



**Myotonic
Dystrophy**
FOUNDATION



Going to School with Myotonic Dystrophy:

**A Guide to Understanding
Special Education and IDEA**

A publication of Myotonic Dystrophy Foundation (MDF)

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Going to School with Myotonic Dystrophy:

A Guide to Understanding Special Education and IDEA

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Why Myotonic Developed A Guide to IDEA

Myotonic Dystrophy Foundation (MDF) developed this guide to help you understand the special education law that supports all children with disabilities in the United States, including infants and young children with congenital myotonic dystrophy, (CDM), and childhood-onset myotonic dystrophy type 1, (DM1).

The law, called **IDEA** (Individuals with Disabilities Education Act), was created to support the early development and education of children with disabilities in the home, in preschool and in public K-12 schools.

The guide will help you understand:

- The basics of IDEA and how it works for children with CDM and childhood-onset DM1
- What your child’s rights are, and tips for getting the right supports and services
- How to work with the school as your child makes key transitions:
 - From home to preschool
 - From preschool to elementary school
 - From elementary to middle school
 - From middle to high school
 - From high school to college, work or other
- How to manage situations that may arise at school as your child grows and his/her CDM or childhood-onset DM1 symptoms change, so your child receives the support and services s/he needs, at every age and stage in school.

Because IDEA is a complex law and many resources already exist, this guide is specifically designed to help parents of children with CDM or childhood-onset DM1 understand how IDEA works, especially at transition points in their child’s development and education. **The guide is meant to help you get started, to understand the essentials and to support your role as an advocate for your child at school.** You will find **Helpful Tools for the Guide**, page 61, and **External Resources**, page 95, in the appendices if you want to learn more.

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QUICK TIP

If you are viewing this guide online or in pdf format, the text in **gray** is hyperlinked to take you directly to the page noted in the text. Your mouse pointer will turn into a pointing finger when you roll over a hyperlink, then just click on it. Try it!



REMINDER

If you are a teacher or staff member, refer to the ‘For Professionals’ section for information on how myotonic dystrophy affects the body, Neuropsychological Functioning Aspects of CDM and Childhood-onset DM1, and frequently asked questions about myotonic dystrophy.



REMINDER

While this guide is comprehensive, parents and caregivers can digest it in bites, based on the age and status of their child or children.

Using the Guide

The guide is formatted to support you at all stages in the parenting journey from early development into K-12 school with your child. It is designed so you can use it as soon as you have your child's diagnosis— as early as birth, early infancy, or in childhood— to gain the knowledge and skills needed to help guide your child's developmental, learning and educational needs.

Come back to the guide throughout your child's development and school career for a refresh, and to know what to expect for the next transition in school.

The guide is organized to help all parents and/or caregivers of children with CDM or childhood-onset DM1.

Where you begin depends on the age of your child. This guide is arranged by age, and then delineated by congenital and childhood-onset forms of the disease.

Because **IDEA** is a complex law, every section of the guide, regardless of the age range covered, includes these supports:

- Special Considerations for CDM or childhood-onset DM1
- Quick Tips
- Parent Insights
- Helpful Tools
- External Resources

NOTE: Bolded, blue terms will be used throughout the document, and indicate that an explanation of the term is available in **Glossary and Abbreviations** in Appendix A on page 62.

The full list of **Helpful Tools in the Guide** can be found in **Appendix A**, page 61.

The full list of external resources (with hyperlinks) can be found in **Appendix B** organized by section. These external resources are available online for viewing and download. If you do not have internet access, check your local public library or with family and friends. Or call **415.800.7777** to reach MDF.

Overview of IDEA

What IDEA Is and Why It Is Important

IDEA is a federal education law that requires states to oversee and help public school districts and schools provide early intervention, special education and services to infants, toddlers, children and youth with disabilities. The law applies to all public schools, including charter schools. **IDEA** can apply to private schools when the district decides to place the child in the private school. **When parents choose a private or religious school on their own, IDEA generally does not apply.**

Because of IDEA, all states must conduct **Child Find** activities to find and possibly serve all children who have disabilities from birth through age 21:

- **For infants and toddlers ages 0-3**, the state must evaluate any child that it knows or suspects may have a disability, and offer families early intervention and support services if the child is found eligible for IDEA. Once eligible, there is a process to develop and annually update an **Individualized Family Service Plan (IFSP)** – for infants and toddlers to age 3. This IFSP development process is led by a state **service coordinator** and includes input from the child’s parents or guardians. This is called IDEA Part C.
- **For children ages 3-21**, all traditional public and charter schools must also conduct Child Find activities and evaluate any child that they know or suspect may have a disability. Districts and schools must provide a **Free Appropriate Public Education (FAPE)** in the **least restrictive environment (LRE)** to every eligible child with a disability. The school provides your child with an education and related services through an **Individualized Education Program (IEP)** – typically for children age 3 through high school graduation or through age 21. This is called IDEA Part B.

IDEA Regulations and State Laws

After Congress passed IDEA in 1975, the U.S. Department of Education developed regulations to help states know how to implement the law. The most recent federal regulations were finalized in 2006. Every state must use the regulations to develop complementary state laws and state regulations to meet IDEA’s requirements.



REMINDER

You will find a list of key terms and abbreviations in **Glossary and Abbreviations** on page 62. All **blue bolded** words and phrases have definitions listed there.



REMINDER

Special education is a service, not a place.

While this guide covers the basics, there are key details in your state and school district regulations that affect how your child's school team will make decisions, such as whether to or how to provide services. After reviewing this guide, you should:

Visit your state department of education website and find information offered on special education. To find your state department of education website see: <https://www2.ed.gov/about/contacts/state/index.html>

Seek out your state's Parent and Training Information Center (PTI), which is funded by the federal government to provide state-specific information for families about IDEA. Every state has at least one PTI. To find your PTI, see: <http://ectacenter.org/contact/ptccoord.asp>

IDEA and Infants and Young Children with CDM

Any child diagnosed with CDM at birth, as an infant or at a very young age will likely qualify under Part C of IDEA for special education and other supports and services as soon as a diagnosis is made – even as early as birth. For infants and toddlers (ages 0-3), IDEA Part C requires that an Individualized Family Service Plan (IFSP) be developed to outline the services and supports the child and family will receive.

Sections 2 and 3 of this guide are specifically for infants and toddlers with CDM and will discuss the IFSP and transitioning to preschool. All other sections of the guide apply to both CDM and childhood-onset DM1 children as they advance through public school.

IDEA and Childhood-onset DM1

Depending on the severity of symptoms and the age at which symptoms begin to affect early development and learning, after a formal **evaluation** as required by IDEA, children with childhood-onset DM1 should qualify for services under IDEA and be provided an **IEP** (ages 3-21). The services and supports the district and school offer will also depend on the age at which your child's symptoms arise, how severe your child's symptoms are and the impact of DM1 on your child's development and how s/he learns. If your child starts having symptoms before the age of two, refer to the sections on congenital myotonic dystrophy cited in the paragraph above.

This guide will help parents of children with childhood-onset DM1 understand how to request the IDEA evaluation, determine a child's eligibility, and establish an IEP- see **Section 4 – Ages 3-12: Developing the Individualized Education Program (IEP)**, page 21 and sections 5-9 of the guide as your child transitions through public school.

IDEA and Health and Medical Services

IDEA requires the state to provide **special education** and **related services** to eligible children. Related services may include medical services to diagnose or support the evaluation of your child's condition, or to provide support from the school nurse. IDEA does not provide direct medical care, nor does it reimburse schools or families for medical care. Your health insurance may be the primary source of coverage for your child's health-related services.

Also, your school may ask you to seek certain services to support your child's development outside the school because they are reimbursable by your health insurance. Examples of such services include occupational, speech, and physical therapy. A discussion on payment of related services is included in **Section 4 – Ages 3-12: Developing the Individualized Education Program (IEP)**, page 21.

If your child is eligible for **Medicaid** in your state, certain services provided for the IFSP or IEP may be paid for by Medicaid. Many schools and districts rely on Medicaid to provide services such as:

- Vision, hearing and other screening
- Hiring certain personnel (e.g. school nurse, aides, therapists, others)
- Updated specialized equipment (e.g., walkers, wheelchairs, exercise and special playground equipment, therapeutic bicycles, hydraulic changing tables, weighted vests, lifts, etc.)
- Assistive technology and items needed for each child to access the school curriculum similar to his/her non-disabled peers

Medicaid eligibility is handled differently in every state. While MDF sought and achieved designation for CDM as a Compassionate Allowance Condition under the Social Security Administration's disability program, helping shorten and simplify the application for disability status/coverage, this designation does not automatically qualify your child for services under IDEA.

IDEA and Your Child's Legal Rights

IDEA includes special legal protections for children and families called **procedural safeguards**. IDEA is the only federal education law that provides a way for families and schools to resolve disagreements that may occur about the child's IFSP, IEP, educational placement or other aspects of special education. See **Your Legal Rights: Individuals with Disabilities Education Act (IDEA) Procedural Safeguards and Dispute Resolution**, page 86.



MEDICAL REMINDER

Always ask for an order from your child's physician while you are at the doctor's office for things you need in your IEP.

RESOURCE RECAP

1



REMINDER

If you are a teacher or staff member, refer to the 'For Professionals' section for information on how myotonic dystrophy affects the body, Neuropsychological Functioning Aspects of CDM and Childhood-onset DM1, and frequently asked questions about myotonic dystrophy.

Section 1 – Overview of IDEA

Here are the resources that were discussed earlier in this section that could be beneficial in preparing your child's education plan.



Appendix A – Helpful Tools in the Guide

- **Your Legal Rights: Individuals with Disabilities Education Act (IDEA) Procedural Safeguards and Dispute Resolution**, page 86. You have rights. Refer to this section to read over what is and isn't allowed when it comes to your child's education



Appendix B – External Resources

- [Department of Education State Contacts](#) – Use this website to learn more about your state-specific guidelines regarding special education
- [Center for Parent Information & Resources – Find Your Parent Center](#) – This site directs you to a 'parent center' in your area that will help you learn about your state-specific guidelines



Read this section if your child has been diagnosed with CDM and is between 0-2 years of age

AGES 0-2:

The Individualized Family Service Plan for Children with Congenital Myotonic Dystrophy

Introduction to the Referral and Evaluation Process

Every state is required to provide early intervention services for infants and toddlers who have a **developmental delay** or **disability** and meet eligibility requirements. The federally-funded program these services come under is called **IDEA** Part C. Every state may call this program something unique but its focus is the same – early support and intervention for infants and toddlers.

Receiving an early diagnosis of congenital myotonic dystrophy (CDM) means that your child may collect supports and services through a referral from the hospital, pediatrician or state-approved child care provider. **If that referral did not occur**, contact your pediatrician and request it.

Your baby or toddler can receive early intervention services through an **Individualized Family Service Plan (IFSP)** from birth through his/her second birthday. Every family receiving early intervention services should be provided a **service coordinator** to act as a point of contact and to help guide you through the early intervention process. You will learn about developing the IFSP below. The type of services your child and family will receive depends on the age of your child and his/her developmental needs. Before your child turns 3, you will meet with your service coordinator and others providing early intervention to your child to discuss transitioning your child from the IFSP to an **Individualized Education Program (IEP)**. Because IDEA Part C works differently in each state, the information in this section describes how the IFSP program *generally* works. Part C state regulations and policies are available at <http://ectacenter.org/partc/statepolicies.asp>.

Early intervention services for babies and toddlers are focused on the basic and new skills they develop during the first two years of life. The services are designed to support families so that babies and toddlers meet developmental milestones and develop new skills. For children with CDM, early intervention is very important to limit the impact of the disorder on the child and to support his/her early development and early learning. Babies and toddlers with CDM or childhood-onset DM1 may need help with:

- Physical skills (reaching, rolling, crawling, and walking)
- Cognition (thinking, learning, solving problems)
- Communication (talking, listening, understanding)
- Social and emotional skills (playing, feeling secure and happy)
- Self-help skills (eating, dressing)



QUICK TIP

If you don't know who your early intervention service coordinator is, get in touch with the **Early Childhood Technical Assistance Center** to find your state contact. This is the contact who should assign your service coordinator: <http://ectacenter.org/partc/ptclead.asp>



QUICK TIP

The state agency in charge of early intervention services (known as the “lead agency”) differs from state to state. Find your state’s lead agency at <http://ectacenter.org/partc/ptclead.asp>



REMINDER

You will find a list of key terms and abbreviations in **Glossary and Abbreviations** on page 62. All **blue bolded** words and phrases have definitions listed there.

Child Age 0-2 with CDM: Referral is Usually Automatic

Once the referral is made, with your **consent**, a team of qualified people coordinated by your service coordinator will talk with you and may want to conduct additional screening(s) or tests (often called an **evaluation**) to learn more about your child’s development and add to the information provided by you and your doctor(s). **The lead agency has 45 calendar days to complete the evaluation and the initial IFSP meeting.**

Evaluation: The law requires the child’s parent or legal guardian be invited to join the evaluation, eligibility and education plan (IFSP) team meetings. It is very important that you participate in every meeting held to discuss what services and resources your child needs. If you have a partner or are married, or a family member(s) helps you parent your child, you should bring them to the meetings too. You know your child best and can add tremendous value as the team makes decisions about your child’s program.

It’s very likely that your service coordinator and members of the team may have never heard of CDM. It is your job to help educate them. Because you may bring anyone you wish to the team meeting(s), you might want to consider including a medical doctor (by phone), another care provider familiar with CDM, a family member or a friend.

Because there is a lot of information exchanged at the meetings, you can ask to record the meeting(s) so that you can listen to the discussion later. If you would like to tape the meeting, let your school know in advance. Everything gathered during the evaluation stage helps support the next step, which is to create your child’s Individualized Family Service Plan (IFSP).

If for some reason you are not happy with the evaluation results (even if your child qualifies for an IFSP) you can request an **Independent Educational Evaluation**, discussed below.

If for some reason your child does not qualify for an IFSP, you have several options:

- Request an Independent Educational Evaluation. See **Independent Educational Evaluation**, page 82
- Accept a 504 Plan. See **Comparison Chart: Individualized Education Program (IEP) to Section 504**, page 79
- Exercise your legal rights. See **Your Legal Rights: Individuals with Disabilities Education Act (IDEA) Procedural Safeguards and Dispute Resolution**, page 86

If You Didn't Receive an Automatic Referral, You Can Request an Evaluation

IDEA allows for parents to request an evaluation for suspected disability. The guide assumes you are making the request to evaluate because an evaluation for IDEA has not occurred at any time, or that a referral has not yet been made by a pediatrician, or other state-recognized early care provider.

Request the evaluation in writing: To request your **evaluation**, write a straightforward letter and provide specific examples of the problems your child is having and describe how this is impacting his/her early development. See **Request to Evaluate Letter - Sample**, page 89.

State Early Intervention (Part C) Office Response: You should receive a written confirmation of your request, along with a copy of your **Procedural Safeguards**. The service coordinator will also follow up to schedule a meeting with you to discuss an evaluation plan. **The state has 45 days to conduct an evaluation and to complete an initial IFSP.**

Deny to evaluate: If the state decides to deny the evaluation, it must provide you with **prior written notice** and include required details about its decision. You can decide your next step by reviewing **Your Legal Rights: IDEA's Procedural Safeguards**, page 86.

Agree to evaluate: You must give **consent** for the evaluation. Following agreement to evaluate, the law provides guidelines for how the evaluation needs to be conducted; however, **the team should be receptive to the information you bring about CDM and how it affects your child.** They should design an evaluation focused on all areas of suspected disability and the need for **special education** and related services. They should include a variety of tests to measure your child's cognitive development, academic and language development, physical, social and emotional development. Evaluations may also include information you submit from a child care provider or physician, and reports the team writes that include observations of your child at home, in childcare, school or other settings.

Writing the IFSP

Following a determination that your child is eligible for special education and related services, together, you and your child's team will then write a plan called the **Individualized Family Service Plan (IFSP)**. It is a legal document and a plan to support your child's early development. The IFSP lists the early intervention services that will help your child reach important milestones and describes when, where, and how the services will be delivered. It is meant to act as a map to guide you and the team working with your family. **It is also a legal document, and you must give your consent before the IFSP services can begin.**



QUICK TIP

Create a binder that includes two sections about your child:

1. All things medical
2. All things educational

Anything you sign as well as the materials from evaluations, screenings, medical tests, discussions with doctors or teachers should be included. This way, you'll have copies of everything when you need them, and you can bring the binder to evaluations and other meetings held to discuss your child's program. You can also scan and save everything onto a computer.



PARENT INSIGHT

EARLY HELP MATTERED TO ZEN:

"When Zen was born, they didn't expect him to live past his first birthday. But with home visiting services and our family support, he learned to swallow, to hold up his head and sit up. He eventually hit the important milestones and entered Early Start (toddler preschool). With preschool and ongoing physical and occupational therapy, he has made tremendous progress."

– Loraine



QUICK TIP

The federal law (IDEA Part C) says: "To the maximum extent appropriate to the needs of the child, early intervention services must be provided in natural environments, including the home and community settings in which children without disabilities participate."

The required components of the Individualized Family Service Plan are:

- Your child's **present level of functioning and need(s)**: physical, cognitive, communication, social and emotional, and adaptive development
- **Family information**, including your priorities and your concerns
- **The goals or outcomes expected** after receiving services
- The **services** your child will receive – see examples of potential services in the chart on the following page.
- The **natural environment** (home, a community center, school) where services will be provided
- The **number of days or sessions** for each service and how long each session will last
- **Who will pay** for the services
- The name of the **service coordinator** overseeing the **IFSP**
- If your child is age 3 or older, information on ways to support your child's **transition** into another program such as preschool
- Other helpful services such as: information about raising a child with a disability, family respite options, finances and more
- A model IFSP form is available at http://www.parentcenterhub.org/wp-content/uploads/repo_items/model.ifsp.form.pdf

Federal law requires that you be included in decision-making and your opinion as a parent is very important. You know your child better than anyone. Do not be afraid to share your concerns, ask questions or make suggestions. **You can ask for time to review the IFSP before you sign it.**



PARENT INSIGHT

ASK WHY?

"Don't feel afraid to ask the team, 'why can't you do it this way for my child?' The team may present very few or only one option for a service or support. You have the right to ask them to find a different way, the right way, to support your child!"

– Sarah

EXAMPLES OF EARLY INTERVENTION IN AN IFSP FOR CHILDREN AGE 0-3

CDM Symptoms	Examples of Early Intervention Services in the IFSP
Muscle weakness such as: <ul style="list-style-type: none"> • Difficulty nursing, swallowing • Facial muscle weakness • Delays or difficulty crawling, walking • Foot drop, toe walking, etc. 	Occupational, physical, speech therapy, therapeutic recreation
Respiratory system distress or weakness such as: <ul style="list-style-type: none"> • Sleep apnea • Breathing difficulty, aspiration 	Occupational and physical therapy, health, medical or nursing services such as respiratory therapy, BiPap, etc
Gastrointestinal dysfunction <ul style="list-style-type: none"> • Constipation, diarrhea • Irritable bowel 	Health, nutrition, medical or nursing services
Intellectual, cognitive deficits or impairments: <ul style="list-style-type: none"> • Developmental delays in speech or motor skills, etc. • Apathy or inertia • Excessive daytime sleepiness • Limited alertness • Inappropriate or challenging behavior • Behavior change 	Speech or other therapy, cued language, assistive technology, early learning and early intervention program, behavioral services, Applied Behavioral Analysis
Vision or hearing impairment or loss	Vision or audiology services, orientation and mobility services
Cardiovascular symptoms: <ul style="list-style-type: none"> • Sudden onset and recovery from • Change in activity level 	Health, medical or nursing services, adaptive physical education, cardiac services
Additional services or supports may be added to the IFSP at any time	Functional behavior assessment , family training, counseling, home visits, social work, transportation, service coordination and case management, assistive technology



QUICK TIP

The law (IDEA Part C) requires that you be offered a choice of services, programs and settings for your child. If the right service does not exist, one must be created. You do not need to accept an inappropriate service or no services. The team must come up with the right set of services for your child.



Your Role on the Team

- Approach every meeting as a positive, willing partner and attend every meeting for your child
- Hold your child and the team to the highest expectations
- Learn about your child's disability and help educate the team about its impact. Contact MDF for more information on CDM and typical impacts on children
- Be a good listener. Ask questions. Listen to what other people say about your child
- Share what you know. You are an expert on your child so share his/her likes and dislikes, ways s/he learns, strengths and needs
- Be up front if you don't agree with the team. Look for common ground and only compromise in ways that will work for your child and family
- Know your rights – especially that you can consider and accept or reject anything presented in the **IFSP**. You don't have to sign anything until you feel comfortable
- Keep good records of all meetings and conversations including dates, names and details of events
- Put every request to meet in writing and keep copies of everything
- Bring others with you to the meeting(s) who know your child and can support you (family, therapist, friend), but be courteous and let the team leader know you are doing so



REMINDER!

- You can ask for time to review and think about the services in the IFSP before you sign it
- You don't have to sign the IFSP the first time you see it
- Keep good records of all meetings and conversations including dates, names, details of events
- Make sure to put every request to meet in writing
- Keep copies of everything in your binder

Individualized Family Service Plan: Who Pays for Services

Your state decides who pays for services outlined on the **IFSP**. Your **service coordinator** will know which services are covered by the state and must provide this to you in writing. However, IDEA always requires the state to pay for evaluations, for developing the IFSP and for the service coordinator.

Some states require families to pay for certain services. Families are usually charged on a 'sliding scale', which means the fees are based on your income. Some services may be covered by your health insurance, by **Medicaid** or by **Indian Health Services**. Your consent is required to allow a representative of the state, which may be your service coordinator, to contact your health insurance. Every state tries to provide services to all infants and toddlers who need help, regardless of income.

Finalizing the Individualized Family Service Plan

To finalize the IFSP, you may have met several times with the service coordinator and the team. Once the document includes the required elements and both you and the team are satisfied that it supports the needs of your child, you are required to sign it. The IFSP is a legal document and once signed, it is a legal contract between you and the state regarding the services it agrees to provide to your child. You do not have to sign it right away, especially if the service coordinator and team have not given you time to review their recommendations. Once you sign the IFSP, services will start for your child. Your consent for services can be revoked at any time.

Updating the Individualized Family Service Plan

The service coordinator is required by IDEA Part C to meet with you at least every six months. This review meeting is your time to share how your child is doing and discuss if your child is making progress toward his/her goals. Whatever your child's goals, s/he should be making some progress. If s/he has achieved all goals quickly, the goals were not challenging enough. If your child is not making enough progress, you should inquire about a meeting to discuss your concerns, ask questions or to request changes.

IDEA Part C requires that the Individualized Family Service Plan be updated at least once a year. The team will look at your child's progress and decide if the plan needs to be changed. You will discuss any changes to your child's health, development or to the family. You will set new goals for your child and family. Any time a change is made to the IFSP, you must give consent. Remember to keep copies of everything you provide to the IFSP team and that the service coordinator and team provide to you. Finally, don't forget that you can ask for time to review the IFSP before you sign it.

