parents should ask the school to create a written document, which can ensure greater accountability and consistency in the 504 plan's implementation, and should try to schedule regular meetings to monitor the plan.

The common goal in both IEPs and 504 plans is that they are designed to assist students in gaining access to a free appropriate public education.

Individualized Education Plan (IEP)

504 Plan

What is it?	An IEP is the educational blueprint to meet a child's special education needs in the "least restrictive environment." It is covered by the Individuals with Disabilities Education Act, or IDEA.	Named after Section 504 of the federal Rehabilitation Act, a civil rights law, 504 plans ensure equal access to education for students with disabilities.
Who qualifies?	To qualify, a child's disability must adversely affect educational performance and progress, even if the child is achieving good grades. A school-funded evaluation determines whether special education services are needed for the child to meet general curriculum requirements. States decide if children who need only "related services" (like occupational or physical therapy) qualify for specialized services.	Section 504 defines a person with a disability as "any person who has a physical or mental impairment which substantially limits one or more major life activities, has a record of such an impairment, or is regarded as having such an impairment." If a school receives federal money, it's required to follow a 504 plan's provisions.
What does the plan cover?	IEPs address physical assistance, academic adaptations, specialized instruction, technological equipment, and related services like occupational, physical and speech therapy.	504 plans address all the same areas as IEPs, with the exception of specialized instruction.
Who creates the plan?	The team includes parents, teachers, administrators and experts in different areas. The IEP team must meet at least once a year. Changes can't be made to the plan without the parents' OK.	504 plans don't have to be written documents, nor are parents required to be part of the decision-making process. In practice, however, parents typically help create and monitor the plan, and schools usually create a written 504 plan.

The IEP assessment

1. The identification of a need for an assessment of whether a 504 Plan or an IEP may be beneficial for a student can be initiated by both parents or teachers. It is important to know that as a parent, you have a legal right to request that your child be assessed for accommodations and special education services through the public school system.
2. In response to a formal request, the school will arrange for the assessments based on the specified areas of concern.
3. Once the assessments are completed, a formalized eligibility meeting will be scheduled to review the assessments and determine whether the establishment of either a 504 Plan or an IEP would help to ensure that the student thrives within the academic setting and is able to fully access his/her school environment. In addition to the school personnel who will be present at this meeting, parents have the ability to include anyone whom they deem appropriate in this meeting. Many families have found that including a member of the MDA clinic team such as a social worker or psychologist or the local MDA team's Health Care Service Coordinator, as well as supporting documentation from the MDA clinic physician, has proven beneficial in justifying desired levels of eligibility. Parents will have access to assessment findings prior to the eligibility meeting.

IEP meeting tips

- Submit request to have an assistive technology assessment completed for your child in order to determine whether there are any energy-conserving devices that could be utilized within the school to assist with completing school work (e.g., iPad, dictation devices, AlphaSmart, etc.).

- Be proactive before the meeting. Do your research and understand the resources available for you and your child (see resource links below). Talk with other parents who have experienced the ARD process at your school or who have children with similar diagnoses and live in your school district prior to attending the meeting. It's a good way to "compare notes" about accommodations provided to other children in the same school district.
- Consider including something that helps to personalize your child (especially for a meeting with participants from outside of the school who may not have previously met your child) such as photos, a brief video, sharing a story, a handout. You also could invite your child to the meeting, and he/she could start off by sharing his/her hobbies, interest, favorite school subjects, etc. with the group.
- Consider inviting someone from MDA or other providers who support you and your child to the IEP meeting.
- Be sure to understand the concept of "least restrictive environment" prior to the meeting.
- The IEP meeting will include a review of your child's most recent standardized test scores and classroom performance evaluations. If you suspect that your child might benefit from testing accommodations (such as extended time, preferential seating, oral instructions, etc.), this is an appropriate opportunity to request that such considerations be made.
- The school's multidisciplinary team will present a tentative plan to help your child achieve measurable short-term and annual goals, and will propose supports to help your child achieve those goals. If you have questions that are not answered or concerns that are not addressed, you have a right to get those addressed before signing the IEP. It doesn't become a binding document until you and the appropriate school personnel have signed it — so don't sign it until you're satisfied. Once it has been signed, the school district can be held accountable for providing what is needed to enable your child to meet the written goals.
- Be careful when the IEP calls for an out-of-class service. For example, are you willing to have your child miss math three days a week to go to occupational or physical therapy? If not, state this in the IEP document.
- Dependent on your child's after-school stamina and energy level, you may consider trying to have extra services (such as tutoring, PT, OT) provided after the school day, so no academic time is sacrificed.
- The progress your child is making on his or her IEP goals must be reviewed and updated at least once a year. You or the school district can call for an earlier review if your child's needs suddenly change or if there are any problems with the implementation of the current plan.

What should be included in an IEP?

All IEP's should include the following in order to comply with IDEA standards:

- present levels of educational performance
- annual goals and measurement of goals
- special education and related services to be provided and a schedule for these services
- participation with nondisabled children
- participation in statewide and district-wide assessments
- dates and locations for services:
 - when services and modifications will begin
 - how often the services will be provided
 - where the services will be provided
 - how long the services will be provided
- transitions services — IEP should address the plan for ensuring that your child meets high school diploma requirements and is receiving supports geared toward transitioning from high school into his/her desired postgraduation setting
- participation in general curriculum
- documentation of needed accommodations and timeline for implementing the accommodations

Assessing needed accommodations

MDA can help you as you consider some important factors:

- Can your child safely maneuver from the drop-off area to the building entrance?
- Can he or she independently enter the building and access all levels of the school?
- How far apart are your child's classes?

- Can a second set of textbooks be kept at home?
- Is preferential seating needed in the classroom?
- What is the emergency evacuation plan for your child? How often will that plan be practiced to ensure your child's awareness of the evacuation route and routine? Is he or she aware of the emergency evacuation plan?
- How will the school help make field trips equally accessible for your child?
- Have physical education classes been adapted to your child's abilities, and has every attempt been made to include him or her in the general P.E. classroom?
- Does your child require the assistance of a notetaker or extra time when taking tests?
- Have arrangements been made for your child to safely and comfortably access the restroom throughout the school day?
- Have you and your child identified adults with whom he/she is comfortable speaking to if a private or uncomfortable situation should arise during the school day? (Young adults often reflect on time when they spent hours in pain or discomfort after an accident because they were too embarrassed to tell an adult about it during the school day.)
- Have you asked for a physical therapy or occupational therapy assessment?
- It is important to know that the purpose of PT and OT within the school setting is very different than within the clinical setting. In the school setting, PTs help to ensure that students can safely access the school environment and participate in physical activities such as physical education and recess; some stretching routines also can be conducted. PTs can instruct faculty members on the proper use of a student's equipment and techniques for transferring students, etc. In the school setting, OTs specialize in fine motor accommodations such as adapted writing implements, adaptive technology assessments, etc.
- How will your child use the restroom facilities during the day?
- If your child needs daily procedures conducted by a skilled nurse, will that be provided?
- Who will be responsible for helping my child maneuver around the school building? Classroom? School campus?

After the IEP is written

A few more reminders:

- Parents and members of the team must all be given a copy of the document — only sign the document once you agree with all elements of the plan. If there are unresolved issues at the conclusion of the IEP meeting, do not sign the IEP until the issues are resolved and goals are written in a way that effectively addresses your concerns.
- Parents must give written permission before the school can implement the accommodations or provides services.
- Each individual who receives the IEP must understand their role and responsibility for carrying out the IEP.
- Parents must be provided a copy of their rights under federal law.

For additional references visit us online at mda.org/Tips_for_Success