If there are issues that come up that cannot be resolved, see **Appendix A – When the Team Can't Agree: Tools for Resolving Conflict**, page 75.



QUICK TIP

The right to meet and discuss your child's IFSP at any time is a key provision of IDEA, so call your service coordinator and ask to meet whenever you think you need to.



PARENT INSIGHT

"When it comes to the services and supports your child needs, it's important to push for the early help the state will give, but also to use the people in your life that love you and your child, such as your parents, siblings, other family and close friends. *Use your village!*"

– Taylor

2



REMINDER

If you are a teacher or staff member, refer to the 'For Professionals' section for information on how myotonic dystrophy affects the body, Neuropsychological Functioning Aspects of CDM and Childhood-onset DM1, and frequently asked questions about myotonic dystrophy.

AGES 0-2: The Individualized Family Service Plan

For children diagnosed with CDM who are between 0-2 years of age, here are the resources that were discussed earlier in this section that could be beneficial for planning your child's IFSP.



Appendix A – Helpful Tools in this Guide

- **Independent Educational Evaluation (IEE)**, page 82. This section describes how to obtain a second evaluation if your child is denied services on the first request
- **Comparison Chart: Individualized Education Program (IEP) to Section 504**, page 79. Learn about the differences between an IEP and a Section 504 plan, which is generally for less affected children
- **Your Legal Rights: Individuals with Disabilities Education Act (IDEA) Procedural Safeguards and Dispute Resolution**, see page 86. You have rights! Refer to this section to read over what is and isn't allowed when it comes to your child's education
- **Request to Evaluate Letter**, see page 89 for an example of a letter you can send to the state requesting an **evaluation** for your child
- **When the Team Can't Agree: Tools for Resolving Conflict**, see page 75. Sometimes the team can't agree on a path forward. If that happens, we've included some helpful tips to mediate this issue



Appendix B – External Resources

- **[Early Childhood Technical Assistance Center](#)** – If you don't know who your early intervention service coordinator is, get in touch with the Early Childhood Technical Assistance Center to find your state contact and the lead agency in your state.
- **[Statement and Resources on Inclusive Preschool Practices](#)** – This government-written document describes how children with disabilities cannot be excluded from early education opportunities, such as preschool.
- **[Department of Education State Contacts](#)** – Use this website to learn more about your state specific guidelines regarding special education.



Read this section when your child has an IFSP, is over 2 years old and will be transitioning to preschool. If your child has not had an initial evaluation, skip to **IDEA Evaluation and Eligibility**, page 56, and then return to this section.

AGES 3-4:

Transition to Preschool

As early as 6 months before your child's third birthday, **IDEA** requires your **service coordinator** to contact you in order to discuss transition planning from home-based services to preschool. The law requires this process to begin at least 90 days before your child turns 3. A separate transition plan is included in the **Individualized Family Service Plan (IFSP)** and may be written as a separate page with transition goals. Be sure to follow up with your service coordinator if you have not heard from him/her within 90 days of your child's 3rd birthday.

This transition from early intervention under IDEA Part C to school-based services under IDEA Part B is important, as your child will likely begin to attend a preschool if he/she hasn't already been attending Early Head Start or another early learning program. S/he may also receive some services at home. In planning the transition to preschool, everyone providing early intervention services to your child should be invited to the transition planning meeting.

Explaining the Transition from the Individualized Family Service Plan (IFSP) to the Individualized Education Program (IEP): Evaluation and Eligibility

To develop the Individualized Education Program (IEP), the team may first decide it needs more information and will conduct an **evaluation**. As previously discussed, you may want certain assessments or screenings conducted due to changes in your child's medical condition or the team may want further information due to your child's growth and development.

If your child has an IFSP and the preschool program determines he/she is eligible to receive services under Part B, you and the district may decide to continue the IFSP, depending on your state laws.



QUICK TIP

When a child turns 3, the local school district becomes responsible for the child's education and your child will receive services in the **Least Restrictive Environment (LRE)** which typically means in a preschool until s/he enters kindergarten. The team, which includes you, makes the decision about the new plan, called the **IEP**.



REMINDER

You will find a list of key terms and abbreviations in **Glossary and Abbreviations** on page 62. All **blue bolded** words and phrases have definitions listed there.



QUICK TIP

Create a binder that includes two sections about your child:

1. All things medical
2. All things educational

Anything you sign as well as the materials from evaluations, screenings, medical tests, discussions with doctors or teachers should be included. This way, you'll have copies of everything when you need them, and you can bring the binder to evaluations and other meetings held to discuss your child's program. You can also scan and save everything onto a computer.

If for some reason you are not happy with the evaluation results, you can request an **Independent Educational Evaluation (IEE)**.

If your child has been receiving early intervention, move on to the next page, **IFSP to IEP Planning Meeting information**.

If you are just coming to the guide with a three or four-year old **who has not yet received any early intervention under IDEA**, see **Section 10 – Individuals with Disabilities Education Act (IDEA) Evaluation and Eligibility Ages 3-21**, page 56.

What Happens in the IFSP to IEP Planning Meeting

At the preschool transition planning meeting, you are making several decisions about what happens **at age 3 and through age 5** regarding special education services for your child. You will help to decide:

- Whether any of the early intervention services provided so far should continue and if so, for how long
- What educational services your child needs in preschool
- What preschool setting is right for your child

How to Select a Preschool

When choosing a preschool, the school district is required to make available a range of options including: being taught in regular classes, special classes, special school(s), home instruction, and instruction in hospitals and institutions, depending on what your child needs. You may need to gather more information about the schools that the team offers and discuss with the team what it recommends, including how they will provide **special education and supplementary aids and related services**. The team should not rush you through this process. You can meet more than once to make a final decision.

The options fall into several categories but could include several school program types for you to consider in the school district:

- **Inclusive early childhood program** – a regular preschool with typical-learning children
- **Segregated early childhood program** – a separate class or a separate school for children with disabilities
- **Home, hospital or institution-based services** combined with regular or segregated preschool services

All options should be carefully discussed and studied. An **inclusive early childhood setting** should be strongly considered at this stage of your child's development because best practice and studies have shown that children with disabilities can make significant developmental and learning progress in inclusive settings compared to children with disabilities educated in separate settings. This is particularly true for children with significant disabilities and the highest needs.



Questions to Consider and Discuss with the Transition Team

Many decisions are made when planning your child's transition from home-based early intervention to school-based learning. Every parent has questions about the transition – here are a few examples:

- Does my child still qualify for additional county or health services? If so, how are they organized and coordinated?
- How will the services be provided in the preschool, after school or home settings?
- What is the student-to-adult ratio in the classroom, the length of the school day and the level of family involvement in schools I am considering?
- What information does the school team need to understand my child's unique needs?
- Does my child qualify for transportation to the new school program?
- What can I do to make sure my child succeeds in the new school program?



REMINDER

Remember to consult your local school district's special education department to understand how it implements the IDEA law. Your state's federally funded parent center can help you find your way. For information, go to

www.parentcenterhub.org

How to Choose the Right School: Inclusive or Segregated Setting

Some parents of children with CDM or childhood-onset DM1 have found that when their young child was placed in the **segregated** class or school, s/he was one of the highest functioning students in the class. This meant their child did not have any students with typical learning skills to play or socialize with or to learn from. They believe this slowed his/her developmental progress.

However, you must make this decision for your child. If you and the team agree that he/she should receive educational services in a segregated class or school setting, the federal law – IDEA – requires that the child’s plan (the **IEP**) include a full explanation and justification as to why this is needed.

Special education is a service, not a place. IDEA says: Special education services should be delivered in regular education classes except “when the nature or severity of the disability of the child is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.”

Next Step: The Team, Including the Parent, Writes the IEP

The next section of the guide walks you step-by-step through writing your child’s Individualized Education Program (IEP), which is both a process and a plan for your child’s school-based education moving forward. See **Section 4 – Ages 3-12: Developing the Individualized Education Program (IEP)**, page 21.

If there are issues that keep coming up during this process that cannot be resolved, see **When the Team Can’t Agree: Tools for Resolving Conflict**, page 75.

Preparing My Child and Family for a New School

Unless you home school your child, you and your child must prepare for the adjustment to school. Perhaps your toddler was already going to school part of the day, and if so, you will already have adjusted to that schedule. However, for those children for whom preschool is a big, new step, it’s important to be prepared as a family for the move.

With school comes a new schedule, teacher(s), routines, classroom activities and expectations from everyone. Take the time you need to:

- Plan and thoughtfully consider the pressure points for your family and your child
- Talk with other families and parents in your local special education community and CDM or childhood-onset DM1 network about what this was like for them (contact MDF for support group information)
- Update your child’s medical, educational, and assessment records
- Include your child in some of the planning – let him/her pick out a new outfit, a few school supplies, take a practice ride on the bus
- Visit the new school and talk with your child about what it will be like. Most children do much better when they have some idea of what to expect
- Read books together about going to preschool
- Set up play dates with other children and encourage your child to communicate
- Learn how to advocate for your child. No matter how smoothly things go at this stage, you will likely experience challenges in making your child understood and supported



REMINDER

If you are a teacher or staff member, refer to the ‘For Professionals’ section for information on how myotonic dystrophy affects the body, Neuropsychological Functioning Aspects of CDM and Childhood-onset DM1, and frequently asked questions about myotonic dystrophy.



OFF TO SCHOOL

Your child will go off to school and your routine and life will change because of it. The school will implement the **Individualized Education Program (IEP)**, and you will adjust to a new routine. Find your daily rhythm. Your child may come home ready to tell you about his/her day. Look for opportunities to quietly listen and respond. Be watchful of his/her attitude, behavior, moods and any change in his/her CDM or childhood-onset DM1 symptoms. Volunteer to help at the school and be part of his/her education as best you can. This connection will help you and your child and will also give you first-hand knowledge of the school, the teaching team, the other children and their families.

For more information about how to update your child’s **IEP**, what to do when your child is not happy at school and more, see **Section 4 – Ages 3-12: Developing the Individualized Education Program (IEP)**, page 21.

3

AGES 3-4: Transition to Preschool

For children between the ages of 3 and 4 years old, here are the resources that were discussed earlier in this section that could be beneficial for planning your child's IEP.



Appendix A – Helpful Tools in the Guide

- **Section 10 – Individuals with Disabilities Education Act (IDEA) Evaluation and Eligibility Ages 3-21**, page 56. This section of the guide is for people who did not receive an evaluation before age 3 and did not have an Individualized Family Service Plan (IFSP). Children with childhood-onset DM1 and not congenital may fit under this category.
- **When the Team Can't Agree: Tools for Resolving Conflict**, page 75. - Sometimes the team can't agree on a path forward. If that happens, we've included some helpful tips to mediate these issues.



Read this section when your child has an IFSP and is older than 2 years old. This section assumes your child has been evaluated and found eligible for special education under IDEA. If your child has not received services under IDEA and a formal evaluation for special education services has not occurred, go to **IDEA Evaluation and Eligibility**, page 56, and then return to this section.

AGES 3-12:

Developing the Individualized Education Program (IEP)

Developing the **IEP** is both a process and a document. Once the IEP process is completed and the document is developed and signed, it is a legal contract between the school and your child (which you have signed on his/her behalf). Together with the school team in one or more meetings, you will develop an IEP by doing the following:

- Choosing at least one disability from the Individuals with Disabilities Education Act (IDEA) list
- Deciding which services your child needs to succeed in school
- Finalizing the details of the IEP
- Meeting each year to update and sign the IEP

Writing the IEP

Choosing a disability category: Using the results of the **evaluation** and the information you and the team bring to the IEP meeting, the team will choose **the primary** disability from the **IDEA** list to qualify your child for special education and classify your child's primary disability(s).

Autism

Blindness

Deafness

Developmental delay

Emotional disturbance (ED)

Hearing impairment (HI)

Intellectual disability (ID)

Multiple disabilities (MD)

Orthopedic impairment (OI)

Other health impairment (OHI)

Specific learning disability (SLD)

Speech, or language impairment (SLI)

Traumatic brain injury (TBI)

Visual impairment (VI)



REMINDER

You will find a list of key terms and abbreviations in **Glossary and Abbreviations** on page 62. All **blue bolded** words and phrases have definitions listed there.



QUICK TIP

Be vigilant in asking questions at this stage so you understand how the primary disability chosen by the team will lead to the **specially designed instruction**, supplementary aids, **related services** and **accommodations** your child needs.



QUICK TIP

Create a binder that includes two sections about your child:

1. All things medical
2. All things educational

Anything you sign as well as the materials from evaluations, screenings, medical tests, discussions with doctors or teachers should be included. This way, you'll have copies of everything when you need them, and you can bring the binder to evaluations and other meetings held to discuss your child's program. You can also scan and save everything onto a computer.

IDEA Disability Categories for the IEP

In some states, the team may assign the disability category **developmental delay** to a young child with CDM and childhood-onset DM1. Not all states opt to use developmental delay as it can only be used as the primary disability category through age 8. Choosing the disability category is determined by how your child's symptoms are impacting his/her ability to learn and benefit from general education.

IEPs are based on **needs** so it's important to understand how the symptoms of CDM and childhood-onset DM1 impact your child and what **needs** they create throughout the school day. While **IDEA** is meant to be individualized, the school uses the disability classification to help decide the **specialized instruction**, supplementary aids, **related services** and **accommodations** needed and in what environment they will be offered. Also, the school may determine that not all the symptoms of CDM and childhood-onset DM1 keep your child from learning in the general education classroom. In that case, the school may limit or deny certain services you want for your child. The assignment of a primary disability category is a requirement for eligibility, but should not dictate or limit the services the child needs in order to benefit. If this happens and you do not agree with the decision, see **When the Team Can't Agree: Tools for Resolving Conflict**, page 75, and **Your Legal Rights: Individuals with Disabilities Education Act (IDEA) Procedural Safeguards and Dispute Resolution**, page 86.

CDM and childhood-onset DM1 have common characteristics for young children, but both impact every child differently, so your school may discuss with you several disability categories in which your child may fit. **The most important part of this discussion is ensuring that your child has access to the services and supports s/he needs regardless of the disability or combination of disabilities the school recommends.**

For instance, if your child needs speech therapy but the school district does not allow that service under the disability "developmental delay", you must persevere to have the IEP recognize that s/he has a speech or language impairment.

The chart on the next page should help you discuss possibilities for considering how your child's CDM or childhood-onset DM1 impacts decisions about IDEA disability categories and inform a discussion about **specially designed instruction, related services, accommodations** and **other health impairment**.

ELIGIBILITY & DISABILITY CATEGORIES FOR AN INDIVIDUALIZED EDUCATION PROGRAM (IEP) – CHILDREN AGE 3-21

CDM and Childhood-onset DM1 Symptoms	Possibilities for Primary IDEA Disability Category
Muscle weakness	Developmental delay*, orthopedic impairment
Respiratory system distress or weakness	Other health impairment
Endocrine	Other health impairment
Gastrointestinal	Other health impairment
Intellectual or cognitive function	Autism, developmental delay*, emotional disturbance, intellectual disability, other health impairment (for attention deficit disorder or attention deficit hyperactivity disorder), specific learning disability, speech or language impairment
Cardiovascular	Other health impairment
Vision or hearing	Visual impairment or hearing impairment

NOTES:

- Some medical conditions and symptoms do not impact a child's ability to make progress in the general curriculum and therefore may not meet **IDEA** requirements for services
- There is a 'multiple disabilities' category that schools may use when a child has multiple conditions that cause severe educational needs. If this is the recommended category for your child, make sure there are adequate services and supports made available in the IEP
- Your child's IEP qualification may make him or her eligible for additional supports such as a full time classroom aide, etc. Ask your **LEA representative** about additional support for which your child may be eligible
- Read below to learn more about how specially designed instruction and related services may be considered for each disability

*Some states allow the use of developmental delay through age 8

Choosing the right specially designed instruction, services and supports: After the team determines the primary disability category that qualifies your child for special education services, it will then discuss and develop the plan to provide services through the IEP. **Because your child will likely need special education throughout his/her school years,** you will quickly learn all the steps needed to write and update your child's IEP. If you are interested in the differences between the Individualized Family Service Plan (IFSP) and the IEP, see **Comparison Chart: Individualized Family Service Plan (IFSP) to Individualized Education Program (IEP)**, page 78.



QUICK TIP

"The IEP must aim to enable the child to make progress. After all, the essential function of an IEP is to set out a plan for pursuing academic and functional advancement."

~ U.S. Supreme Court,
March 2017



QUICK TIP

Remember to bring your binder to the IEP meeting. Include updated information about your child's medical condition, school records, emails with teachers and therapists and other important documents you have collected.

IEP Team: Children Ages 3 - 21

IDEA requires the child's parent, or legal guardian to join the IEP team for the duration of the program. As discussed in other sections, it is very important that you participate in the meeting(s). If you are married or have a legal partner, you and your spouse or partner should both try to attend together because you know your child best. In addition, the school is required to include the following meeting participants:

- **One regular education teacher** (if the child is or may be participating in regular education) – in subsequent meetings, you should request that this be one of the teachers teaching your child
- **One special education teacher** – in follow-up meetings, request that this be one of the teachers teaching your child
- **One representative who is qualified to supervise and provide special education** – this is typically the principal, vice principal or someone they designate
- **One professional qualified to interpret the evaluation(s) and results** – typically the school psychologist
- **Others who have knowledge or expertise regarding the child** – this could be an aide, therapist or others
- **The child** when appropriate – parents and teachers decide together when the child may be ready to attend, although the earlier children begin to participate in decision-making, the better they will be able to advocate for themselves



IDEA allows parents to bring anyone to the meeting who can help the school team learn and understand the child and how CDM or childhood-onset DM1 affects his/her daily life. You can bring a friend to help take notes, an advocate to make sure all of IDEA is followed, a medical provider or therapist to share how CDM and childhood-onset DM1 impacts the child, a tutor, or an attorney. You do not have to let the school know you are bringing someone, but it is a courtesy and helps build a partnership if you let them know ahead of time. *An invitation should also be sent to the Part C service coordinator or other representatives of IDEA Part C system if this is the initial IEP meeting for a child transitioning from Part C to Part B.*

The Individualized Education Program (IEP) Document

The team will meet to develop the IEP. It will likely take more than one meeting, so be prepared. IDEA requires that at least these basic elements be included in the IEP:

- **PLAAFP:** The team discusses and writes into the IEP the child's **Present Levels of Academic Achievement and Functional Performance (PLAAFP)**. The PLAAFP describes how the child is doing academically, how the disability affects the child's involvement and progress in the general curriculum and the child's functional skills

- **Annual goals:** The team sets measurable annual goals for the child to achieve in one school year. A good IEP includes standards-based goals which use the state academic content standards as the basis for setting academic or learning goals. Goals should target all areas of need, and may include functional skills such as speaking clearly, social development etc. See **Standards-based Individualized Education Program (IEP) Goals**, page 83
- **Special education and related services:** The team discusses and decides what specialized instruction, therapies, services and accommodations will be provided to the child in order to achieve the measurable annual goals
- **Services provided:** IEP outlines when services, therapies, **modifications** and **accommodations** begin, how often they will be provided, where they will be provided, and how long they will last. See **Examples of Intervention Services for CDM and Childhood-onset DM1, Ages 3-6**, page 11
- **Setting for classroom instruction and placement:** The setting(s) where the child will be educated – in an **inclusive** classroom with peers, in a pull-out classroom for part of the day, or in a **segregated** classroom or school; should include percent of time in and out of regular education
- **Setting for PE, lunch, extras:** The setting where the child will receive physical education, eat lunch, or participate in extracurricular (after school) activities and clubs
- **Participation in state assessments:** The team decides how the student will participate in state and district assessments (tests) and what **accommodations** are needed. Depending on your state, preschoolers may not be taking a state or district-level assessment. This discussion becomes more important at the IEP meeting in the spring of 2nd grade to prepare for 3rd grade. State and district testing in reading/language arts, math and science generally begins in third grade and continues through high school. See **Why Testing Decisions Matter**, page 85
- **Measuring progress:** The IEP states when periodic reports on the child's progress toward meeting annual goals will be provided to parents
- **Special factors:** The IEP team should also discuss special factors and the strategies and supports the child may need related to:
 - **Behavior**
 - **Limited English proficiency**
 - **Vision or hearing impairment**
 - **Communication needs**
 - **Assistive technology devices or services**

Look for every opportunity to encourage the use of **Universal Design for Learning (UDL)** in your child's classrooms and school to promote and provide multiple ways for your child to access the curriculum and learn alongside his/her peers.



REMINDER

If you and the team agree that your child should receive educational services in a segregated classroom or school, IDEA requires that the IEP include a full explanation and justification as to why this is the least restrictive environment (LRE) for your child.



QUICK TIP

A model IEP form is available at https://sites.ed.gov/idea/modelform1_iep-2/

Use the chart below to support the discussion about the types of specially designed instruction, related services and accommodations your child needs on the IEP.

THE INDIVIDUALIZED EDUCATION PROGRAM (IEP): AGES 3-21

CDM and Childhood-onset DM1 Symptoms	Possibilities for Primary IDEA Disability Services
Distal muscle weakness (fingers, wrist flexors, neck muscles, ankles, eyelids)	Occupational, physical or speech therapy, adaptive physical education, personal aide, brace, walker, cane, or wheelchair
Respiratory system distress or weakness	Occupational and physical therapy
Gastrointestinal	Delayed start to the school day
Intellectual or cognitive function	Speech therapy, specially designed instruction and intervention programs or services, assistive technology, devices, software, Universal Design for Learning (UDL), applied behavioral analysis (ABA) therapy, executive function support, counseling, paraprofessional
Social/emotional impairments	Remediation programs to enhance social/emotional abilities (visual contact, joint attention, emotional regulation)
Vision or hearing impairment	Classroom accommodation, vision or audiology services, aide
Other	Modified schedule or desk arrangement, verbal and nonverbal cues when on or off task, emails with updates daily or weekly, buddy assignment for halls and lunch, home school, functional life skills classes, testing accommodations, peer support

NOTES:

- The child's **Present Levels of Academic Achievement and Functional Performance (PLAAFP)** and measurable annual goals determine the specially designed instruction, related services, supports and accommodations needed
- There should be great flexibility and collaboration in determining what the child needs and how to provide it
- If you cannot agree, see **When the Team Can't Agree: Tools for Resolving Conflict**, page 75
- See additional **Neuropsychological Functioning Aspects of CDM and Childhood-onset DM1** on page 69

Your input into the Individualized Education Program (IEP) is required by IDEA and your opinion matters. You know your child better than anyone, so share your concerns, ask questions or make suggestions. You can ask for time to review and think about what is in the IEP. You do not have to sign it the first time you see it. *You* will be required to give **written informed consent** for the initial IEP before services can begin, but not for annual reviews.

The school is required to update the IEP annually, though there is no requirement regarding when the annual IEP meeting is to be held. In some states, the local education agency (LEA) or **LEA representative**, who is usually a school administrator, holds annual IEP meetings on a rolling basis, while others cluster meetings in the spring or towards the end of the year. Often, children with CDM or childhood-onset DM1 will qualify for **extended school year services**, such as year-round or summer learning programs, which the team should discuss. The school is also required to update your child's evaluation (assessments, screenings, etc.) at least every three years. You have the responsibility to keep the team updated on any new medical or other developments with your child. Consider requesting an informal IEP meeting in the fall or start of the school year as a friendly introduction or check-in meeting.

When your child is or is not happy: At any time, you can send an email to a teacher, principal, or director about your child's joys or concerns. School teachers and leaders are generally interested in feedback from parents, and you may be able to resolve very small concerns this way, avoiding the need to call the IEP team together (see below on how to do that). You must use your best judgment as you form a partnership with your child's school team and determine when something informal such as an email or quick call will solve the problem. It really depends on the severity of your concern, the frequency of the problem and whether the school is responsive. Every school year brings both wonderful opportunities to see your child grow and new relationships at school for you to develop and navigate on your child's behalf.

Working with Your Child's Individualized Education Program (IEP) Team: Asking for an IEP Review

The IEP is about your child's needs and those needs are what drive the instruction, services and supports the school is to provide. If something is missing and your child's educational experience is being affected, you must ask to have it added.

Tips on Changing or Updating the IEP:

- **IEP meetings can be held throughout the year:** If you have any concerns about how your child is doing with his/her current **IEP** – and the services and supports it outlines – you do not have to wait until the end of the school year to meet with the team. You or the school can call an **IEP** meeting **at any time**.



PARENT INSIGHT

"When it comes to making sure your child's IEP truly matches your vision for what your child needs, be the squeaky wheel! Also, don't sign it if you don't like it. You can have as many versions of the IEP as you want."

– Sarah



REMINDER

Remember to consult your local school district's special education department to understand how they implement the IDEA law. Your state's federally funded parent center can help you find your way. For information, go to www.parentcenterhub.org

- **When the IEP is not quite right:** There could be several reasons why the IEP is not working for your child such as:
 - Your child is not happy, has communicated something concerning or consistently doesn't want to go to school
 - Your child has met one or more of the goals written in the IEP
 - Your child no longer needs a service outlined in the IEP
 - You believe the IEP may have missed something
 - You feel your child needs more services or other services to make progress
 - Your child has experienced a major change in his/her health or developed new CDM or childhood-onset DM1 symptom(s)

NOTE: If your child's behavior has changed in a negative way and the school has or is taking some type of action (corporal punishment, in and/or out of school suspension, expulsion, seclusion or restraint), see **Behavior and Your Child with DM**, page 72.

- **Request Individualized Education Program (IEP) meetings in writing:** You can request a meeting in-person, by phone, or over email, but it is always best if you do it in writing. Take time to write your letter. List each concern. Be specific, thorough and give concrete examples of what is or is not happening according to the current IEP. Add new details and information about your child's medical condition if there is something new to share. Send it to your contact at the school. See **Individualized Education Program (IEP) Review Meeting Letter (sample)**, page 91
- **When you request an IEP meeting:** The school team must respond to your request to convene an IEP meeting in a timely manner. You should come to the meeting prepared with a copy of your well written, fully-detailed letter and your binder to discuss why the current IEP is not working. The school may either offer to work with you to update the IEP or decline your request. Do not give up if they initially say they want to keep the IEP as-is. At each step (because it's likely you'll need more than one meeting to settle your concerns), ask for the school's written response via a **prior written notice**. You can decide from there how you want to proceed

Hopefully, your experience is positive, and the team will agree to work together to update the **PLAFFP**, write new goals and update the services to meet your child's needs. However, if there are disagreements that cannot be resolved, see **Appendix A – When the Team Can't Agree: Tools for Resolving Conflict**, page 75, and **Your Legal Rights: Individuals with Disabilities Education Act (IDEA) Procedural Safeguards and Dispute Resolution**, page 86.



Your Role on the Team

- Approach every meeting as a positive, willing partner and attend every meeting for your child
- Hold your child and the team to the highest expectations
- Learn about your child's disability and help educate the team about its impact. Contact MDF for more information on CDM and childhood-onset DM1 and typical impacts on children
- Be a good listener. Ask questions. Listen to what other people say about your child
- Share what you know. You are an expert on your child so explain likes and dislikes, ways s/he learns, and strengths and needs
- Be honest if you do not agree with the team. Look for common ground and only compromise in ways that will work for your child and family
- Know your rights – you can consider and either accept or reject anything presented in the Individualized Family Service Plan (IFSP) or IEP. You do not have to sign until you feel satisfied with the plan
- Keep good records of all meetings and conversations including dates, names and details of events in your binder
- Put every request to meet in writing and keep copies of everything in your binder
- Bring others with you to the meeting(s) who know your child and can support you, but be courteous and let the team leader know you are doing so

Questions? Contact MDF

✉ info@myotonic.org

🌐 www.myotonic.org

☎ 415.800.7777

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REMINDER

If you are a teacher or staff member, refer to the 'For Professionals' section for information on how myotonic dystrophy affects the body, Neuropsychological Functioning Aspects of CDM and Childhood-onset DM1, and frequently asked questions about myotonic dystrophy.

AGES 3-12:

Developing the Individualized Education Program (IEP)

For children between the ages of 3 and 12 years old, here are the resources that were discussed earlier in this section that could be beneficial for planning your child's IEP.



Appendix A – Helpful Tools in the Guide

- **Section 10 – Individuals with Disabilities Education Act (IDEA) Evaluation and Eligibility Ages 3-21**, page 56. This section is for people who did not receive an evaluation before age 3 and do not have an Individualized Family Service Plan (IFSP). Children with childhood-onset DM1 and not congenital may fit under this category
- **Your Legal Rights: Individuals with Disabilities Education Act (IDEA) Procedural Safeguards and Dispute Resolution**, page 86. You have rights. Refer to this section to read over what is and isn't allowed when it comes to your child's education
- **Comparison Chart: Individualized Family Service Plan (IFSP) vs. Individualized Education Program (IEP)**, page 78. Learn about the difference between an IFSP and an IEP
- **Standards-based Individualized Education Program (IEP) Goals**, page 83. This section provides an in-depth look at the types of goals that could be selected for your child, along with examples
- **Why Testing Decisions Matter**, page 85. Standardized testing is a large part of the American public school system. Test possibilities for your child are outlined in this section
- **When the Team Can't Agree: Tools for Resolving Conflict**, page 75. Sometimes the team can't agree on a path forward. If that happens, we've included some helpful tips to resolve issues
- **Behavior and Your Child with DM**, page 72. Your child may display behavior(s) that the school (and you) believe are inappropriate. This section describes some ideas for intervention
- **Individualized Education Program (IEP) Review Meeting Letter (sample)**, page 91. A template for when you need to request a meeting with your child's IEP team to review the current IEP



Appendix B – External Resources

- [IEP Meeting Review Resources](#) – A resource if you need assistance requesting a meeting to review your child's IEP, including tips for letter writing and the correct verbiage for specific situations, page 95
- [Roadmap to IDEA 2004: What You Need to Know About IEPs & IEP Meetings](#) – An external resource about IEPs if you want more information, page 95



Read this section when your child has already had an evaluation and will be transitioning to kindergarten. If your child has not had an initial evaluation, go to **IDEA Evaluation and Eligibility**, page 56, and return to this section after evaluation.

AGES 4-5:

Transition from Preschool to Kindergarten

Individualized Education Program (IEP) Basics and Reminders

If your child has an Individualized Education Program (**IEP**) and is receiving special education services in preschool, you should have had at least one IEP meeting since your child entered preschool at age 3. It's now time to discuss your child's transition to kindergarten in a meeting similar to the other IEP meetings you attended.

If for some reason your child with CDM or childhood-onset DM1 is not yet receiving special education services from a preschool or school, see **Section 10 – Individuals with Disabilities Education Act (IDEA) Evaluation and Eligibility Ages 3-21**, page 56.

As with any IEP meeting, bring new medical or other helpful information to the team. Bring your binder so that you will have everything you need. Together, you will first decide whether to conduct further **evaluation** of your child's progress and condition. You will then proceed to update each section of your child's IEP for kindergarten. If you need a refresher about the meeting process and developing the IEP, go back and review **Section 4 – Ages 3-12: Developing the Individualized Education Program (IEP)**, page 21.

Choosing a kindergarten: One decision you will need to make as preschool is winding down is where to have your child attend kindergarten. Depending on your school district and what is available, you may need to visit several schools to make this decision. Consider bringing your child with you on one or two visits. Seeing your child in the setting can sometimes help you make decisions and it provides a way to begin a conversation about the transition that is coming.

Your school district may offer half-day or full-day kindergarten in one or more school settings such as:

- A traditional public school
- A public charter school
- A school or center designed for children with disabilities (which may or may not have non-disabled children)
- A public school or charter with a separate program for children with disabilities housed within the school for children with disabilities (sometimes called a 'center')



REMINDER

You will find a list of key terms and abbreviations in **Glossary and Abbreviations** on page 62. All **blue bolded** words and phrases have definitions listed there.



PARENT INSIGHT

TAKE SOMEONE WITH YOU TO THE MEETINGS:

"If you don't have the personality or energy to meet with the team or to challenge them when you think they're wrong, find an advocate to help you. Ideally, this is someone who knows your child, knows the law and knows about myotonic dystrophy and its impact on children. You have to be proactive!"

– Taylor



PARENT INSIGHT

“Unless you are prepared to remove your child from public school forever, you need to view your relationship with the school as a marriage without the possibility of divorce.”

– Ted



Special Considerations At This Age and Stage

TRANSITIONAL KINDERGARTEN

Families with a child diagnosed with CDM or childhood-onset DM1 may want to consider transitional kindergarten, which is offered in some states. This option provides children not quite ready for kindergarten with a program that is more rigorous than preschool, but is not quite as challenging or overwhelming as kindergarten. Children with CDM or childhood-onset DM1 may benefit from this extra year due to ongoing medical challenges and **developmental delays**. Check with your school team to see if this option is available where you live.

Choosing where your child will attend kindergarten is a personal decision and must meet your child’s needs. Keep in mind the advice offered in this guide’s preschool section, **Section 3**, page 15, about the decision to segregate your child early in his/her education.

Things to Consider in the Kindergarten IEP

In updating the **Present Levels of Academic Achievement and Functional Performance (PLAFFP)** and annual goals in the IEP, the kindergarten IEP may provide the first opportunity to connect your child’s annual goals to the state’s academic content standards in reading, math and other subjects. While your child should have goals designed to meet all the needs outlined in the IEP, best practice – especially for young children with disabilities who benefit greatly from early intervention – shows that standards-based IEPs can make a remarkable difference in the outcomes for children with disabilities.

Standards-based IEP: Every state has established academic content standards in all core subjects. Public schools, including public charter schools, are required to develop curriculum and assessments that show how children are progressing toward state standards. Often the standards are designed with the expectation that children will be taught to, and expected to meet state benchmarks and goals as early as kindergarten.

While children with CDM or childhood-onset DM1 may have developmental delays or some cognitive impairment, they can still be capable of working at grade level with their peers when they receive special education services.

Although IEP goals for early learning and early skill development and achievement may have been designed in preschool, these goals become more prominent in kindergarten and into the early grades because young children are expected to learn to read, write and compute by the end of third grade. It is important to set IEP goals that

are aligned to the state standards for all children in kindergarten. If the goals are not standards-based, you run the risk of the **IEP** setting a lower standard for your child, which can reduce classroom expectations by the teacher and the team. Look for every opportunity to encourage the use of **Universal Design for Learning (UDL)** in your child's classrooms and school – to promote and provide multiple ways for your child to access the curriculum and learn alongside his/her peers.

To read more and review samples of standards-based goals, see **Appendix A – Standards-based Individualized Education Program (IEP) Goals**, page 83.

Other school settings: Because the symptoms of CDM or childhood-onset DM1 such as poor swallowing, difficulty chewing, excessive daytime sleepiness, sleep apnea, toileting issues, muscle weakness and related needs for orthopedic support and attention-deficit hyperactivity disorder (ADHD) may be present as your child grows, the team should discuss how to support the associated challenges these and other symptoms may cause throughout the school day. In addition to decisions about the classroom instruction and support, the IEP team must also consider other settings and aspects of school in which all other children participate such as:

- Walking up and down stairs and in the hallway(s)
- Toileting
- Lunchtime
- Physical education
- Recess
- Extracurricular activities

Physical education (PE): IDEA requires physical education, including special PE for children with disabilities. PE must be available to every child with a disability receiving a **Free Appropriate Public Education (FAPE)**, unless the school does not provide physical education to children without disabilities in the same grades. IDEA defines **physical education** as the development of:

- Physical and motor fitness
- Fundamental motor skills and patterns
- Skills in aquatics, dance, and individual or group games and sports (including intramural and lifetime sports)
- Special physical education, adapted physical education, movement education, and motor development

Parents often report that adaptive and specially designed PE is one of the highlights of school for their CDM and childhood-onset DM1 children. So, when meeting with the team, strive to have them include in the IEP at minimum:



PARENT INSIGHT

PHYSICAL ACTIVITY MATTERS:

“Push to place the child in extracurricular activities and programs, adaptive swimming, skiing, karate, horseback riding, etc. It will help with depression, mental health, self-esteem.”

– Taylor



QUICK TIP

Peer support may be included in the IEP to help your child meet a goal to increase socialization, stay on task or work in small groups. However, it should not be considered specialized instruction.

- A summary of present level of performance in physical education
- How often and how long PE will last
- Measurable goals and objectives about PE content
- The place where PE will be provided

Ideally, the school has a qualified adaptive PE instructor to work with your child and the school staff to provide a rewarding experience. If not, the school must design a program for your child that fits his/her needs.

Peer support: A strategy to encourage socialization and learning:

Kindergarten may be the age and setting where the school introduces peer support to enhance your child's school experience. Peer support is not specialized instruction and is not a substitute for it. Peer support is a classroom strategy that involves placing students in pairs or in small groups to participate in learning activities that support academic instruction and social skills. Sometimes called **Peer Assisted Learning Strategies (PALS)**, this research-based method shows that participating students have a stronger sense of belonging and can increase gains in student achievement. Schools committed to an inclusive approach are more likely to propose and use peer support to engage and include your child and others throughout the school day.

Time to Start Kindergarten

Preparing your family: Preparing your child to attend kindergarten is important. The suggestions made in this guide's **Section 3 – Ages 3-4: Transition to Preschool**, page 15, also apply for this setting, as you think through what your family and your child needs to adjust to:

- A new school
- A new bus ride, walk, commute
- A new teacher or class
- A new schedule (possibly with lunchtime and perhaps the elimination of naps)
- A new playground

The school: The school and teacher have the IEP, but you may also want to prepare a short (2 to 3 page) letter that contains easy-to-read information about your child. List strengths, challenges, likes, dislikes, and specific strategies to support your child. You can share this along with any information about CDM or childhood-onset DM1 that you believe will help the teacher and school team learn more about your child and his/her condition and especially how the symptoms may impact him/her throughout the day. See **For Professionals**, pages 68-70.

Kindergarten is also the time to jump in and start volunteering at school if you or a family member or friend can. Spend time in the classroom, at school activities, with other parents and show support to the school staff. Get to know everyone in your child's new community. Volunteering may give you the best idea of how things are going, especially if your child still struggles to communicate. Most importantly, keep a positive attitude about this new step. Everyone wants a successful transition.

- Remember you can ask to review the [IEP](#) at any time. See **Section 4 – Ages 3-12: Developing the Individualized Education Program (IEP)**, page 21.
- Review your role on the team. See **Section 4 – Ages 3-12: Developing the Individualized Education Program (IEP)**, page 21.
- If you cannot agree as a team, see **When the Team Can't Agree: Tools for Resolving Conflict**, page 75. Look for every opportunity to encourage the use of [Universal Design for Learning](#) in your child's classroom and school – to promote and provide multiple ways for your child and others to access the curriculum and learn alongside his/her peers.



REMINDER

If you are a teacher or staff member, refer to the 'For Professionals' section, pages 68-70 for information on how myotonic dystrophy affects the body, Neuropsychological Functioning Aspects of CDM and Childhood-onset DM1, and frequently asked questions about myotonic dystrophy.

AGES 4-5: Transition from Preschool to Kindergarten

For children between the ages of 4 and 5 years old, here are the resources that were discussed earlier in this section that could be beneficial for the transition from preschool to kindergarten.



Appendix A – Helpful Tools in the Guide

- **Section 10 – Individuals with Disabilities Education Act (IDEA) Evaluation and Eligibility Ages 3-21**, page 56. This section is for people who did not receive an evaluation before age 3 and did not have an [Individualized Family Service Plan \(IFSP\)](#). Children with childhood-onset DM1 may fit under this category
- **Standards-based Individualized Education Program (IEP) Goals**, page 83. This section provides an in-depth look at the types of goals that could be selected for your child, along with examples
- **When the Team Can't Agree: Tools for Resolving Conflict**, page 75. Sometimes the team can't agree on a path forward. If that happens, we've included some helpful tips to mediate this issue



Appendix B – External Resources

- [School Transitions in the Elementary Grades](#) – An external resource on transitioning between schools, adapted from the Autism Society.

RESOURCE RECAP

5

6



Read this section when your child has already had an evaluation and will be transitioning to the early grades. If your child has not had an initial evaluation, go to **IDEA Evaluation and Eligibility**, page 56, and return to this section after evaluation.

AGES 6-10:

Transition from Kindergarten into the Early Grades Individualized Education Program (IEP) Basics and Reminders

If your child has an **Individualized Education Program (IEP)** and is receiving special education services in kindergarten or early grades, you are familiar with the IEP process. In your child's kindergarten or early grade years, or earlier in the year if needed, the school will reach out to schedule a meeting structured in the same way as the previous IEP meeting(s).

People attending the IEP meeting will include those who have worked with your child this school year. In addition, the team should also include at least one teacher or special education teacher – hopefully the receiving teacher(s) who will teach your child in the coming year.

As with any IEP meeting, you should bring new medical or other helpful information to the team. Bring your binder so that you will have everything you need with you. Together, you will first decide whether to conduct further evaluation of your child's progress and condition. You will then proceed to update your child's **Present Levels of Academic Achievement and Functional Performance (PLAAFP)**, goals, specially designed instruction, related services, setting for instruction/services, setting for PE, measurement of goals and other special factors for kindergarten. If you need a refresher about the meeting process and developing the IEP, go back and review **Section 4 – Ages 3-12: Developing the Individualized Education Program (IEP)**, page 21.



REMINDER

You will find a list of key terms and abbreviations in **Glossary and Abbreviations** on page 62. All **blue bolded** words and phrases have definitions listed there.



QUICK TIP

Remember, even if the school says, 'we don't do it that way,' you can still request that they try. IDEA provides great flexibility and seeks to ensure that your child is provided more than minimal access and services to gain an education.

Evaluate every 3 years: Separate and distinct from the IEP's required yearly discussion of your child's progress and depending on the first Individuals with Disabilities Education Act (IDEA) **evaluation** conducted, the law includes the option of reevaluating your child every three years, but allows the school and parent to agree that no additional data are needed and forgo reevaluation. The school will initiate this and will discuss with you any new areas of challenge including physical or cognitive dysfunction that should be tested. You will be asked to give **consent**.

Standards-based Individualized Education Program (IEP): Every state has designed standards of learning in all core subjects. Public schools, including public charter schools, are required to develop curriculum and assessments that show how children are progressing toward state standards. Often, the standards are designed with the expectation that children will be taught to, and expected to meet, state benchmarks and

goals as early as kindergarten and first grade. While children with CDM or childhood-onset DM1 may have **developmental delays** or some cognitive impairment, they may still be capable of working at grade level with their peers when they receive special education services.

Updating the IEP goals: The IEP goals related to early learning and early skill development and achievement may have been discussed in your previous meetings. However, these goals become more important in the early grades because young children are expected to learn to read, write and compute by the end of third grade. It is important to set IEP goals that are aligned to state standards for all children in kindergarten. If the goals are not standards-based, you run the risk of the IEP setting a lower standard for your child, which can reduce the team and teacher's expectations for your child. To learn more and review samples of goals, see **Appendix A – Standards-based Individualized Education Program (IEP) Goals**, page 83.

Grade retention or social promotion: If you believe it is in your child's best interest, you may ask the school or IEP team to have your child repeat kindergarten or first grade. Also, states can require automatic retention in second or third grade if the child is not reading at grade level, although most states have specific provisions that apply to students with disabilities, so consult your state's federally funded parent center. In this case, you need to weigh in and decide if this is appropriate for your child because his/her unique needs are what matter most.

The IEP team makes this decision together and the driving question for either retaining or promoting your child should be: What will we do differently in the IEP to assure the child's success? If the IEP team cannot answer that question, the child will not be well served in the coming year.

2nd Grade – Participation in State Assessments 3rd Grade to High School

Each year the IEP team is required to discuss how your child will participate in state and district-wide assessments and what testing **accommodations** will be needed. In the IEP meeting at the end of 2nd grade, this decision may have distinct implications for your child as s/he enters 3rd grade and beyond.

The Every Student Succeeds Act requires all states to test students annually in reading and math and every three years in science. The tests measure how students are doing in meeting state academic content standards. Your state may also have tests in other subjects like civics or social studies. The state is required to assure that testing accommodations (e.g. extra time, computers, answer in test booklet, assistive technology, large print, etc.) are made available to students with disabilities and that teachers are trained to support and assist students with testing.

The state is also required to assess at least 95% of all students and 95% of all students with disabilities in the state. This testing occurs in grades 3 through 8 and once in high school (depending on your state).



PARENT INSIGHT

COMING OUT OF MY SHELL

"I learned I had to come out of my shell and advocate for my child. I knew the school wasn't even trying to learn about his disease. It was unfortunate the way they acted – they mispronounced his diagnosis repeatedly – but by bringing doctor's notes, they started delivering more of what he needed."

– Suzette



QUICK TIP

Create a binder that includes two sections about your child:

1. All things medical
2. All things educational

Anything you sign as well as the materials from evaluations, screenings, medical tests, discussions with doctors or teachers should be included. This way, you'll have copies of everything when you need them, and you can bring the binder to evaluations and other meetings held to discuss your child's program. You can also scan and save everything onto a computer.



PARENT INSIGHT

TEACHERS ARE PART OF THE TEAM

"Some of the most effective Individualized Education Program (IEP) meetings that we had happened after I realized the school was not the enemy. Working with the teachers, I managed to rewrite (IEP) goals and get as much as I could for my son."

– Ted

It's important to know what your options are for your child with CDM or childhood-onset DM1 and what your choice could lead to. Here are the essentials. Remember these are also outlined in **Appendix A – Why Testing Decisions Matter**, page 85, and throughout this guide.

Why Testing Decisions Matter

1. General or alternate assessment: The team is required to discuss whether your child takes the general assessment(s) or the alternate assessment. Every state offers both. The general assessment is the test every child takes except for a very small number of children with the most significant cognitive disabilities. These children take the state's alternate assessment aligned to alternate academic achievement standards.

You will need to decide which assessment type is best for your child. If you choose the alternate assessment, the law supports your child taking an alternate assessment in one subject and the general assessment in another.

2. Testing decisions and instructional setting: Testing decisions can drive whether the child is taught in an **inclusive** or regular classroom learning the general curriculum or in a **segregated** classroom where the instruction may be modified or designed to the to the alternate academic achievement standards. If you choose a **segregated** classroom, make sure you understand whether your child has access to the general curriculum.

NOTE: In some states, once the team chooses the alternate assessment (as early as 3rd grade), the child's classroom instruction is automatically assigned to the **segregated** classroom and s/he spends very little time in the regular classroom (e.g. art, music, recess and lunch). Make sure you understand the impact of these decisions on the curriculum and programming your child receives.

3. Testing decisions and high school graduation: Because testing decisions can impact whether your child has access to the regular classroom, and the general curriculum, it can also impact his/her access to the instruction and courses s/he needs to receive a **regular high school diploma**. Federal law now requires the IEP to discuss the impact of choosing an alternate assessment on earning a regular diploma.

4. Opting out: Check with your school district to find out if you can opt your child out of state and district testing, as this varies by state. If your state allows you to opt your child out of testing, you will not have the same end-of-year testing information that shows how s/he is doing compared to his/her peers in core areas such as reading and math.

This information is also included in this guide's **Appendix A – Why Testing Decisions Matter**, page 85.

Remember you can ask to review the IEP at any time. See **Section 4 – Ages 3-12: Developing the Individualized Education Program (IEP)**, page 21.

Review your role on the team. See this guide's **Section 4 – Ages 3-12: Developing the Individualized Education Program (IEP)**, page 21. If you cannot agree as a team, see **Appendix A – When the Team Can't Agree: Tools for Resolving Conflict**, page 75.



Special Considerations At This Age and Stage

- Encourage next year's teacher to visit the classroom and observe your child before the end of the current school year
- Inform all appropriate school staff about special factors related to your child. For example, if your child is struggling to chew or swallow and needs extra time at lunch, the teachers and cafeteria workers should be provided information about services and supports
- Identify peers who will support and help your child in the hallways, on stairs and elevators, at recess, during group time in class, etc. The Individualized Education Program (IEP) team, teacher and others can help with this
- Closely monitor early learning needs and assure appropriate intervention is being provided. Some schools use a **Multi-tiered System of Support (MTSS)** for reading and math, which can be of great benefit to children with CDM or childhood-onset DM1 experiencing learning challenges
- **Ensure that your child is not the victim of teasing or bullying. Given the possibility of apathy and/or poor socialization skills, s/he may not be aware of his/her situation**
- Promote independence when possible while making sure s/he has support in critical needs (e.g. toileting)
- Cultivate new interests and enhance your child's curiosity. **IDEA** requires the school to provide nonacademic and extracurricular services and activities on par with what it is providing others
- Look for every opportunity to encourage the use of **Universal Design for Learning (UDL)** in your child's classroom and school to promote and provide multiple ways for your child and others to access the curriculum and learn alongside his/her peers



REMINDER

Remember to consult your local school district's special education department to understand how they implement the IDEA law. Your state's federally funded parent center can help you find your way. For information, go to www.parentcenterhub.org

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REMINDER

If you are a teacher or staff member, refer to the 'For Professionals' section for information on how myotonic dystrophy affects the body, Neuropsychological Functioning Aspects of CDM and Childhood-onset DM1, and frequently asked questions about myotonic dystrophy.

AGES 6-10:

Transition from Kindergarten to the Early Grades

For children between the ages of 6 and 10 years old, here are the resources that were discussed earlier in this section that could be beneficial for the transition from preschool to kindergarten:



Appendix A – Helpful Tools in the Guide

- **Standards-based Individualized Education Program (IEP) Goals**, page 83. This section provides an in-depth look at the types of goals that could be selected for your child, with examples
- **When the Team Can't Agree: Tools for Resolving Conflict**, page 75. Sometimes the team can't agree on a path forward. If that happens, we've included some helpful tips to resolve issues
- **Why Testing Decisions Matter**, page 85. Standardized testing is a large part of the American public school system. We've outlined the possibilities for your child in this section



Read this section when your child has already had an evaluation and will be transitioning to middle school. If your child has not had an initial evaluation, skip to **IDEA Evaluation and Eligibility**, page 56, and then return to this section.

AGES 11-14:

Transition from Elementary to Middle School

Individualized Education Program (IEP) Basics and Reminders

If your child has an **IEP** and is receiving special education services in 4th, 5th, or 6th grade, you are familiar with the IEP process. Prior to entering middle school, the school will contact you to schedule a meeting structured in the same way as the previous IEP meeting(s).

Attending the IEP meeting will be those who have worked with your child this school year. In addition, the team should also include at least one teacher or special education teacher – hopefully the teacher(s) who will teach your child in the coming year. A representative from the middle school should also attend.

As with any IEP meeting, you should bring new medical or other helpful information to the team. Bring your binder so that you will have everything you need with you. Together, you will first decide whether to conduct further **evaluation** of your child's progress and condition. You will then proceed to update each section of your child's IEP.

If you haven't done so before, this is likely the perfect age to bring your child to the meeting. Have him/her talk about what worked this year and what didn't. His/her input can be invaluable to the IEP team as you build the next plan. If you need a refresher about the meeting process and developing the IEP, go back and review this guide's **Section 4 – Ages 3-12: Developing the Individualized Education Program (IEP)**, page 21.

Evaluate Every 3 Years: Separate and distinct from the IEP's required yearly discussion of your child's progress, and depending on the first **IDEA evaluation** conducted, the law allows but does not require the school to reevaluate your child every three years. The school will initiate this evaluation and will discuss with you any new challenges, including physical or cognitive dysfunction that should be tested. You will be asked to give consent. See this guide's **Special Considerations for Evaluations of Children with CDM or Childhood-onset DM1**, page 74.



REMINDER

You will find a list of key terms and abbreviations in **Glossary and Abbreviations** on page 62. All **blue bolded** words and phrases have definitions listed there.



QUICK TIP

Create a binder that includes two sections about your child:

1. All things medical

2. All things educational

Anything you sign as well as the materials from evaluations, screenings, medical tests, discussions with doctors or teachers should be included. This way, you'll have copies of everything when you need them, and you can bring the binder to evaluations and other meetings held to discuss your child's program. You can also scan and save everything onto a computer.



PARENT INSIGHT

BULLYING HAD TO STOP

“Billy Dean was bullied in the hallway in junior high. Working with the school, we did an educational fundraiser – Hoops for Billy – at a basketball game and had everyone give a donation to a national organization. Once people understood that Billy Dean had a condition, it changed the dynamic for him at school.”

– Suzette



QUICK TIP

One of the main purposes of special education is to prepare children to lead “productive and independent adult lives to the maximum extent possible.”

– Individuals with Disabilities Education Act (IDEA) 2004(c) (5)(A)

Middle School

If you haven’t raised a teenager yet, get prepared. It will be a time of both challenge and opportunity for you and your child. The middle school environment, schedule, approach to teaching and discipline, etc. are very different from elementary school. This switch in environments also coincides with several major changes for young adolescents as their bodies and need for independence mature.

Most middle school students are in the throes of puberty; they’re becoming more self-aware and self-conscious, and their thinking is growing more critical and complex. At the same time, adolescents are often in a slump when it comes to academic motivation and performance. This transition for typical students includes a drop in grades, a reduced interest in school, and lower self-confidence.

Adolescents with CDM or childhood-onset DM1: For DM1 adolescents, the complicating factors of their physical, cognitive and psychological symptoms makes this time incredibly challenging for you and for them. While their cognitive function may level off or plateau, they may now be aware that they do not fit in and you may witness isolation and loneliness, or they may be apathetic and unaware of social norms, choosing to spend afternoons and weekends alone in their rooms. Not all children with CDM or childhood-onset DM1 experience these extremes, but you should be prepared.

DM families have shared that while their children’s physical pain and discomfort may be easier to manage with medication, there are still complex factors that impact daily living and their educational experience. The chance your child may be bullied goes up in middle school, as does your child’s exposure to social situations s/he may not be ready for. Children with childhood-onset DM1 are at greater risk of anxiety and depression, which may lead them to experiment with drugs, alcohol and sex far earlier than you would expect or like.

Depending on how well your child is doing in the general elementary school classroom, the team may recommend a more segregated school or classroom setting for middle school. Districts often struggle to provide an inclusive education to students with complex disabilities because it is much harder for them in a setting that includes numerous classrooms, teachers, and schedules – but they can do it. As you have done before, you will need to examine your options. Take some time to visit several schools. If the right choice is not available, push to have the school design or offer something more meaningful for your child.



Special Considerations At This Age and Stage

- School placement will be determined by state/district policies and the IEP team. Generally, students must attend the school for their geographic area, but exceptions are sometimes made. Prepare for this transition just as you did earlier in his/her life. If it's your first transition to a new school, see **page 19** for further information
- Update the team on developments with changes in symptoms. Help them design the IEP to address issues that may include attention deficit hyperactivity disorder (ADHD), anxiety, muscle cramping, sleep apnea, diabetes, etc.
- As you did in the early grades, think ahead regarding your child's future and what your priorities and his/her own dreams and goals are. Keep in mind that when you choose a more segregated setting in middle school, your child will likely be in a segregated setting for high school
- Push to continue (and have the school provide and support) extracurricular services and activities such as clubs, sports, etc. Families, research and best practice all tell us that these are often the lifesavers that help adolescents build confidence and self-esteem and that assure perseverance through difficulty
- Talk with your child about the new school and find out any concerns s/he may have
- You may want to identify a person to whom your teen may go if he or she feels confused, anxious, or overwhelmed. This person might be a school counselor, social worker, or other designated staff member
- Ask to convene a meeting at the beginning of the school year and request that every teacher attend. Invite your child. Work with him/her to share how the teachers can help. Review the IEP. Ask for the best way to communicate about your child's progress and challenges
- Look for every opportunity to encourage the use of **Universal Design for Learning (UDL)** in your child's classroom and school to promote and provide multiple ways for your child to access the curriculum and learn alongside his/her peers
- If your state begins **transition planning** at age 14 or sooner, see this guide's **Section 8 – Ages 15-22: Transition from Middle to High School**, page 45
- Remember you can ask to review the IEP at any time. See **Section 4 – Ages 3-12: Developing the Individualized Education Program (IEP)**, page 21
- Review your role on the team. See **Section 4 – Ages 3-12: Developing the Individualized Education Program (IEP)**, page 21
- If you cannot agree as a team, see **When the Team Can't Agree: Tools for Resolving Conflict**, page 75



PARENT INSIGHT

YOUR CHILD CAN ADVOCATE TOO

"We have strongly encouraged our son Ben to advocate for himself. We taught him to speak up if he has questions and seek help when he needs it. We also challenge him to always try to have a positive attitude and be grateful for support. It makes people so much more willing to help."

– Erica

Questions to Consider for Individualized Education Program (IEP) Planning in Middle School and in High School

- Has the team considered your child's interests, strengths, and future plans in selecting classes and activities?
- What accommodations are available for extracurricular activities?
- With whom will my child eat lunch?
- What are the attendance, conduct and discipline policies?
- Are accommodations needed in the cafeteria, library, restroom, or locker room?
- Have transportation needs been addressed?

The middle school Individualized Education Program (IEP) team knows how typical kids act at this age and they may think they know how CDM or childhood-onset DM1 affects children. But what they do not know is your child. One parent whose child has childhood-onset DM1 commented,

RESOURCE RECAP

7

AGES 11-14: Transition from Elementary to Middle School

For children between the ages of 11 and 14 years old, here are the resources that were discussed earlier in this section that could be beneficial for the transition from elementary school to middle school.



Appendix A – Helpful Tools in the Guide

- **Special Considerations for Evaluations of Children with CDM or Childhood-Onset DM1**, page 74. In this section you can find examples of specific tests that can be used to help evaluate your child's symptoms. This will help you accommodate your child in the best way possible
- **When the Team Can't Agree: Tools for Resolving Conflict**, page 75. Sometimes the team can't agree on a path forward. If that happens, we've included some helpful tips to mediate



Read this section when your child has already had an evaluation and will be transitioning to high school. If your child has not had an initial evaluation, skip to **IDEA Evaluation and Eligibility**, page 56, and then return to this section.

AGES 15-22:

Transition from Middle to High School

While in middle school, your child has been working on many of the skills s/he will need to adapt and function in high school. S/he made friends, changed classes and likely worked with more than one teacher, navigated the hallways, managed social situations, completed homework, worked in small groups and used a locker. High school is similar in many ways. However, your child may encounter new situations, such as:

- A new building, new teachers, new schedule
- Choosing electives
- Meeting graduation requirements
- Social situations (e.g. sports, dances, clubs, dating)
- Becoming a legal adult (age of majority)
- Planning for employment or continued education

Just like other transitions with your child, with a little bit of planning you can help improve the transition for everyone.

Individualized Education Program (IEP) Basics and Reminders

If your child has an **IEP** and is receiving special education services in 6th, 7th, or 8th grade, you are familiar with the IEP process. Prior to entering high school, the school will reach out to schedule a meeting structured in the same way as the previous IEP meeting(s). As with any IEP meeting, you should bring new medical or other information helpful to the team. Attending the IEP meeting will be those who have worked with your child this school year. In addition, the team should include at least one teacher or special education teacher - hopefully the teacher(s) who will teach your child in the coming year. A representative from the middle school should also attend. Update the team on changes in symptoms and help them design the IEP to address symptoms that may include ADHD, anxiety, muscle cramping or lack of mobility, sleep apnea, diabetes, changes in cognitive functioning, etc. Bring your binder so that you will have everything you need with you. If you need a refresher about the meeting process and developing the **IEP**, go back and review this guide's **Section 4 – Ages 3-12: Developing the Individualized Education Program (IEP)**, page 21.



REMINDER

You will find a list of key terms and abbreviations in **Glossary and Abbreviations** on page 62. All **blue bolded** words and phrases have definitions listed there.



QUICK TIP

It's your job to help the school see the sweetness, sensitivity and curiosity buried beneath your child's physical and other challenges. Help them see who s/he wants to become. Without that knowledge, the school will give you a basic IEP that will fulfill the requirements of the law, but will fail to really meet your child's short and long-term needs. Use all your advocacy skills in these important school years. Be vigilant, sensitive and flexible. It will be worth it.



PARENT INSIGHT

FRIENDS

“My daughter (who was not diagnosed until much later in life) has a normal IQ and could make friends but she couldn’t keep them. She struggled with social cues, having conversations and fitting in. Her challenges led her to quit high school.”

– Loraine



REMINDER

Remember to consult your local school district’s special education department to understand how they implement the IDEA law. Your state’s federally funded parent center can help you find your way. For information, go to www.parentcenterhub.org

Individualized Education Program (IEP) team members-new faces:

Attending the **IEP** meeting will be those who have worked with your child this school year. A new addition to an older student’s IEP meeting is a representative of the public agency providing and supervising the transition activities or **transition services** you will discuss and, if appropriate, representatives of other participating agencies. In certain states, you may also be assigned a support coordinator.

The 9th grade Individualized Education Program (IEP): To assist students and youth with disabilities to achieve their post-school and career goals, Congress enacted two key statutes that address the provision of transition services: **IDEA** and the **Workforce Innovation and Opportunity Act (WIOA)**. In the ninth grade (or earlier if the IEP team decides it is needed), the IEP shifts from a plan focused on the delivery of special accommodations, programs and tactics to support your child’s education to a plan that adds in long-range postsecondary planning and coordination between the school and community-based resources to help your child meet his/her goals after high school. This is called **transition planning**.

IDEA requires school districts to start transition planning in the IEP that will be in effect when the child turns 16. However, some states require this as early as age 14. IDEA requires the school to start transition planning immediately if your child is at-risk of dropping out of school. The transition process is guided by federal and state special education law and you may need to seek out more information via your local school district and state websites in order to find out what they require and offer.

While the IEP will continue to include the **Present Levels of Academic Achievement and Functional Performance (PLAAFP)** and goals for education and functional needs, at this stage, IDEA also requires the IEP team to consider age-appropriate transition assessments and your child needs as they relate to:

- Instruction
- Community experiences
- Development of **competitive, integrated employment**
- Other post-school adult living objectives

Daily living skills and a **functional vocational evaluation** may also be included. **If the IEP team decides your child does not need services in one or more of the areas outlined in the bullets above, the IEP must contain a statement explaining why.** The focus is to have your child help identify and take steps to begin achieving his/her vision of the future in this IEP and the IEPs that follow over the next several years.

Questions the Individualized Education Program (IEP) Team Should Consider When Discussing Transition Services

Do we expect him/her to:

- Complete district and state graduation requirements? If so, how do we help him/her achieve that? If not, what is the pathway to work and independent living?
- Take some or all regular education classes? If so, what does s/he need to be successful? If not, what courses will s/he take instead?
- Use modified curricula?
- Participate in general or alternate state assessments?
- Be eligible for support from adult community service providers?
- Need special education through the age of 21 (or age allowed by the state)?
- Go on to college or other postsecondary training?
- Need assistance to live independently?

CDM or childhood-onset DM1 and high school: Your child must be assigned to a high school that meets that meets his/her needs. Again, this is a time to consider the physical, cognitive and psychological symptoms and demands the disorder places on your child. Continue to have the highest of expectations for him/her tempered by the realities of his/her challenges.

Keep in mind the considerations offered throughout this guide regarding whether and when to segregate your child. IDEA requires that your child be educated in the **Least Restrictive Environment (LRE)**, meaning the place where typical peers are educated as much as possible. The school cannot offer a segregated setting as the only option. If you choose the segregated school or classroom, the Individualized Education Program (**IEP**) team must document the reasons why.

Diploma options: Because CDM or childhood-onset DM1 affects every young adult differently, within these several years of IEP team meetings you will help decide whether your child is prepared to exit high school with a regular diploma, either on time or with an extension as allowed by state law. While states determine graduation requirements (and the requirements and options vary greatly), IDEA provides flexibility in deciding when your child exits school and whether this includes a **regular high school diploma**.

While students with disabilities are graduating with regular diplomas at rates higher than ever, it's important for you to learn about all available options. Discuss with the IEP team what makes the most sense for your child.



QUICK TIP

The vast majority of students with disabilities should have access to the same high-quality academic coursework as all other students in their state. The coursework should reflect grade-level content for the grade in which the student is enrolled, and it should provide assessment of grade-level achievement standards.

– U.S. Department of Education, 2017



REMINDER

If you are a teacher or staff member, refer to the 'For Professionals' section for information on how myotonic dystrophy affects the body, Neuropsychological Functioning Aspects of CDM and Childhood-onset DM1, and frequently asked questions about myotonic dystrophy.

The IEP team may struggle to make sure your child is granted graduation credit for resource room (non-regular education) courses or regular education classes that are extensively modified. One legally correct solution is for the district to establish what the essential minimum requirements are for credit toward graduation. The requirements can be adhered to throughout high school as long as reasonable modifications are allowed in how he/she fulfills them. The IEP should lay out the understandings clearly and explicitly.

IDEA services through age 21: IDEA also provides the option for your child to continue to receive instruction, transition services and community experiences, including vocational rehabilitation and training, through the age of 21, unless your state laws specify younger. Some states extend this beyond age 22. This option may require that your child move to a special school at a certain point (after his/her senior year) and another transition may be required. As you meet each year and include your child in the discussion, you will make this decision together.



Special Considerations At This Age and Stage

- Federal law requires that a student be involved in his/her IEP meetings where transition services are discussed
- IDEA recommends that transition planning begin immediately for any student at risk of dropping out of school – regardless of age
- Activities identified in a student's transition plan must be directly linked to each student's post-school goals and must reflect a student's individual choices, preferences, and needs in the areas of education and training, employment, adult living arrangements, and community experiences
- Encourage the IEP team to explore the **Career Pathways Model** when developing work-based experiences for your child
- Self-determination and self-advocacy are critical skills. Your child can practice applying these skills by taking increasing responsibility for planning and conducting his/her IEP meetings
- Every state decides when the age of majority is reached, meaning when your child is considered a legal adult. IDEA requires that beginning **at least one year before your child reaches the age of majority**, the IEP must include a statement that he/she has been told about his/her IDEA rights
- Students can invite their parents to their IEP meetings when they reach the age of majority

Tips for Helping Your Child Transition to High School

- Visit the new high school and bring your child with you. Prepare for his/her transition as you have done in the past
- Buy your child a school sweatshirt or attend a school sporting event or activity
- Talk with your child about the new school and find out any concerns he/she may have
- Arrange a visit the week before school starts for your child to meet teachers and staff, practice self-advocacy skills, and become familiar with the building before it is crowded with other students
- It may be helpful to:
 - Locate restrooms and water fountains, the nurse's and counselor's offices, the cafeteria, and the special education resource room
 - Determine the best routes between classrooms
 - Practice using the hall and gym lockers
- Ask to convene a meeting at the beginning of the school year and request that every teacher attend. Invite your child. Have him/her share how the teachers can help. Review the IEP. Ask for the best way to communicate about your child's progress and challenges
- Look for every opportunity to encourage the use of **Universal Design for Learning** in your child's classrooms and school – to promote and provide multiple ways for your child to access the curriculum and learn alongside his/her peers
- Remember you can ask to review the IEP at any time. See this guide's **Section 4 – Ages 3-12: Developing the Individualized Education Program (IEP)**, page 21
- Review your role on the team **Section 4 – Ages 3-12: Developing the Individualized Education Program (IEP)**, page 21
- If you cannot agree as a team, see **When the Team Can't Agree: Tools for Resolving Conflict**, page 75
- IDEA says the IEP team "must take other steps to ensure that the child's preferences and interests are considered (in transition planning)"



PARENT INSIGHT

SUCCESSFUL TRANSITION PLANNING IS STUDENT-FOCUSED

"I have two sons with childhood-onset DM1. One is on a path to a regular diploma and will go to a local community college. The other is receiving a certificate (of high school completion) and will attend a life skills program run by the school district. They are individuals with distinct needs and desires. As parents, we want to see continuous improvement and we want them both to be happy."

– Erica



PARENT INSIGHT

THE PHYSICAL CHALLENGES

"There wasn't a time when my son wasn't dealing with some physical challenge. One school year, he was in the hospital – from intensive care to regular care and then into a long-term nursing home. This took a toll and we almost lost him. When he came back home he had a tracheotomy. The school and the bus driver had to go through a special training in case something went wrong. He was extremely medically fragile and could no longer handle a full day of school. They worked with us and he received services until his 22nd birthday."

– Ted

Examples of instruction and transition services that may be offered throughout high school:

- Internships, apprenticeships or other on-the-job training experiences
- Mentorships
- Resume building
- Employment soft skills training
- Money management skills training
- Specialized training in e.g. film, computer science, technology, etc.
- Specialized certification programs in e.g. culinary arts, healthcare, hospitality, horticulture etc.

NOTE: Services vary in each state and local community.

Successful transition planning requires partnerships between high schools, colleges, vocational rehabilitation (VR) agencies, employers, workforce development boards, social service agencies, students, and their families to identify and secure a career uniquely suited to each child. It is essential that youth with disabilities, along with their families and professional support staff, examine numerous and challenging programs so they can be prepared to achieve their desired post-school goals.

Once high school starts: Just as you have done throughout your child's school years, listen, observe and respond to your child's joys and concerns. While high school can be challenging, it can also be rewarding, and can help position your child for post-school success and satisfaction. If the experience for your child is not matching what the team planned, reconvene the team and adjust the IEP and the transition plan.

AGES 15-22:**Transition from Middle to High School**

For children between the ages of 15 and 22 years old, here are the resources that were discussed earlier in this section that could be beneficial for the transition from middle school to high school.

**Appendix A – Helpful Tools in the Guide**

- **When the Team Can't Agree: Tools for Resolving Conflict**, page 75. Sometimes the team can't agree on the way forward. If that happens, we've included some tips to help with mediation

**Appendix B – External Resources**

- [Sample Transition Individualized Education Program \(IEP\) with Transition Goals](#) – This site includes a sample transition goal form to help you get started
- [Transition Guide to Postsecondary Education and Employment for Students and Youth with Disabilities](#) – If you are looking for even more information, the United States Department of Education has written this 62-page guide on transition planning
- [Career Pathways](#) – This model is designed to facilitate an individual's career interests and advancement with multiple entrance and exit points in the individual's career over his or her lifetime

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REMINDER

You will find a list of key terms and abbreviations in **Glossary and Abbreviations** on page 62. All **blue bolded** words and phrases have definitions listed there.



PARENT INSIGHT

STAY THROUGH SCHOOL TO AGE 21 OR EXIT AT 18?

"Billy Dean didn't want to stay in high school through age 21. Thankfully, he had a great teacher who made a big difference during his last two years of high school. That teacher helped him prepare to be somewhat independent. I built a roommate floor plan house for us and he lives on one side and I live on the other. I built his side handicap accessible to assist me in caring for him as we both age. He was denied services through Vocational Rehabilitation as too medically fragile to work."

– Suzette



Read this section when your child **has already had an evaluation** and will be transitioning to postsecondary education or out of high school. If your child has not had an initial evaluation, skip to **IDEA Evaluation and Eligibility**, page 56, and then return to this section.

AGES 18-22:

Transition from High School to Postsecondary Education or Vocational Rehabilitation

At this point, the transition from high school should not be a new topic and everyone on the **IEP** team (including your child) should be aware that it is happening in the coming year. The previous IEP meetings (at least 3 and possibly 5 or more) should have included a discussion and active transition planning to support your child's goals beyond high school. It's now time to finalize the transition plan and prepare him/her to exit school. As a young adult, s/he now has some insight as to who s/he is, what his/her challenges are due to the DM disability, and what goals s/he wants to accomplish as s/he becomes an adult and gains further independence.

The End of Individuals with Disabilities Education Act (IDEA) Services

When your child exits **IDEA** services (either with a regular diploma or because s/he will soon age out of IDEA), the IEP team is no longer required to plan or coordinate the disability-related services that your child may have been receiving and may continue to need as a young adult.

Regardless of how your child exits special education, the school is required to provide to him/her a **Summary of Performance (SOP)**. **This document is a summary of your child's academic achievement and functional performance, and includes recommendations on how to assist him/her in meeting his/her postsecondary goals.** This summary of the student's achievement and performance can be used to assist in accessing postsecondary education and accommodations or employment services.

Upon exiting IDEA, s/he will have to take responsibility for understanding, applying for, and coordinating the services s/he needs. This can be challenging as each of the agencies that provide services, therapies, transportation, etc. have their own eligibility rules and applications. As you prepare for your child to exit, the IEP team can help families decide which adult services are available and how to access them, make connections and referrals. It is important that these connections are established before graduation if possible. **This planning, along with ensuring your child has the support s/he needs in his/her final year under IDEA, are the priorities of the IEP team.**

The Rehabilitation Act of 1973

Because the Rehabilitation Act defines a ‘youth with a disability’ as ages 14-24, your child may continue to be able to receive community-based training and other services as described on the previous page. This depends on where you live and what is available. Your IEP team will help you make this decision. See this guide’s **Appendix B – External Resources**, page 95, for detailed information about vocational rehabilitation and other post-high school services that some states offer to people with disabilities.

Federal Laws Protecting People with Disabilities

After the protections of IDEA end, your child continues to be protected by federal law from discrimination based on disability and has access to reasonable accommodations (at work, in college, for housing and transportation etc.) under the **Americans with Disabilities Act**. For college students, if the college or university accepts federal funding of any kind, any person enrolled with a disability is also protected under **Section 504**. Your child should be made aware of the protections and special programs s/he has access to as s/he enters the next phase of his/her life. MDF also offers resources on Social Security Disability Insurance. See www.myotonic.org, or call MDF at 415.800.7777.

Agencies or individuals that may provide community, employment, or adult living experiences or support to young adults and adults with disabilities:

- **State Vocational Rehabilitation Agencies:** services for people who have physical or mental disabilities to assist with employment: <http://soar.askjan.org/IssueConcern/214>
- **Service agencies:** programs and services for individuals with intellectual disabilities or mental health concerns: <https://www.acl.gov/programs>
- **Independent living centers:** help people with disabilities seeking to achieve and maintain self-sufficiency within the community:
 - **State:** <http://www.ilru.org>
 - **Local:** <http://www.ncil.org>
- **Social Security Administration:** federally-funded program that provides benefits for people who are unable to do substantial work and have a severe mental or physical disability: see Applying for Social Security Benefits at <https://www.myotonic.org/toolkits-publications> or call MDF at 415.800.7777

NOTE: Individuals who receive Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) benefits are presumed to be eligible for vocational rehabilitation services, unless there is clear and convincing evidence that they are unable to benefit from vocational rehabilitation services.



REMINDER

If you are a teacher or staff member, refer to the ‘For Professionals’ section for information on how myotonic dystrophy affects the body, Neuropsychological Functioning Aspects of CDM and Childhood-onset DM1, and frequently asked questions about myotonic dystrophy.



QUICK TIP

States are required to ensure that qualified students receive referrals to employment, including a variety of options that do more than point the young adult to sheltered workshops where employees are paid a sub-minimum wage and are at-risk of discrimination and exploitation.

• Other

- Specialists in guidance counseling, support to at-risk teens, employment, vocational education
- Representative for housing, higher education, transportation and community recreation agencies, including Special Olympics
- Employers associations and agents, including Chambers of Commerce, individual employers, industry trade organizations
- Social service and religious organizations, disability advocates and various nonprofits

Federal law requires that youth with significant disabilities be provided training for competitive, integrated employment. Depending on the severity of your child's CDM or childhood-onset DM1, s/he may qualify for this training.

Tips for Final Transition Planning

- If your child has a support coordinator from the local Office of Mental Health, Behavioral Health, or Intellectual or Developmental Disabilities, invite him/her to the IEP meetings during the last year of high school, if appropriate. S/he can help to coordinate post-high school services
- If your child will be eligible for services through vocational rehabilitation (VR), schedule an appointment for an intake interview and file the paperwork ahead of time. Request that a VR counselor attend the IEP meeting no later than springtime of your child's last year in high school
- Discuss your child's transportation needs. If s/he will need assistance getting to and from work, request and fill out applications for public transportation services
- Request information about post-high school training programs at local technical education schools, community colleges, business schools, and state or other specialized training schools
- Request information about social or recreational opportunities for young adults with disabilities in your community
- Research and explore postsecondary options that fit your child's goals, lifestyle, and personality. See [External Links, page 95 for Transition Guide to Postsecondary Education and Employment for Students and Youth with Disabilities](#)
- Make sure the [Summary of Performance \(SOP\)](#) is thorough. This is the document your child will use when requesting accommodations in postsecondary education and may be needed when applying for other community services
- Condense the binder down to key medical records showing symptoms, therapies, medications, etc. Include the SOP

AGES 18-22: Transition from High School to Postsecondary Education or Vocational Rehabilitation

For children between the ages of 18 and 22 years old, here are the resources that were discussed earlier in this section that could be beneficial for the transition from high school to postsecondary education or vocational rehabilitation.



Appendix B – External Resources

- [Transition Guide to Postsecondary Education and Employment for Students and Youth with Disabilities](#) – If you are looking for even more information, the United States Department of Education has written a guide on transition planning
- [Vocational Rehabilitation Agency](#) – A listing of all state vocational rehabilitation agencies
- [Service Agencies](#) – The administration of community living has put together a list of agencies that can support your child in a variety of different ways
- [State Independent Living Centers](#) – Find assistance for independent living in your state
- [Local Independent Living Centers](#) – Find assistance for independent living closer to home
- [Social Security Administration](#) – MDF’s guide, *Applying for Social Security Benefits: A Toolkit for People Living with Myotonic Dystrophy*, provides comprehensive information on navigating the application process. See www.myotonic.org, or call MDF at 415.800.7777
- [National Technical Assistance Center on Transition](#) – An organization that provides technical assistance to all states and U.S. territories to ensure transition-age youth with disabilities receive high-quality education services

10



This section of the guide applies only to families whose child with childhood-onset DM1 **has not yet received services** under IDEA.

AGES 3-21:**Individuals with Disabilities Education Act (IDEA) Evaluation and Eligibility****Seeking Special Education for Your Child with Childhood-onset DM1**

You are reading this section of the guide because the symptoms of your child's childhood-onset DM1 are impacting him/her at home **and** at preschool or school. It may be that you've met with the school previously to discuss one or more of your child's challenges. Perhaps symptoms such as his/her sleepiness and apathy have been mislabeled as laziness or he/she has struggled with reading, writing, paying attention or participation.

Regardless of where you are in the journey, it's important when beginning the conversation with the district or school to know that it is quite common for children and adolescents with childhood-onset DM1 to have one or more of these symptoms that alone or in combination may impact him/her at school:

- Delays in motor skills or development, speech
- Muscle problems in the face, neck, and/or weakness in the legs and feet including the characteristic high-stepping, toe-dragging or shuffling gait that leads to falls
- Sleep apnea, disrupted sleep, excessive fatigue or severe headaches
- Gastrointestinal problems that cause constipation, diarrhea, irritable bowel, etc
- Developmental delays that lead to learning disabilities in reading, writing, or computing
- Cognitive impairments that create and exacerbate an attitude of apathy or inertia and contribute to a lack of normal socialization with peers
- Psychiatric disorders including Attention Deficit Hyperactivity Disorder (ADHD) or Attention Deficit Disorder (ADD), anxiety, depression, or substance abuse

**REMINDER**

You will find a list of key terms and abbreviations in **Glossary and Abbreviations** on page 62. All **blue bolded** words and phrases have definitions listed there.

Requesting the Evaluation

The first step you must take is to request an **evaluation** to determine whether your child qualifies as a child with a disability and needs special education. **IDEA** provides this option to both parents and to schools. This guide assumes that **you are making the request to evaluate**. If your child's school has already initiated this, you can skim and review this section to make sure the process it has undertaken follows the requirements of IDEA.

Request an evaluation in writing: Write a straightforward letter and provide specific examples of the problems your child is having and describe how this is impacting him/her at school. You can add details from medical reports or notes from medical professionals.

- If your child is age 3 or 4, request the evaluation from your school district **early intervention program** or preschool

If your child is age 5 or older, request the evaluation from your local public school or school district. **See Appendix A – Request to Evaluate Letter**, page 89.

District or school response: You should receive a written confirmation of your request from the school, along with a copy of your **procedural safeguards**. The school will also follow up to schedule a meeting with you to discuss an **evaluation** plan. The school must meet with you and conduct the evaluation within 60 calendar days of receiving parental consent for the evaluation. Some states require shorter timelines for initial evaluations.

Agree to evaluate: School districts have protocols they require schools to follow for evaluations; however, **the school team should be open to the information you bring about childhood-onset DM1 and how it affects your child**. They can design an **evaluation** that focuses on all areas of suspected disability and the need for **special education and related services**. They should include a variety of tests to measure your child's cognitive ability, academic skills, language skills, and social and emotional status. Evaluations may also include information you submit, as well as reports the school writes about your child that include observations of your child in the classroom and other school settings.

Deny to evaluate: If the school decides to deny the evaluation, it must provide you with **prior written notice** and include required details about its decision. You can decide your next step by reviewing **Appendix A – Your Legal Rights: Individuals with Disabilities Education Act (IDEA) Procedural Safeguards and Dispute Resolution**, page 86.

Special considerations for evaluations of children with childhood-onset DM1: For children with childhood-onset DM1, it is important that the evaluation include all screenings, assessments and cognitive skill tests to ensure that a comprehensive evaluation is conducted. **If your child has physical disabilities, abnormal facial appearance or lack of facial**



QUICK TIP

Create a binder that includes two sections about your child:

1. All things medical
2. All things educational

Anything you sign as well as the materials from evaluations, screenings, medical tests, discussions with doctors or teachers should be included. This way, you'll have copies of everything when you need them, and you can bring the binder to evaluations and other meetings held to discuss your child's program. You can also scan and save everything onto a computer.

expression, it is particularly important that the school adjusts the testing for the child's physical disabilities. This correction is important because the presence of any one of the physical symptoms of childhood-onset DM1 can result in children with mild cognitive impairment appearing more markedly affected than is accurate. These mistaken impressions can occur during casual interactions and on formal neuropsychological testing unless the evaluator appropriately corrects for them.

Medical professionals who understand childhood-onset DM1 recommend that testing of childhood-onset DM1 children should be considered whenever early signs of cognitive or developmental issues are present. Any evaluation should accommodate the physical impairments that may be present and differentiate between physical and mental issues that may be perceived as cognitive dysfunction.

Tests for childhood-onset DM1 children should include these cognitive skills tests:

- Age appropriate IQ (e.g. the **Wechsler Preschool and Primary Scale of Intelligence (WPPSI)** and the **Wechsler Intelligence Scale for Children (WISC)**)
- Executive function and higher cognition skills
- Visual-spatial ordering skills
- Visual perception, construction, and memory skills
- Attention skills
- Verbal abstract reasoning skills
- Temporal-sequential ordering skills
- Processing speed
- Language and learning

Tests for other neuropsychological functions should include:

- Attention Deficit Hyperactivity Disorder (ADHD)
- Energy levels, social skills and general behavior
- Emotional facility (such as evaluation of anxiety, withdrawal, depression, conduct disorders)
- Motivation and apathy

Eligibility

After the evaluation is completed and a report is written, you will be invited to meet with the school team to discuss whether your child is eligible for special education. IDEA requires the **child's parent or legal guardian** to join the team. It is very important that you participate in the meeting(s). If you have a partner or are married, or a family member(s) helps you parent your child, you should bring him/her to the meetings as well.



REMINDER

Remember to consult your local school district's special education department to understand how they implement the IDEA law. Your state's federally funded parent center can help you find your way. For information, go to www.parentcenterhub.org

You should be provided a copy of the **evaluation** at no cost for review prior to the meeting. Request one if the district or school doesn't offer it to you. If English is not your first language, the district or school must provide a translator for you.

Requirements to qualify for an IEP: To determine that a child is eligible for special education, **IDEA** requires that children meet two requirements (or prongs) under the law. They are:

Prong 1 – Does your child have a diagnosed disability? The team will look at the test results and determine under which of the 13 disability categories your child would qualify.

IDEA Disability Categories for the IEP

Autism

Blindness

Deafness

Emotional disturbance (ED)

Hearing impairment (HI)

Intellectual disability (ID)

Multiple disabilities (MD)

Orthopedic impairment (OI)

Other health impairment (OHI)

Specific learning disability (SLD)

Speech or language impairment (SLI)

Traumatic brain injury (TBI)

Visual impairment (VI)

Developmental delay (in some states through age 7)

Prong 2 – Does the diagnosed disability adversely affect your child's educational performance? Does your child require specially designed instruction to receive a **Free, Appropriate Public Education (FAPE)**? The team must be able to show that even with a disability such as childhood-onset DM1 your child absolutely requires specially designed instruction to benefit from education. The team will look at the test results and at your child's current functional and other skill levels and compare that to:

- Skill levels appropriate for his/her current age or grade
- Your child's scores on state and district assessments
- Cognitive skills tests
- Neuropsychological functions, etc. to determine educational impact

If the team can answer 'yes' to both questions or prongs, then your child will qualify for an **IEP**. See this guide's **Section 4 – Ages 3-12: Developing the Individualized Education Program Individualized Education Program (IEP)**, page 21.



REMINDER

If you are a teacher or staff member, refer to the 'For Professionals' section for information on how myotonic dystrophy affects the body, Neuropsychological Functioning Aspects of CDM and Childhood-onset DM1, and frequently asked questions about myotonic dystrophy.

Prong 3 – Does your child require specially designed instruction to receive a Free Appropriate Public Education (FAPE)? The team must be able to show that even with a disability such as childhood-onset DM1 your child absolutely requires specially designed instruction to benefit from education. If the team can answer ‘yes’ to all three questions or prongs, then your child will qualify for an IEP. See this guide’s **Section 4 – Ages 3-12: Developing the Individualized Education Program Individualized Education Program (IEP)**, page 21.

When the Evaluation Fails Your Child:

- **If for some reason you are not happy with the evaluation results (even if your child qualifies for an IEP) you can request an Independent Educational Evaluation**, page 82
- If for some reason your child does not qualify for school-based special education services through an IEP, you have several options:
 - Request an Independent Educational Evaluation. See **Appendix A – Independent Educational Evaluation**, page 82
 - Accept a **504 Plan**. See **Appendix A – Comparison Chart: Individualized Education Program (IEP) to Section 504**, page 79
 - Exercise your legal rights. See **Appendix A – Your Legal Rights: Individuals with Disabilities Education Act (IDEA) Procedural Safeguards and Dispute Resolution**, page 86

RESOURCE RECAP

10

AGES 3-21:

Individuals with Disabilities Education Act (IDEA) Evaluation and Eligibility

Here are the resources that were discussed earlier in this section.



Appendix A – Helpful Tools in the Guide

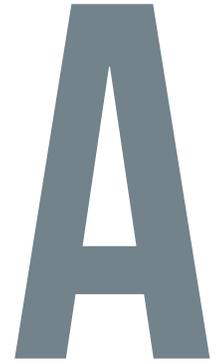
- **Independent Educational Evaluation (IEE)**, page 82. This section describes how to obtain a second evaluation if your child is denied on the first request
- **Special Considerations for Evaluations of Children with CDM or Childhood-onset DM1**, page 74. In this section you can find examples of specific tests that can be used to help evaluate your child’s symptoms. This will help you accommodate your child in the best way possible
- **Your Legal Rights: Individuals with Disabilities Education Act (IDEA) Procedural Safeguards and Dispute Resolution**, page 86. You have rights. Refer to this section to read over what is and isn’t allowed when it comes to your child’s education



Helpful Tools in the Guide

The following tools were created specifically for this guide. They provide additional insight and support for parents of children with CDM or childhood-onset DM1 as different needs arise throughout the child's school experience.

For additional support, call MDF at **415.800.7777**.



Glossary and Abbreviations

A

accommodations Supports that are provided to a child throughout the school day that do not significantly alter what is being taught or how the child participates in school activities. Examples include preferential seating, extended time on tests, daily communication logs to share information between school and home, use of spell check or a computer, enlarged print, and books on tape.

adapted physical education A physical education program that has been modified to meet the specific needs of a student with disabilities; e.g., inclusion of activities to develop upper body strength in a student with limited arm movement.

age of majority The age of majority is the threshold of adulthood as recognized or declared in state law. It is the moment when minors cease to be considered children and assume legal control over their persons, actions, and decisions, thus terminating the control and legal responsibilities of their parents or guardian over them.

Americans with Disabilities Act (ADA) The ADA prohibits discrimination against people with disabilities in employment, transportation, public accommodation, communications, and governmental activities.

appropriate education Education that is comparable to the one provided to general education students.

autism A developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age 3, that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences.

B

behavioral function Behavior in the context of social environment.

Behavior Intervention Plan (BIP) This plan considers the data gathered through an individual's **Functional Behavioral Assessment (FBA)** and employs that data to create a plan of action toward changing and improving that individual's behavior.

blindness The state or condition of being unable to see because of injury, disease, or a congenital condition.

C

Career Pathways Model A model designed to facilitate an individual's career interest and advancement with multiple entrance and exit points in the individual's career over his or her lifetime. Key program design features include contextualized curricula, integrated basic education and occupational training, career counseling, support services, assessments and credit transfer agreements that ease entry and exit points towards credential attainment.

Child Find A state and local program mandated by IDEA to identify individuals with disabilities between the ages of birth and twenty-one and to direct them to appropriate early intervention or educational programs.

cognitive function Means and mechanisms of acquiring knowledge (i.e., reasoning, memory, perception, awareness, attention, judgment, and language).

competitive, integrated employment Employment that meets all three of these conditions: competitive earnings; integrated location; and opportunities for advancement.

consent Parental permission, usually given by signing a letter or form, agreeing to let the state, district, or school take action that affects a child's education. Consent is required before a child can be evaluated or receive special education services under Individuals with Disabilities Education Act (IDEA).

D

deafness A hearing impairment that is so severe that the child is unable to process linguistic information through hearing, with or without amplification, that adversely affects a child's educational performance.

deaf-blindness A combination of hearing and visual impairments, that causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness.

developmental delay Describes slower than normal development of an infant or child in one or more areas.

disability A problem or condition which makes it hard for an individual to do things in the same manner as most other students and may be short-term or permanent.

due process hearing There are times when the parties have been unable or unwilling to resolve the dispute themselves, and so they proceed to a due process hearing. There, an impartial, trained hearing officer hears the evidence and issues a hearing decision. Learn more here: <http://www.parentcenterhub.org/hearings/>

due process complaint A complaint letter filed by a parent on matters of conflict related to the identification, evaluation, or educational placement of a child, or the provision of a **Free Appropriate Public Education (FAPE)** to the child.

E

early childhood technical assistance center

The entity that supports state Part C and Section 619 programs in developing high-quality early intervention and preschool special education service systems, increasing local implementation of evidence-based practices, and enhancing outcomes for young children with disabilities and their families.

early intervention service A system of coordinated services that promotes the child's age-appropriate growth and development and supports families during the critical early years.

emotional disturbance A condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree that adversely affects a child's educational performance:

- An inability to learn that cannot be explained by intellectual, sensory, or health factors
- An inability to build or maintain satisfactory interpersonal relationships with peers and teachers
- Inappropriate types of behavior or feelings under normal circumstances
- A general pervasive mood of unhappiness or depression

A tendency to develop physical symptoms or fears associated with personal or school problems. The term includes schizophrenia. The term does not apply to children who are socially maladjusted,

unless it is determined that they have an emotional disturbance.

evaluate, evaluation Evaluation is the first step in the special education process for a child with a disability. Before a child can receive special education and related services, a full **evaluation** must be conducted to see if the child has a disability and is eligible for special education. Informed consent must be obtained before an evaluation may be conducted.

executive function Cognitive processes necessary for the cognitive control of behavior.

extended school year services Special education and related services that are provided to a child with a disability beyond the normal school year of the public agency; are in accordance with the child's IEP; and are at no cost to the parents of the child.

F

504 plan A plan that is developed to ensure that a child who has a disability identified under the Rehabilitation Act and is attending an elementary or secondary educational institution receives accommodations that will ensure his/her academic success and access to the learning environment.

Free Appropriate Public Education (FAPE) The words used in the federal law, IDEA, to describe a student's right to a special education program that will meet his or her individual special learning needs, at no cost to the family.

Functional Behavioral Assessment (FBA) The FBA is a structured data gathering process an Individualized Family Service Plan (**IFSP**) or Individualized Education Program (**IEP**) team uses to help identify positive behavior interventions and supports to be used to advance the child's development and enhance the learning process. An FBA is used to determine the answers to the following three questions: 1. Why does the student have challenging behavior? 2. What reinforces the challenging behavior? 3. What positive interventions help decrease the challenging behavior and increase the desired behavior?

functional vocational evaluation A systematic process of evaluating an individual's skills, aptitudes, and interests as they relate to job preparation and choice. Assessments include work sampling, standardized tests, and behavioral observation.

H

hearing impairment An impairment in hearing, whether permanent or fluctuating, that adversely affects a child's educational performance, but that is not included under the definition of deafness in this section.

home, hospital, institution based services

Programs that are delivered specifically in the home, hospital or institution.

I

IDEA The Individuals with Disabilities Education Act, which was created to support the early development and education of children with disabilities in the home, in preschool and in public K-12 schools.

IDEA evaluation The process of conducting an evaluation to see if the child is a "child with a disability," as defined by IDEA.

inclusive early childhood program Refers to including children with disabilities in early childhood programs, together with their peers without disabilities; holding high expectations and intentionally promoting participation in all learning and social activities, facilitated by individualized accommodations; and using evidence-based services and supports to foster their development (cognitive, language, communication, physical, behavioral, and social-emotional), friendships with peers, and sense of belonging. This applies to all young children with disabilities, from those with the mildest disabilities, to those with the most significant disabilities.

inclusive early childhood setting A program in which children with and without disabilities can participate in the same routines and play experiences.

Independent Educational Evaluation (IEE) An evaluation or assessment of a student conducted by one or more professionals not employed by the school district. The person(s) doing the evaluation must be fully trained and qualified to do the kind of testing required.

Indian Health Services An agency within the Department of Health and Human Services responsible for providing federal health services to American Indians and Alaska Natives.

Individualized Education Program (IEP)

A written plan for each student in special education describing the student's present levels of performance, annual goals including short-term objectives, specific special education and related services, dates for beginning and duration of services, and how the IEP will be evaluated.

Individualized Family Service Plan (IFSP)

A written plan for each infant or toddler receiving early intervention services that includes goals and outcomes for the child and family. It also includes a plan for making the transition to services for children over age 2.

intellectual disability Significantly sub-average general intellectual functioning, existing concurrently (at the same time) with deficits in adaptive behavior and manifested during the developmental period, that adversely affects a child's educational performance. Previously known as mental retardation.

L

LEA representative A principal, special education director, teacher, or anyone who represents the Local Education Agency and can be sure the services in the IEP are provided to the child. This person must know about the regular education curriculum and the school district's resources. The LEA representative must have the authority to commit resources.

least restrictive environment (LRE) Placement of a student with disabilities in a setting that allows maximum contact with students who do not have disabilities, while appropriately meeting the student's special education needs.

M

Medicaid A federal or state program that provides medical services primarily to individuals with low incomes.

modifications Changes in the learning goals for an individual student. Modifications are used when the general curriculum is too advanced for a student and modifications usually involve changing an assignment or objective.

multiple disabilities Simultaneous impairments (such as intellectual disability, blindness, orthopedic impairment, etc.), the combination of which causes such severe educational needs that they cannot be accommodated in a special education program

solely for one of the impairments. The term does not include deaf-blindness.

Multi-tiered System of Supports (MTSS) A Multi-tiered System of Supports is a systemic, continuous improvement framework in which data-based problem-solving and decision making is practiced across all levels of the educational system for supporting students. The framework utilizes high quality evidence-based instruction and intervention, and assessment practices to ensure that every student receives the appropriate level of support to be successful. MTSS helps schools and districts to organize resources through alignment of academic standards and behavioral expectations, implemented with fidelity and sustained over time, to accelerate the performance of every student to achieve or exceed proficiency.

N

natural environments A term used in early intervention to describe the settings that infants and toddlers would be in if they did not have a disability such as home, day care, and other community environments.

O

orthopedic impairment An impairment caused by congenital anomaly (e.g., clubfoot, absence of some member, etc.), impairments caused by disease (e.g., myotonic dystrophy, poliomyelitis, bone tuberculosis, etc.), and other causes (e.g., cerebral palsy, amputations, and fractures or burns that cause contractures).

other health impairment Having limited strength, vitality or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that is due to chronic or acute health problems such as asthma, attention deficit disorder (ADD) or attention deficit hyperactivity disorder, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, and sickle cell anemia; and adversely affects a child's educational performance.

P

Peer Assisted Learning Strategies (PALS) Peer-tutoring instructional program that supplements the primary reading curriculum and is intended to improve reading accuracy, fluency, and comprehension.

Positive Behavior Interventions and Supports

(PBIS) PBIS is an evidence-based, data-driven framework proven to reduce disciplinary incidents, increase a school's sense of safety, and support improved academic outcomes for all students.

Present Levels of Academic Achievement and Functional Performance (PLAAFP)

The portion of the child's IEP that details how he/she is doing academically at the moment.

prior written notice The right to receive prior written notice from the school each time that the school proposes to take (or refuses to take) certain actions with respect to your child.

procedural safeguards The right under IDEA to ensure parents have the opportunity to be partners in the educational decisions made regarding their child.

psychosocial function Relating to the combination of psychological and social behavior.

R

regular high school diploma A regular high school diploma is the standard high school diploma awarded to the majority of students in a state that is fully aligned with the state's standards and does not include a general equivalency diploma, certificate of completion, certificate of attendance, or any other similar or lesser credential, such as a diploma based on meeting Individualized Education Program (IEP) goals. The term "regular high school diploma" also includes any "higher diploma" that is awarded to students who complete requirements above and beyond what is required for a regular high school diploma.

related services Related services help children with disabilities benefit from their special education by providing extra help and support in needed areas, such as speaking or moving. Related services can include, but are not limited to: speech-language pathology and audiology services, interpreting services, psychological services, physical and occupational therapy, recreation, including therapeutic recreation, early identification and assessment of disabilities in children, counseling services, including rehabilitation counseling, orientation and mobility services, medical services for diagnostic or evaluation purposes, school health services and school nurse services, social work services in schools, parent counseling and training, transportation.

S

Section 504 Individuals with disabilities may not be excluded from participating in programs and services receiving federal funds. It also prohibits job discrimination against people with disabilities in any program receiving federal financial assistance. Students not eligible for an Individualized Education Program (IEP) may be eligible for a 504 plan.

segregated early childhood education To educate students with special needs in an exclusive setting that only serves children with disabilities.

service coordinator Every family receiving early intervention services should be provided a person to act as a point of contact and to help guide you through the early intervention process. If you don't know who your early intervention **service coordinator** is, get in touch with the Early Childhood Technical Assistance Center to find your state contact. This is the contact who should assign your service coordinator. <http://ectacenter.org/contact/ptccoord.asp>

special education Specially designed instruction, at no cost to the parents, to meet the unique needs of a child with a disability.

special factors IDEA requires the Individualized Education Program (IEP) to consider special factors including: behavior, limited English proficiency, blindness or visual impairment, communication needs or deafness.

specially designed instruction Means adapting, as appropriate, the content, methodology, or delivery of instruction to address the unique needs of a child that results from the child's disability; and to ensure that the child has access to the general curriculum, so that he or she can meet the educational standards adopted by the state.

specific learning disability A disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, that may manifest itself in an imperfect ability to listen, think, speak, read, write, spell, or to do mathematical calculations, including conditions such as perceptual disabilities, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. The term **does not** include learning problems that are primarily the result of visual, hearing, or motor disabilities, of

intellectual disability, of emotional disturbance, or of environmental, cultural, or economic disadvantage.

speech or language impairment A communication disorder, such as stuttering, impaired articulation, language impairment, or a voice impairment, that adversely affects a child's educational performance.

Summary of Performance (SOP) A statement of your child's academic achievement and functional performance which includes recommendations on how to assist him/her in meeting his/her postsecondary goals. This summary of the student's achievement and performance can be used to assist in accessing postsecondary education and accommodations or employment services.

T

transition planning Careful preparation by the student, parents, educators, and other service providers when the student leaves high school. The plan is written in the individualized transition plan.

transition services A coordinated set of activities for a student that promotes movement from school to post-school activities, including postsecondary education, vocational training, integrated employment, continuing and adult education, adult services, independent living, or community participation.

traumatic brain injury An acquired injury to the brain caused by an external physical force, resulting in total or partial functional disability or psychosocial impairment, or both, that adversely affects a child's educational performance. The term applies to open or closed head injuries resulting in impairments in one or more areas, such as cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem-solving; sensory, perceptual, and motor abilities; psychosocial behavior; physical functions; information processing; and speech. The term does not apply to brain injuries that are congenital or degenerative, or to brain injuries induced by birth trauma.

U

Universal Design for Learning (UDL) A set of principles for curriculum development that give all individuals equal opportunities to learn. Learn more about UDL at <http://udlguidelines.cast.org/>

V

visual impairment: An impairment in vision that, even with correction, adversely affects a child's educational performance. The term includes both partial sight and blindness.

W

Wechsler Adult Intelligence Scale (WAIS) is an IQ test designed to measure intelligence and cognitive ability in adults and older adolescents.

Wechsler Preschool and Primary Scale of Intelligence (WPPSI) is an intelligence test designed for children ages 2 years 6 months to 7 years 7 months.

Workforce Innovation and Opportunity Act (WIOA) This federal law prohibits discrimination on the basis of disability in programs conducted by Federal agencies or receiving Federal financial assistance, in Federal employment, and in the employment practices of Federal contractors. The standards for determining employment discrimination under the Rehabilitation Act are the same as those used in Title I of the Americans with Disabilities Act.

written informed consent The process for getting permission before conducting a healthcare intervention on a person.

For Professionals

How Myotonic Dystrophy Affects the Body

Myotonic dystrophy (DM) is a multisystemic disorder that can affect all age groups. Because of the range of systems affected, management requires a more expansive approach than most disorders and care is best provided by a coordinated, multidisciplinary team.

VISION

- Cataracts, blurred vision
- Damage to the retina
- Drooping eyelids (ptosis)

ENDOCRINE

- Diabetes
- Insulin resistance
- Low thyroid hormone levels
- Premature frontal balding in men

CARDIOVASCULAR

- Heart rhythm problems (arrhythmias)
- Enlarged heart muscle (cardiomyopathy)
- Low blood pressure
- Sudden death

GASTROINTESTINAL

- Difficulty swallowing
- Pain and bloating after meals
- Constipation, diarrhea, irritable bowel syndrome, reflux
- Poor nutrition and weight loss
- Gallstones
- Enlarged colon
- Chronic infections

GENETICS

- Inherited disease, autosomal-dominant mutation
- 50% chance of passing mutated gene to each offspring
- More severe with each generation ("anticipation")

BRAIN

- Difficulty with thinking and problem solving
- Emotional and behavior problems
- Excessive daytime sleepiness
- Nerve damage in feet and hands

RESPIRATORY

- Breathing problems in newborns
- Frequent lung infections
- Aspiration of food or fluids into airways
- Inability to breathe in enough oxygen
- Sleep apnea

IMMUNE

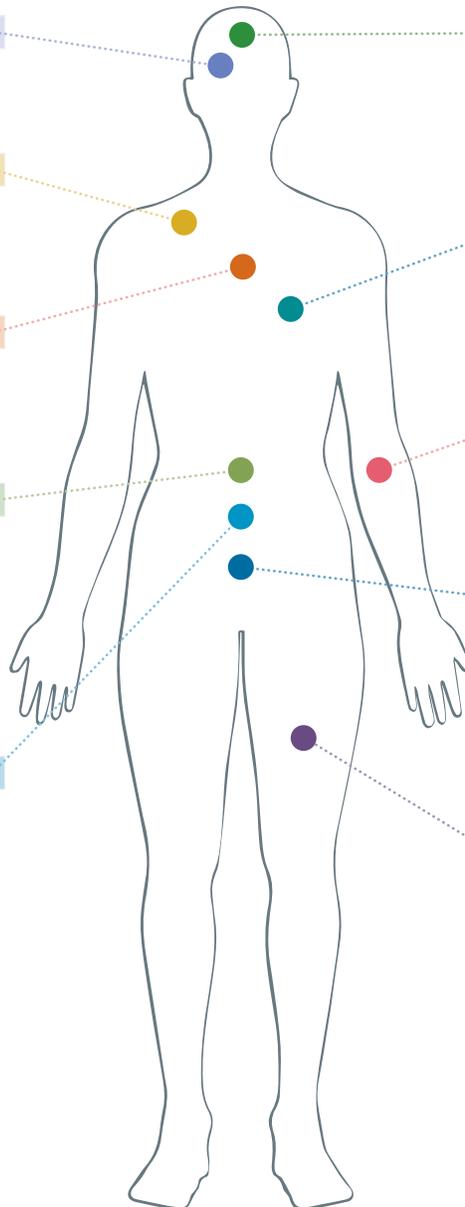
- Lower levels of antibodies in blood stream (hypogammaglobulinemia)
- Higher risk of benign skin tumor (pilomatrixoma)

REPRODUCTIVE

- Males: low testosterone levels, low sperm count, small testes, testicular failure, gonadal atrophy
- Females: higher risk of miscarriage and stillbirth, pregnancy and delivery complications, early menopause
- Newborn complications

MUSCULAR

- Muscle weakness (myopathy)
- Muscle pain, stiffness, trouble relaxing a muscle (myotonia)
- Muscle wasting that gets worse over time (atrophy)
- Severe muscle weakness, delayed development in newborns and infants



Understanding the Neuropsychological Functioning Aspects of CDM and Childhood-onset DM1

The neuromuscular disorder myotonic dystrophy affects more than physical function. It is also a brain disorder that impacts thinking and behavior, especially in children with the congenital (CDM) and childhood-onset forms of the disease. Cognitive functioning, the mental processes necessary for learning, remembering, problem solving, and paying attention, may be mildly to severely impaired in children with CDM and childhood-onset DM1.

Commonly Associated Cognitive and Psychosocial Symptoms that May Develop and Change with Disease Progression

- Attention problems
- Concentration problems
- Executive function impairment in one or more of the following:
 - Emotional control (emotional reaction to change)
 - Inhibition (stopping self from saying or doing something)
 - Initiation (difficulty starting a task)
 - Monitoring (underestimate/lack awareness of time it takes to complete tasks)
 - Organization of materials
 - Planning/organization
 - Shift (switching tasks, difficulty with transitions)
 - Working memory
- Intellectual disability
- Language problems
- Learning disorders
- Memory deficits (auditory, visual, working memory)
- Mood symptoms (e.g., anxiety, apathy, depression, flat affect)
- Motivation
- Perseveration
- Personality changes
- Problem solving or decision making (too many choices perceived)
- Processing speed (slowed)
- Thinking difficulty (thinking may be linear, circular, or disjointed)
- Visuoconstructional and visuospatial impairment

Changes in cognitive function may be subtle, occur gradually, and wax and wane due to environment and psychological stressors, and they may be unique to the affected individual.

Cognitive function problems exhibited by children with CDM and childhood-onset DM1 are not issues of physical function, motivation, or unwillingness. Affected children are unable to complete tasks and follow directions in the same way as neurotypical children. The approach to addressing cognitive changes can be adapted to the child's level of functioning so that s/he can successfully complete tasks.

Ways to Address Changes In Cognitive Function

- Determine individualized strategies that work for the child
- Introduce new information in steps
- Allow extra time for instructions and transitions
- Provide visual cues to help process information
- Help child initiate or start a project or task
- Create a system for organizing and planning (encourage child to be involved):
 - Use calendars (agenda planning)
 - Utilize check-lists for self-monitoring
- Address working memory problems:
 - Provide clear instruction
 - Use short sentences
 - Divide information and tasks into smaller sections or chunks
 - Ask for information to be repeated
- Check in: does the child understand?
- Repeat, repeat, repeat! (affected children may need to hear information many times and in different ways before they adapt their behavior)
- Reassess needs and strategies regularly

Myotonic Dystrophy Foundation

✉ info@myotonic.org

🌐 www.myotonic.org

☎ 415.800.7777

Cognitive functions can be impacted by emotions and behaviors.

Children with CDM or childhood-onset DM1 will have normal emotional and/or behavioral reactions to disease progression. Affected children (and their families) may cycle through the stages of grief (denial, anger, bargaining, depression, and acceptance) as their disease progresses. Emotional and behavioral reactions may increase with an increase in physical and cognitive symptoms due to disease progression, and when affected individuals feel stuck because of their disease in comparison to their unaffected peers. Affected children may experience feelings of anxiety, hostility, depression and apathy, and may exhibit behaviors such as passivity or tantrums.

When addressing psychosocial concerns, it is important to respond as you would to any child having an emotional reaction to change and/or circumstances.

Naming a child's emotional response to and feelings associated with the given situations helps to normalize and validate his/her reactions. Mourning disease progression and loss of function helps move toward acceptance. Working together to openly address emotions provides learning opportunities for affected children and parents/caregivers to engage in active listening, increase awareness of emotions and associated behaviors, and to problem solve.

Planning activities that affected children can successfully complete creates a positive experience that may increase sense of control, motivation to continue, and healthy coping strategies. Open discussion of disease symptoms, disease progression and impact is crucial to reducing associated feelings of anxiety and depression, and empowers affected children to control their emotional experience of living with CDM or childhood-onset DM1.

Frequently Asked Questions About Myotonic Dystrophy

What is myotonic dystrophy?

Myotonic dystrophy (DM) is a multi-systemic inherited disease that affects 1 in every 2,550 people, or over 130,000 in the U.S. alone. Although often viewed as a muscle disease, individuals affected by DM may have skeletal muscle problems, heart function abnormalities, breathing difficulties, cataracts, issues with speech and swallowing (dysarthria and dysphagia), cognitive impairment, excessive daytime sleepiness, and diabetic symptoms. Any single individual is unlikely to have all or even most of these symptoms. Myotonic dystrophy is one of the most variable and complicated disorders known. The systems affected, the severity of symptoms, and the age of onset of those symptoms vary greatly between individuals, even in the same family.

What is the prognosis for myotonic dystrophy diagnoses?

Myotonic dystrophy is a progressive or degenerative disease. Symptoms tend to worsen gradually over several decades, though symptoms worsen at a different pace for different people. While no treatment currently exists that slows the progression of myotonic dystrophy, management of its symptoms can greatly improve patient quality of life. Early intervention can reduce or avert complications that sometimes arise. DM2 tends to be less severe than DM1 and has minimal impact on life expectancy. DM1 is much more variable and the prognosis for an affected individual is difficult to predict. Some people may experience only mild stiffness or cataracts in later life. In the most severe cases, respiratory and cardiac complications can be life-threatening even at an early age. In general, the younger an individual is when symptoms first appear, the more severe symptoms are likely to be. However, how myotonic dystrophy affects one individual can be completely different from how it manifests in another, even for members of the same family. It is impossible to predict how the disease will affect any single individual. Prognosis is as variable as the symptoms of this disease, thus it is difficult to make an accurate prognosis due to varied progression.

Why do many patients have problems with diarrhea and constipation?

Most problems are due to intestinal motility. Selection of foods is important. Appropriate amounts of fiber supplements may be useful, although overuse may produce impaction if the patient becomes constipated. Stool softener and non-irritant laxatives are useful to prevent constipation.

What does one do when swallowing becomes a problem?

Swallowing problems come from both oropharyngeal muscle weakness and abnormal motility of the esophagus. The patient should be evaluated by a speech pathologist and a gastroenterologist with fibroscopic and manometric testing. If patients are not able to do these studies, the modified barium swallow test should be done to assess the risk for aspiration. The speech therapist should be able to give useful advice to alleviate the problem. If the problem imposes high aspiration risks, G tube insertion should be considered. Chewing, drinking fluids, and pureed foods may help. If aspiration occurs, or may have occurred and fever starts, go to an emergency center for treatment.

How should DM patients exercise?

Overdoing is counter-productive, thus low intensity aerobic training may be useful, such as resistive exercises in water. For more information, read the exercise section of the physical therapy guidelines on the MDF website, <https://www.myotonic.org/toolkits-publications>

Is there a medication to help with daytime sleepiness?

Modafinil is a common choice although it is expensive, but can often be covered by insurance when documentation meets the requirements. Sleep apnea contributes to the daytime somnolence but patients often continue to have daytime sleepiness after CPAP.

Behavior and Your Child with DM

Your child may display behavior(s) that the school (and you) believe are inappropriate. In fact, the behaviors or a combination of the behavior and other symptoms of his/her diagnosis may be the reason your child has an Individualized Education Program (IEP) and is provided special education services.

If your child's behavior gets in the way of his/her learning or the learning of other children, IDEA requires the IEP team to address the behavior. The IEP team must review and revise the IEP to ensure your child receives appropriate positive behavioral interventions, supports and other strategies.

To determine what the main challenges are with your child's behavior and how to provide these supports, the IEP team must conduct a **functional behavioral assessment (FBA)**. IDEA requires that when a student with disabilities is *removed from school for more than 10 days* in a school year, an FBA must be conducted. You can also request an FBA if there are behaviors occurring that interfere with your child gaining access to the general curriculum.

The FBA is a comprehensive and individualized strategy to:

- Identify the purpose or function of a student's problem behavior(s)
- Develop and implement a plan to modify variables that maintain the problem behavior
- Teach appropriate replacement behaviors using positive interventions

It is very important for the IEP team to respond to problem behaviors immediately, and to bring additional professional help to the school to do a functional behavioral assessment so that a **behavior intervention plan (BIP)** can be developed as part of the IEP. The BIP assures positive behavior interventions, supports and other strategies that can be provided at school and at home. The school should recommend and use **positive behavior intervention and supports (PBIS)** to address your child's needs.

If you believe your child needs an FBA or if the school has taken disciplinary action against your child such as in-school or out-of-school suspension

or expulsion, you should immediately **write a letter and request that the IEP team meet** to discuss the behavior or event and conduct an FBA.

Examples of Behaviors that the Individualized Education Program (IEP) Team Must Address:

- Angry responses to teacher(s), therapists, school team (e.g. refusing to work on tasks, complete assigned work, participating as appropriate etc.)
- Irritating, disruptive, defiant actions
- Breaking school code of conduct rules
- Harming her/himself or others

Communication Between Home and School is Key

Concerns about your child's behavior should not be introduced for the first time at an IEP meeting. You and your child's teacher(s) should communicate frequently and share concerns or problems when they happen.

Children with CDM or childhood-onset DM1 may:

- Have difficulty communicating their wants and needs
- May not like letting go of an activity they enjoy
- May challenge adults when beginning an activity they don't like or have failed at in the past
- May need help preparing for transitions in the day or in learning how to get positive attention from friends or teachers
- Not stop themselves from saying or doing something that may be inappropriate or may be perceived as inappropriate
- Underestimate or lack awareness of the amount of time it takes to complete tasks.

Some children with significant learning or emotional needs can engage in challenging behavior when they are upset or angry. The behavior intervention plan can help support your child's strengths and help him/her work on the things that frustrate or upset him/her.

Restraint and Seclusion

Many teachers and school personnel do an outstanding job of educating students with behavioral challenges, including students with disabilities; however, too often school personnel who have not been thoroughly trained in research-validated methods for promoting positive behavior change and crisis de-escalation resort to inappropriate, abusive methods. Abusive methods such as restraint and seclusion not only place the student at risk of serious physical and psychological harm, but also violate his/her dignity and right to be free from abusive treatment.

Both research and best practice show that restraining or secluding children inflicts damage rather than providing a benefit and that there are safe and positive ways to help and support your child. If your child tells you s/he was sent somewhere alone to cool off, was put in a time out, placed somewhere and couldn't get out, was strapped to his/her chair or desk etc., it is very important that you immediately **convene an IEP meeting and request that the district representative attend in person.** The IEP team must not approve or allow these approaches when your child's behavior escalates. You must insist that they provide **positive behavior intervention and supports (PBIS)** and programs that are based in research and have been proven to support your child. Only 18 states require that the school notify parents when their child is restrained or secluded, so you may need legal support in this process. Although schools and districts have been notified that "restraint and seclusion should never be used for punishment or discipline," many schools and districts continue to use these harsh practices.

Restraint and Seclusion Should Never Be Used

The U.S. Department of Education emphasizes that schools and districts must "conduct the planning, implementation, and monitoring of preventative measures that create positive academic learning environments to be able to address the individual needs of students, and provide teachers and other school personnel with the skills and knowledge to identify ways to reduce challenging behaviors in students."

Suspension and Expulsion

The school **cannot suspend your child for more than 10 days in a row or for a total of more than 10 days in a school year** for violating school rules or a student code of conduct.

- If the school wants to suspend your child for more than 10 days, it must determine if his/her behavior was caused by his/her disability. This is called manifestation determination
- If the school team determines that your child's behavior was not a result (manifestation) of his/her disability, the school **may use the same discipline procedures as with non-disabled children**
- If the team finds that your child's behavior was related to the disability or an improperly implemented **IEP**, he/she is returned to the original education setting unless you agree to a new placement as part of the behavior intervention plan

However, if the school suspends or expels your child or removes him/her from the current placement, the school must continue to provide him/her with a **Free Appropriate Public Education (FAPE)**. IDEA says that a child with a disability who is suspended or expelled shall continue to receive educational services, participate in the general education curriculum, and make progress toward his/her IEP goals.

Serious Offenses

The school can move your child to an interim alternative educational setting for up to 45 school days – even if the conduct is determined to be related to his/her disability. The offenses that could lead to this are:

- **Weapons:** If a student carries or possesses a weapon on school property or at a school function
- **Drugs:** If the student knowingly possesses or uses illegal drugs or sells or solicits the sale of illegal drugs while at school or at a school function
- **Serious bodily injury:** If a student has inflicted serious bodily injury upon another person while at school, on school premises or at a school function

Every child is entitled to be treated with dignity and respect. No child with a disability should be subjected to abusive treatment under the guise of providing educational services.

The school does not need your permission or agreement to remove your child for these offenses, nor does a hearing officer need to be involved.

IDEA also allows the school to seek to remove a student for up to 45 school days if the school believes that returning the student to the same educational

placement is 'substantially likely' to result in injury to the student or other students. The school must do this by making a request to a hearing officer.

If you disagree with the school or district about the behavior intervention plan or any disciplinary action and the IEP team cannot reach agreement about how to proceed, you can use the IDEA protections to oppose the school's decision. See: **Appendix A – Your Legal Rights: Individuals with Disabilities Education Act (IDEA) Procedural Safeguards and Dispute Resolution**, page 86.

Special Considerations for Evaluations of Children with CDM or Childhood-onset DM1

Evaluations for children with CDM or childhood-onset DM1 include all screenings, assessments and cognitive skill tests to ensure a comprehensive evaluation is conducted. **If your child has physical disabilities such as unclear speech, dysmorphic facial appearance or lack of facial expression, it is particularly important that the school knows to adjust the testing for the child's physical disabilities.**

This correction is important because the presence of any one of the physical symptoms of childhood-onset DM1 can result in children with mild cognitive impairment appearing more markedly affected than is accurate. These mistaken impressions can occur during casual interactions and on formal neuropsychological testing unless the evaluator appropriately corrects for them.

Medical advisors and clinicians who understand CDM or childhood-onset DM1 recommend that testing in children should be routinely considered when early signs of cognitive or developmental issues are present.

Any IDEA evaluation should accommodate the physical impairments that may be present and differentiate between physical and mental issues that may be perceived as cognitive dysfunction.

Tests for children should include cognitive skills tests:

- Age appropriate IQ (e.g. the **Wechsler Preschool and Primary Scale of Intelligence (WPPSI)** and the **Wechsler Intelligence Scale for Children (WISC)**)
- Executive function and higher cognition skills
- Visual-spatial ordering skills
- Visual perception, construction, and memory skills
- Attention skills
- Verbal abstract reasoning skills
- Temporal-sequential ordering skills

Tests for other neuropsychological functions:

- Attention Deficit Hyperactivity Disorder (ADHD)
- Energy levels, social skills and general behavior
- Emotional facility (such as **evaluation** of anxiety, withdrawal, depression, conduct disorders)

When the Team Can't Agree: Tools for Resolving Conflict

Individualized Education Program(s) (IEP) team meetings can be demanding, draining and challenging. As a reminder, in preparation and as part of the IEP team process, you should always do the following:

- Prepare well and bring all medical reports, test results and anything else to help the team understand your child's CDM or childhood-onset DM1. Bring your binder
- Think ahead about what your child needs to be successful in school. If you don't know, be prepared to ask the questions the guide offers you along the way
- Bring someone with you to every meeting. You should never attend IEP meetings alone
- Know that the school team has met together before they meet with you. They have discussed your child's **evaluation** and IEP, have decided what they are prepared to offer you and may have pre-written parts of the IEP ready for you to read
- Depending on how well you know the team, you may know which members are more likely to be helpful and which may be more difficult. Anticipate where this may be helpful or challenging as you make the case for what your child needs
- Be positive and remember that you can ask to slow the meeting down, pause, have things repeated or stop the meeting. You don't have to sign anything. You have power as the parent, so take your time
- Staying calm is best, but if you get emotional, that is ok
- It's in everyone's best interest to try and work things out; however, sometimes it is impossible to reach agreement

Per **IDEA**: "**Parents are equal partners** with school personnel in making these decisions, and the **IEP** team must consider the parents' concerns and the information that they provide regarding their child in developing, reviewing, and revising IEPs."

Resolving Conflict

There may be times when you do not agree with your child's **evaluation(s)** and IEP. The fact that your child's symptoms may change, that the school is likely to have little or no experience with the condition, and that school resources are always stretched thin means disagreement may arise between you and your child's school team occasionally.

Transitions for your child to a new school or a new team may cause you to feel uncomfortable and you may struggle as you get to know the team and how it is providing services and support for your child. For example, your child's teacher may not be as sympathetic or experienced as you would like, or the team may not understand the medical and physical challenges that your child faces. While any of this may be true and challenges may arise, it's important to focus on ways to negotiate and work things out with the school team.

Here are several strategies to consider:

- **Eliminate misunderstandings:** If you've hit a point after meeting several times where talking at each other isn't working and your issues aren't being addressed, agree to reconvene. Take the time to describe your concerns in writing. Walk through your issues and questions – point by point
- **Keep negotiating:** Schedule more than one follow-up meeting, with the agreement that you may need all the meeting dates to reach an understanding. This takes the pressure off holding long, rushed, exhausting and emotion-filled meetings
- **Stay child-focused:** Sometimes when there's conflict, the discussion veers away from what is best for the child and adult egos take over. Keep a photo of your child in the center of the table, point to it, and talk about your child as if s/he is in the room. If you decide to have your child attend, help him/her convey what is most important, and what is working and what isn't

- **Use data and facts:** In addition to talking positively about your child, you should also bring and refer to recent school work, test results, medical reports, etc. Bring your binder. Use every bit of practical and informational data and facts to make key points about your child and his/her needs. Keep in mind that school teams respond better to facts than emotion
- **Persuade:** Your job is to help the school see your child as a unique learner whose physical and other challenges are just part of what makes him/her special and important. While **IDEA** may require the school to provide services and supports, your ability to persuade can help them see how they can provide some that are unique and effective for your child

The IEP has great flexibility. For example, the IEP team can agree to try out a plan of instruction, intervention or classroom placement for a certain period. During or at the end of that period, the team meets again and discusses how the child is doing, how well the temporary compromise addressed the original concern, and what to do next. The trial period may help parents and the school come to a comfortable agreement on how to best help the child.

If Agreement Can't Be Reached

If the team cannot reach consensus:

- IDEA requires the school to provide you with **prior written notice** about what it proposes or refuses to do
- IDEA allows you to exercise your child's legal rights. See **Your Legal Rights: Individuals with Disabilities Education Act (IDEA) Procedural Safeguards and Dispute Resolution**, page 86

Participation in State Assessments 2nd or 3rd Grade to High School

The IEP team is required each year to discuss how your child will participate in state and district-wide assessments and what **accommodations** are needed. In the IEP meeting at the end of 2nd grade, this decision may have distinct implications for your child as s/he enters 3rd grade and beyond.

Federal education law, the Every Student Succeeds Act, requires all states to test students annually in reading and math and every three years in science. The tests measure how students are doing in meeting the state academic content standards. Your state may also have tests in other subjects like civics or social studies. The state is required to assure that testing accommodations (e.g. extra time, computers, answer in test booklet, assistive technology, large print, etc.) are made available to students with disabilities and that teachers are trained to support and assist students with testing.

The state is also required to assess at least 95% of all students and 95% of all students attending public school. This testing begins in 3rd grade and continues through 10th or 11th grade (depending on your state).

For your child with CDM or childhood-onset DM1, it's important to know what your options are and what your choice could lead to. See **Appendix A – Why Testing Decisions Matter**, pg. 85.

POTENTIAL POINTS OF DISAGREEMENT AND STRATEGIES FOR RESOLVING CONFLICT

Issue	Suggested Strategy
I don't agree with the proposed IEP	Consider trying something temporary to see if it can work. Alter the instruction, services, or accommodations and monitor his/her progress. See below.
School says it is giving him/her all it can	<p>Ask for a district representative to attend the follow-up meeting(s). Discuss options such as:</p> <ul style="list-style-type: none"> • Changing the composition of the school support and services team • Tweaking services, supports, accommodations • Looking at other local schools that may better meet your child's needs
I don't agree with the proposed placement (where your child attends school or receives services)	<p>If the issue is that you want either more general education, more special education, or services time for your child, try altering the ratio of time spent in one setting or the other. Discuss and push for flexibility and a placement that benefits your child.</p> <p>If you want a different setting altogether, you must provide the data and facts to support why that setting makes sense.</p> <p>If you are pushing for the district to pay for private school, you will need to prove it cannot provide a Free, Appropriate Public Education (FAPE) in the setting it has offered.</p> <p>Remember: the school must document why an inclusive placement is not what is being proposed for your child – even if you agree to the placement.</p>
I disagree with the evaluation results	Request an Independent Educational Evaluation (IEE) in writing. See Appendix A – Independent Educational Evaluation , page 82.
I don't believe my child is receiving agreed-upon services	<p>Communicate with your case manager or school contact directly. If they cannot provide details:</p> <ul style="list-style-type: none"> • Write a short letter requesting information about the number of program or service sessions, including dates and minutes • Ask to see notes of the sessions, details of intervention sessions and any related paperwork <p>Do not rely on an aide, therapist or provider to provide the details</p>
I don't like my child's IEP goals	<p>Help the team focus on the critical elements of each goal.</p> <p>All IEP goals (academic, social, functional, organizational, behavior) must be written in a manner that is strategic, measurable, and attainable and must contain these five critical elements:</p> <ol style="list-style-type: none"> 1. The student ... (WHO) 2. Will do what ... (BEHAVIOR) 3. To what level or degree ... (CRITERION) 4. Under what conditions ... (CONDITIONS) 5. In what length of time ... (TIMEFRAME) <p>For more on goals see: Appendix A – Standards-based Individualized Education Program (IEP) Goals, page 83.</p>

Comparison Chart: Individualized Family Service Plan (IFSP) to Individualized Education Program (IEP)

For families affected by myotonic dystrophy, early intervention, support and the transition to preschool are all critical to a child's development, growth and academic success. This chart helps parents understand what the major components of a child's plan from ages 0-3 (**IFSP**) are as compared to the plan from ages 3-21 (**IEP**).

Individualized Family Service Plan (IFSP)	Individualized Education Program (IEP)
Used in early intervention for children ages birth through 2 and their families.	Used to support special education services and supports for children ages 3 through 21, depending on state laws.
Includes information about the child's present levels of development.	Includes information about the child's present levels of education performance and participation in developmentally-appropriate activities.
With the family's approval, it may include information regarding the family's resources, priorities, and concerns related to the development of the child.	Includes information about the family's concerns and ideas for enhancing the child's education.
After the team determines a list of priorities and concerns, the family helps determine which outcomes will be included on the IFSP.	The IEP team, including the parents or guardians and related service providers who work with the child, determines the child's goals.
Includes the major outcomes desired for the child and the family, as well as the methods, timelines, and a plan to measure progress.	Includes measurable annual goals, academic and functional, designed to: <ul style="list-style-type: none"> • Enable the child to be involved in and make progress in the general curriculum • Describe how progress will be measured and how often • Describe how progress will be reported to the family
Includes the natural environments (settings) where services will be provided.	Describes services provided in the least restrictive environment (LRE) and an explanation of the extent, if any, to which the child will not participate with typically developing children (sometimes call the child's 'placement').
Includes the early intervention services and supports necessary to meet the unique needs of the child and the family to achieve the identified outcomes.	Includes the special education, related services, supplemental aides and services, modifications, and supports to be provided to help the child make progress in the general curriculum.
Team membership includes: <ul style="list-style-type: none"> • A parent/parents or legal guardian of the child • Other family members as requested by the parent • An advocate or person outside the family, if parent requests that the person participate • Service coordinator • A person or persons involved in conducting evaluations and assessments 	Team membership includes: <ul style="list-style-type: none"> • A parent or parents or legal guardian of the child • Regular education teacher • Special education teacher • A representative of the school or district who can commit resources • A person who can interpret results of the evaluations • Others who have knowledge or special expertise about the child

Comparison Chart: Individualized Education Program (IEP) to Section 504

This chart compares the major parts of **IDEA** with **Section 504** of the **Rehabilitation Act of 1973**. Both are laws providing civil rights protections to students with disabilities.

Content of the Law	IEP	Section 504
Purpose	IDEA is a federal education law, the purpose of which is to ensure free and appropriate education services for children with disabilities who fall within one of the specific disability categories as defined by the law.	Is a broad civil rights law which protects the rights of individuals with disabilities in any agency, school or institution that receives federal funds to fully participate with their peers to the greatest extent possible.
Who is Protected	Covers eligible students ages 3–21 whose disability adversely affects their educational performance and ability to benefit from general education.	Prohibits discrimination against persons with disabilities in educational settings due to their disability. Section 504 defines a person with a disability as: <ul style="list-style-type: none"> • Having a physical or mental impairment which limits one or more major life activities • Having a record of such an impairment; or are regarded as having an impairment
Services	Provides individual supplemental educational services and supports in addition to what is provided to students in the general curriculum to ensure that the child has access to and benefits from the general curriculum. This is provided free of charge to the parent.	Requires schools to eliminate barriers that would prevent the student from participating fully in the programs and services offered in the general curriculum.
Requirements for Delivering Services	Requires a written IEP with specific content addressing the disability directly and specifying educational services to be delivered, mandating transition planning for students 16 and over, and a behavior intervention plan (BIP) for any child with a disability that has a behavioral issue. Appropriate education is defined as a program reasonably calculated to provide educational benefit to the student. Related services are provided as required for the student to benefit from the educational process and are aligned with specially designed instruction (e.g., counseling, speech, transportation, occupational and physical therapy, etc.).	Does not require a written IEP but does require a documented plan. Referred to as a 504 plan. Appropriate education means comparable to the one provided to general education students. Section 504 requires that reasonable accommodations be made for children with disabilities. Requires the school to provide reasonable accommodations, supports and auxiliary aides to allow the child to participate in the general curriculum.
Funding	Provides additional funding to states for eligible students.	Does not provide additional funds. Additionally, IDEA funds may not be used to serve children found eligible under section 504 only.

Continued on following pages

Comparison Chart: Individualized Education Program (IEP) to Section 504 *(continued)*

This chart compares the major parts of **IDEA** with **Section 504** of the **Rehabilitation Act of 1973**. Both are laws providing civil rights protections to students with disabilities.

Content of the Law	IEP	Section 504
Evaluation Procedures	<p>A full multi-faceted evaluation is required, using a variety of assessment tools and strategies to gather relevant functional and developmental information, including information provided by the parent that may assist the team in determining whether the child has a disability and how it affects the child’s educational program.</p> <p>Multiple assessment tools must be used to assess the child in all areas of the suspected disability.</p> <p>Written consent is necessary by parent or guardian before an initial evaluation is conducted.</p> <p>Requires re-evaluation every three years by IEP team to determine if services are still needed to address student disability unless the parent and other members of the IEP team agree it is not necessary.</p> <p>Reevaluation is not required before a change of placement.</p>	<p>The evaluation draws on information from a variety of sources in the area of concern. A group decision is made with persons knowledgeable about the student, evaluation data, and available educational placement options.</p> <p>Written consent is not necessary before completing an evaluation; however, notice must be provided to parent or guardian. Requires yearly reevaluations or periodic review.</p>
Independent Evaluation	<p>Allows parents to request an independent educational evaluation (IEE) at the school district’s expense if parent or guardian disagrees with the evaluation obtained by the school district. The independent evaluator must meet the same criteria as the district requires for his/her employees and must be approved by all parties.</p>	<p>Does not allow independent evaluations at the district’s expense or the ability to request an independent educational evaluation.</p>
Procedural Safeguards	<p>Requires written notice to parent or guardian prior to identification, evaluation and placement of child.</p> <p>Changes of services or placement must have written notice before any change can take place.</p> <p>Requires due process rights to be followed at all times and manifestation determination review for discipline procedures.</p> <p>For any child with behavioral concerns, a Functional Behavior Assessment (FBA) must be completed and a Behavior Intervention Plan (BIP) written to assist student in learning appropriate behaviors and providing supports to enable student to be successful in his/her learning community.</p>	<p>Does not require written notice.</p> <p>Requires notice before a “significant change” in placement — requires due process rights if referred for formal evaluation under IDEA, and the team determines not to evaluate.</p>

Continued on following page

Comparison Chart: Individualized Education Program (IEP) to Section 504 *(continued)*

This chart compares the major parts of **IDEA** with **Section 504** of the **Rehabilitation Act of 1973**. Both are laws providing civil rights protections to students with disabilities.

Content of the Law	IDEA	Section 504
Placement Decisions	<p>Requires district and schools to use information from a variety of sources, and consider all documented information and use a team approach to make eligibility decisions.</p> <p>Team members are identified under IDEA and must be knowledgeable about the child, evaluation data, and the continuum of placements and services available.</p> <p>Requires that student receives a free appropriate public education (FAPE) with his/her non-disabled peers in the least restrictive environment (LRE).</p> <p>IEP meeting is required before any changes in placement or services are made.</p> <p>Students are eligible for a full continuum of placement options including regular education with related services as needed.</p>	<p>Requires district and schools to use information from a variety of sources, consider all documented information, and use a team approach to make eligibility decisions, with team members who are knowledgeable about the child, evaluation data, and the continuum of placements and services available.</p> <p>The student must receive a free appropriate public education (FAPE) with his/her non-disabled peers.</p> <p>A team meeting is not required for a change of placement.</p> <p>Students are served in general education with or without modification.</p> <p>Possible accommodations under a 504 plan could be:</p> <ul style="list-style-type: none"> • Structured learning environment • Repeated or simplified instructions • Behavior management or intervention strategies • Modified testing procedures: small group; oral testing; extended time; test read to student, software, spell checkers, calculators, computers, word processor, etc. • Modified or adjusted homework, workbooks, second set of textbooks • Electronic textbooks, etc. (many accommodations and modifications used in an IEP can be included in a 504 plan)
Due Process	<p>Requires district to provide resolution meetings and due process hearings for parents or guardians who disagree with identification, evaluation, implementation of IEP or student's least restricted environment (LRE) placement.</p>	<p>Requires districts to provide a grievance procedure for parents and students who disagree with identification, evaluation, and implementation of the 504 Plan.</p> <p>A grievance procedure must be provided to parents and employees to follow and a 504 coordinator identified in the district to assist individuals as needed.</p> <p>A due process hearing is not required before Office for Civil Rights (OCR) involvement or court action unless student is also covered by IDEA. Compensatory damages possible.</p>

Independent Educational Evaluation (IEE)

You have the right to obtain an **Independent Educational Evaluation (IEE)**, when you do not agree with the results of the school's **evaluation** of your child under **IDEA**. Here are three questions to help guide whether you should ask for an IEE:

- Are you dissatisfied with your child's most recent special education assessment?
- Is the school denying your child special education eligibility or a necessary service or support based on the recommendations of a poorly-done evaluation?
- Have you asked for an IEE and been ignored by the school and district or told "no"?

If you answered **yes** to any of these questions, then you should request an IEE **in writing** from the school.

Here Are the Essentials:

After you ask for an IEE in writing, the school is required by IDEA to respond in **one of two ways**:

- 1. Agree to the IEE and take the steps to provide it – this includes obtaining your written consent.**

The results then come back to the IEP team to discuss.

See a sample **Independent Educational Evaluation Request Letter** on page 90.

- 2. File a due process complaint and request a due process hearing to demonstrate that its evaluation of your child was appropriate. The case goes before a hearing officer.**

If your child's case goes before a hearing officer, he/she will either:

- Agree with you and ask that an IEE be conducted by a qualified evaluator and the school pays

OR

- Agree with the school. Then, the school does not provide a new evaluation. **You still have the right to an IEE but not at public expense. You will need to pay for it**

You always have the right to have your child evaluated independently at your own expense.

The results of an IEE are required to be included in the IEP process (**NOTE:** when the same tests are repeated in a short period of time, the validity of the results decreases).

You may only request one IEE at public expense each time the school conducts an evaluation and a disagreement occurs.

If you are required to go to a **due process hearing**, it is recommended that you bring an advocate or an attorney. This guide offers additional information about due process hearings and dispute resolution. See **Appendix A – Your Legal Rights: Individuals with Disabilities Education Act (IDEA) Procedural Safeguards and Dispute Resolution**, page 86.

Standards-based Individualized Education Program (IEP) Goals

Since 2001, under what is now the Every Student Succeeds Act (ESSA), federal K-12 education law has required each state to apply the same challenging academic content and achievement standards for reading, math and science to all schools and all children in the state, which includes children with disabilities. States can have challenging academic standards in other subjects as they wish.

The U.S. Department of Education has clarified that these standards are grade-level standards. To assist children with disabilities in meeting these grade-level academic content standards, many states have adopted and implemented procedures for developing standards-based IEPs that include IEP goals that reflect the state's challenging academic content standards.

Children with CDM or childhood-onset DM1 need specially designed instruction to achieve at grade level. As you work with the IEP team to develop annual goals for your child, understanding the basics of a standards-based approach to IEP goal setting can help you and the team set high expectations for your child's progress and agree to the specially designed instruction, support, related services and accommodations that best fit your child's needs. Lowering expectations instead of providing intensive services is an inadequate approach to helping your child progress in school with his/her peers.

ESSA makes an exception for students with the most significant cognitive disabilities and allows states to develop alternate academic achievement standards. Some children with CDM or childhood-onset DM1 who have significant cognitive impairment may be considered for alternate standards (and alternate assessments).

The Basics of a Standards-based Individualized Education Program

Every state has academic content standards that describe what students are expected to know – generally from preschool to grade 12. **The standards are a framework for teachers to help guide what they teach, but not how to teach.** Teachers have flexibility to differentiate instruction for students with special learning needs including students with disabilities, English learners or others.

A standards-based approach to developing IEPs combines the best of special education and standards-based education. Aligning your child's special education program with the learning expectations for all students helps ensure he/she will benefit from school just as all other students.

Developing the Present Levels of Academic Achievement and Functional Performance (PLAAPP) in the IEP

Starting with the **Present Levels of Academic Achievement and Functional Performance (PLAAPP)** in the IEP, here are several important questions to consider:

- What are the content standards for your child's enrolled grade?
- Where is he/she performing in relation to the grade-level standards?
- What strengths and needs does your child have related to learning the state standards?
- How does his/her disability affect involvement and progress in the general curriculum?
- What other needs—beyond academic skill-building—in areas such as organizational, social, behavioral, and/or functional life impact his/her involvement and progress in the general curriculum?
- What strategies, accommodations, or interventions have been successful in helping your child make progress in the general curriculum?
- What strategies, accommodations, or interventions have been unsuccessful?

Writing Standards-based Goals in the Individualized Education Program (IEP)

When you begin to write the IEP goals, answer the following:

- What skills must he/she learn to become proficient on the grade-level standard(s)?
- What access skills related to the grade-level standard(s) must he/she learn?
- What growth and progress can be reasonably expected of him/her in the coming year?
- Will the expected growth and rate of progress help close the achievement gap for him/her?

All IEP goals (academic, social, functional, organizational, behavior) must be written in a manner that is strategic, measurable, and attainable and must contain these five critical elements:

1. The student ... (WHO)
2. Will do what ... (BEHAVIOR)
3. To what level or degree ... (CRITERION)
4. Under what conditions ... (CONDITIONS)
5. In what length of time ... (TIMEFRAME)

Example of a Properly Written Standards-based Goal

Jacob (WHO) will read 90-110 words of connected text (CONDITION) per minute (BEHAVIOR) with 100% accuracy (CRITERION) at the end of 36 weeks (TIMEFRAME).

Benefits of a Standards-based IEP Approach

In a well-designed standard-based IEP, the following should be true for your child:

He/she will:

- Receive specially designed instruction linked to the general education curriculum for his/her enrolled grade
- Receive appropriate accommodations designed to support his/her achievement at grade level
- Be better prepared to earn a regular high school diploma and enjoy success beyond secondary school

You will:

- Have a better understanding of what is expected of all students in your child's grade, and of where your child is functioning in relationship to what the state expects
- Be better equipped to support your child's learning at home

Teachers will have a closer working relationship with your child and will develop a greater understanding of what he/she needs to help reach grade-level achievement.

Schools will give time for general education teachers and special education teachers to collaborate and support his/her learning.

Why Testing Decisions Matter

General or alternate assessment: The IEP team must determine how your child will participate in state and district-wide assessments, either by taking the state's general assessment or alternate assessment aligned to alternate academic achievement standards. Every state offers both.

NOTE: the IEP team may not decide to exempt a student with a disability from participating in state or district assessments.

- The general assessment is the test every child takes. Students with disabilities take the general state assessment for their enrolled grade, with or without appropriate accommodations
- The alternate assessment is aligned to alternate academic achievement standards. This assessment is designed only for children with the most significant cognitive disabilities
- Not all children with CDM or childhood-onset DM1 have a significant cognitive disability, so you will need to decide which assessment is best for your child. If you choose the alternate assessment, you can decide to have your child take an alternate assessment in one subject and the general assessment in another

Decision testing and instructional setting: Testing decisions can determine whether your child is taught in an **inclusive** or regular classroom, learning

the general curriculum or in a **segregated** classroom where the instruction may be significantly modified. If you choose a **segregated** classroom, make sure you understand whether he/she has access to the general curriculum.

- In some states, once the team chooses the alternate assessment (as early as 3rd grade), the child's classroom instruction is automatically assigned to the **segregated** classroom and s/he spends very little time in the regular classroom

Test participation and high school graduation:

Because testing decisions can impact whether your child has access to the general curriculum, it can also impact his/her access to the instruction and courses s/he needs to receive a regular high school diploma.

- Federal law now requires the IEP to discuss the impact of choosing an alternate assessment on achieving a regular diploma

Opting out: If your state allows you to opt your child out of all state and district testing, and you chose to do so, you won't necessarily know how he/she is doing each year – as compared to his/her grade level peers – in core areas such as reading and math. Some parents may choose to have their child participate in testing in order to have the information needed to formulate a standards-based IEP.

Your Legal Rights: The Individuals with Disabilities Education Act (IDEA) Procedural Safeguards and Dispute Resolution

You have the right to disagree with anything related to your child's **IEP**. When you do disagree, **IDEA** guarantees certain protections to you and your child, and offers both the school and parents options for resolving any disagreements. It's important to know your rights and speak up for your child when things aren't going well at school.

While most disagreements can be ironed out by the IEP team, something may happen or you may reach a point where you know agreement cannot be reached and you must explore and exercise your child's rights.

The major and most commonly-needed procedural safeguards in IDEA are:

- You must receive a complete explanation of the procedural safeguards from the school at least once per school year, including **prior written notice**
- You have the right to review your child's confidential school record. This includes tests, evaluations, teacher or other observations, school work, professional reports etc.
- You may also add information (from physicians, health providers, therapists, **an Independent Educational Evaluation (IEE)** etc.) to your child's record
- You have the right to participate in meetings related to the identification, evaluation, placement for how a **Free Appropriate Public Education (FAPE)** is provided to your child
- You have the right to request an IEE at public expense or pay for an IEE if you don't agree with your child's evaluation
- You can give or deny **consent** before the school may provide any IDEA service or take any action toward your child
- You may disagree with recommendations or decisions made by the school and team
- You may use IDEA's legal options to solve disagreements with the school, including appealing formal decisions

Dispute Resolution Options: When the IEP Team Cannot Agree

When agreement with the IEP team cannot be reached, IDEA offers you and your child several routes to try and secure what you believe your child needs through his/her IEP. They are:

- **Mediation:** A process conducted by a qualified and neutral mediator to resolve a disagreement between you and the school or district about any matter related to your child and his/her services under IDEA. Mediation may also be used as a way to try to resolve the differences if you have filed a **due process complaint**
- **Due process complaint (also called a 'hearing request')**: You or the school or district can file a complaint to initiate an impartial **due process hearing** on any matter relating to the identification, evaluation, or educational placement of your child, or the provision of Free Appropriate Public Education (FAPE) to him/her

Why file a due process complaint?

- You disagree with the results of your child's evaluation regarding his/her eligibility for special education and related services. See **Appendix A – Independent Educational Evaluation**, page 82
- You think the IEP doesn't meet his/her special education and related service needs. You've met with the IEP team to try and come to an agreement (perhaps more than once) and it refuses to make any changes
- You believe the school is not providing the services included in your child's IEP and the IEP team isn't willing to make the needed adjustments
- You disagree with the school or district placement decision for your child and they will not offer your child the placement that you believe is best for him/her

You will need to check your state department of education website for complaint-filing instructions

- **Resolution process:** This provides you and the school district an opportunity to attempt to resolve the issues in your due process complaint before the due process hearing is conducted. The school district must convene a resolution meeting within 15 days of receiving notice of your due process complaint, and within 7 days of receiving notice of your due process complaint regarding a discipline matter. The resolution meeting isn't required if you and the school district agree in writing to waive the resolution meeting or agree to use mediation as described in IDEA. Other strict timelines apply if a hearing takes place
- **Resolution period:** IDEA requires that the resolution process begins thirty (30) days from the date the school district receives your due process complaint notice. However, this timeline changes to 15 days if the school district receives a due process complaint involving a discipline matter
- **Resolution meeting:** This meeting is convened by the school district within 15 days of receiving your notice of a due process complaint and prior to a due process hearing. For discipline matters, the school district has 7 days to convene the resolution meeting
 - **Meeting purpose:** The meeting is for you to discuss the due process complaint and the facts that form the basis of it so that the school district has the opportunity to resolve the disagreement
 - **Who attends:** The parent(s) and the member(s) of the IEP team, who have specific knowledge of the facts in the due process complaint
- **Resolution agreement:** If the family and school agree upon a plan, it is recommended that a resolution agreement be completed that details the resolution of the problem. Agreements that families and schools develop together are more likely to be followed. Written resolution agreements that are signed by both the parent and school district can be enforced in court, and in some states, by the state education agency
- **State complaint:** A written and signed complaint made to the state educational agency, such as the Dept. of Education, claiming that a district has violated a requirement of IDEA. The state is required to review the complaint and respond
- **Discrimination complaint:** In addition to protections provided by IDEA, you are also allowed under federal law to file a complaint of discrimination with the Office for Civil Rights (OCR) at the U.S. Department of Education. A complaint filed with OCR focuses on your child rights under **Section 504 of the Rehabilitation Act of 1973** or the **Americans with Disabilities Act**. The OCR complaint process is explained here: <https://www2.ed.gov/about/offices/list/ocr/complaintintro.html>



The following section provides examples of various letters, requests and programs that you may need during your child's school experience

Model Letters

Request to Evaluate Letter (sample)

Request an Independent Educational Evaluation Letter (sample)

Individualized Education Program (IEP) Review Meeting Letter (sample)

Individualized Education Program (IEP) Goals (sample)

Request to Evaluate Letter (sample)

Your name
Your street address
Your city and state
Your phone number
Your email address (if appropriate)

Date

Principal's name
School name
School address
Reference: Student's name, date of birth, name of school and enrolled grade

Dear _____ (principal's name),

I am writing to you because my child is experiencing difficulties in school.

My child is having difficulties with ____ (provide detailed information on problems, including specifics such as grades, test scores, teacher comments, observations, reports from doctors, etc.)

For these reasons, I believe that it is crucial for (CHILD'S NAME) to be evaluated under the Individuals with Disabilities Education Act. I understand that you will send me an evaluation plan explaining the tests that may be given to my child. Once you receive my approval for the evaluation, would you please let me know when the evaluation will be scheduled?

I would also appreciate any other information you have regarding the evaluation, how eligibility is determined, and the general Individualized Education Program (IEP) process.

If you need more information, please call me at home (your home phone) or at work (your work phone), or send me an email (your email address).

Thank you very much for your kind assistance. I look forward to your prompt reply.

Sincerely,

Your name

Request an Independent Educational Evaluation Letter (sample)

Your name
 Your street address
 Your city and state
 Your phone number
 Your email address (if appropriate)

Date

Name of the person to whom you are writing (your independent evaluator)
 Person's title
 Street address
 City, state, zip code

Reference: Student's name, date of birth, name of school and enrolled grade

Dear _____ (person's name),

My son (or daughter), (child's name), is in the (__) grade at (name of school), in (teacher's name) class. S/he was evaluated for special education services in (month and year). I am writing to request an Independent Educational Evaluation at public expense, for the following reasons:

(BRIEFLY list your reason(s). Be very specific.

For example:

"I disagree with the evaluation results because . . ."

"The evaluation should have included . . ."

"Evaluation should have been done in . . ."

I would like this Independent Educational Evaluation to be done as quickly as possible so that we can fully address (child's name) needs. Please respond as soon as possible and send me copies of the school's guidelines for this. My daytime telephone number is (your phone number) and my email is (your email address). Thank you.

Sincerely,

Your name

cc: your child's principal
 your child's teacher(s)

Individualized Education Program (IEP) Review Meeting Letter (sample)

Your name
 Your street address
 Your city and state
 Your phone number
 Your email address (if appropriate)

Date

Teacher's name
 School name
 School address
 Reference: Student's name, date of birth, name of school and enrolled grade

Dear _____ (teacher's name),

I am writing to request an IEP review meeting for my child. I would like to discuss making some changes in (child's name)'s IEP. I am concerned about (state your general reasons, but don't go into detail about the specific changes you want to make—save those for the meeting).

EXAMPLES:

(Child's name) has made no progress or has met the goal in speech therapy.

(Child's name) has new symptoms of CDM or childhood-onset DM1 that the doctor has verified.

I would also like to have (names of specialists or other staff) attend. I think his/her/their ideas about the changes we may need to make will be valuable.

I can arrange to meet with you and the other members of the IEP team on (days of the week, eg. Monday and Wednesday) between (give a range of time, such as between 2:00 and 4:00). Please let me know what time would be best for you.

Please call me at home (your home phone) or at work (your work phone), or send an email (your email address).

Thank you very much for your kind assistance. I look forward to your prompt reply.

Sincerely,

Your name

Individualized Education Program (IEP) Goals (sample)

Overview: Every goal in the **IEP** must relate to a need identified in the **Present Level of Academic Achievement and Functional Performance (PLAAFP)**. In many cases, the goal will require your child to make more than one year's progress in an academic school year to close his/her learning or other gap.

If the IEP does not include measurable academic and functional goals, the IEP is defective and open to a challenge that it denies the child a **Free Appropriate Public Education (FAPE)** as required by **IDEA**.

Also:

- Annual goals are written only for areas of the general curriculum that are directly affected by the student's disability
- The student's goals should be prioritized, clearly indicating the skills and knowledge most important to the student's long-term academic, organizational and functional success
- Goals are different than objectives (or short-term objectives as your school or district may call them). Short-term objectives are required for any student who participates in an alternate assessment

All IEP goals (academic, social, functional, organizational, behavior) must be written in a manner that is strategic, measurable, and attainable, and must contain these five critical elements:

1. The student ... (WHO)
2. Will do what ... (BEHAVIOR)
3. To what level or degree ... (CRITERION)
4. Under what conditions ... (CONDITIONS)
5. In what length of time ... (TIMEFRAME)

Examples of a Properly Written Annual Goal:

- Jacob (WHO) will read 90-110 words of connected text (CONDITION) per minute (BEHAVIOR) with 100% accuracy (CRITERION) at the end of 36 weeks (TIMEFRAME)
- Using real money, Jane (WHO) will be able to show how much money she has left (BEHAVIOR)

after she receives two weeks of allowance, and how much money she will have left after she buys one object (CONDITION), with 75 percent accuracy (CRITERION) measured twice weekly each quarter (TIMEFRAME)

- Alex (WHO) will write and edit a five-sentence paragraph (CONDITION) that addresses a given subject twice a month (CONDITION). Each paragraph will include a topic sentence, at least four details and a conclusion (CRITERION). He will earn a score of 75 percent or higher on a writing scale for each writing assignment (CRITERION). There will be at least four writing assignments per quarter (TIMEFRAME)
- When provided with evidence-based anger management training and adult support, Becky (WHO) will be able to remove herself from environments (BEHAVIOR) that cause her to lose control of her behavior (CONDITIONS) so that she has no disciplinary notices, (CRITERION) as measured weekly (TIMEFRAME)
- Given a structured social activity, Ryan (WHO) will use language in an age appropriate manner (BEHAVIOR) to communicate with peers and teachers (CONDITIONS) without conflict (CRITERION) and with the opportunity to have all ideas conveyed accurately as measured twice weekly (TIMEFRAME)
- Given a structured or unstructured classroom setting, Annie (WHO) will increase her meaningful communication interactions and intelligibility (BEHAVIOR) by: decreasing her rate of speech during all tasks; using appropriate phrasing (pitch, volume, rate, stress) during sentence production or conversation (CRITERION); using correct sequencing of syllables during multisyllabic word production (CRITERION); and applying targeted speech intelligibility skills in educational and social settings (CRITERION) in 3 out of 4 instances (CONDITIONS) as measured weekly (TIMEFRAME) by clinician or teacher observation, other informal assessments and data collection

APPENDIX

B

Resources/Bibliography

Adams, R C, et al. "Early Intervention, IDEA Part C Services, and the Medical Home: Collaboration for Best Practice and Best Outcomes." *Advances in Pediatrics*, U.S. National Library of Medicine, Oct. 2013, www.ncbi.nlm.nih.gov/pubmed/24082001

"CADRE (The Center for Appropriate Dispute Resolution in Special Education)." *CADRE Continuum* | *CADRE*, 1 Jan. 1970, www.cadeworks.org/

Center for Appropriate Dispute Resolution in Special Education (CADRE), editor. "IDEA Special Education Due Process Complaints/ Hearing Requests." *IDEA Special Education Due Process Complaints/ Hearing Requests*, 2014. www.cadeworks.org/sites/default/files/resources/DueProcessParentGuide_FINAL_10.24.14.pdf

Cortiella, Candace, and National Center for Learning Disabilities. *IDEA Parent Guide: A Comprehensive Guide to Your Rights and Responsibilities under the Individuals with Disabilities Education Act (IDEA 2004)*. National Center for Learning Disabilities, 2006, www.nclld.org/wp-content/uploads/2014/11/IDEA-Parent-Guide1.pdf

Cortiella, Candace, and National Center for Learning Disabilities. *Understanding the Standards-based Individualized Education Program (IEP)*. National Center for Learning Disabilities, 2006. *Advocacy Institute*, www.advocacyinstitute.org/resources/UnderstandingStandards-basedIEPs.pdf

"Council of Parent Attorneys and Advocates, Inc." *Council of Parent Attorneys and Advocates*, www.copaa.org/

Disability Rights California. "How To Obtain An Independent Educational Evaluation At Public Expense." *Home* | *Disability Rights California*, June 2009, publication #5476.01, www.disabilityrightsca.org/publications/how-to-obtain-an-independent-educational-evaluation-at-public-expense

"Due Process Hearings." *Center for Parent Information and Resources*, 20 Sept. 2017, www.parentcenterhub.org/hearings/

"End Use of Restraint, Aversives, Seclusion - Council of Parent Attorneys and Advocates, Inc." *Council of Parent Attorneys and Advocates*, Mar. 2011, www.copaa.org/page/restseclusion

Howey, Pat. *What You Need to Know About IDEA 2004: IEPs for Children with Behavior Problems* by Pat Howey, *Special Education Advocate*. Wrightslaw, 17 Feb. 2014, <https://www.wrightslaw.com/howey/iep.special.factors.htm>

Howey, Pat. *What You Need to Know about IDEA 2004: Suspending Children from School* by Pat Howey - *Ask the Advocate*. Wrightslaw, 8 May 2007, <https://www.wrightslaw.com/howey/idea.suspend.htm>

"IEP Goal Bank." *Speaking of Speech.com, Inc.*, www.speakingofspeech.com/iep-goal-bank.html

Indiana Resource Center for Autism. "School Transitions in the Elementary Grades: Practical Suggestions for Families." *Autism Advocate*, Dec. 2009, pp. 13–16, <https://www.autism-society.org/wp-content/uploads/2014/04/school-transitions-in-the-elementary-grades.pdf>

Laing, Steven O, and Mae Taylor. "Functional Behavior Assessment." *LRBI Positive Behavioral Supports and Selection of Least Restrictive Behavioral Interventions for Use with Students with Disabilities*, Utah State Board of Education, 2001, www.iseesam.com/content/teachall/text/behavior/LRBIpdfs/Functional.pdf

"Middle School Malaise." *Monitor on Psychology*, American Psychological Association, www.apa.org/helpcenter/middle-school.aspx

Myotonic Dystrophy Foundation. *MDF Toolkit*. <https://www.myotonic.org/toolkits-publications>

PACER Center, Inc. (2011) What is the difference between an IFSP and an IEP? (ACTion Sheet: PHP-c59). Minneapolis, MN: PACER Center. <https://www.pacer.org/parent/php/PHP-c59.pdf>

PACER Center, Inc. (2012) Preparing for transition from early intervention to an Individualized Education Program (ACTion Sheet: PHP-c158). Minneapolis, MN: PACER Center. www.pacer.org/parent/php/php-c158.pdf

PACER Center, Inc. *Minnesota Secondary Transition Toolkit for Families: A Guide to Preparing Your Child with a Disability for Life Beyond High School*. 2017, www.pacer.org/publications/MDE-Toolkit-2017.pdf

"Parental Rights under IDEA." *Center for Parent Information and Resources*, 5 Oct. 2017, www.parentcenterhub.org/parental-rights/

"Right to Obtain an Independent Educational Evaluation." *Center for Parent Information and Resources*, 6 Oct. 2017, www.parentcenterhub.org/iee/

U.S. Department of Education, *Guiding Principles: A Resource Guide for Improving School Climate and Discipline*, Washington, D.C., 2014, <https://www2.ed.gov/policy/gen/guid/school-discipline/guiding-principles.pdf>

U.S. Department of Education, US Department of Education (ED), www.ed.gov/

U.S. Department of Health and Human Services, HHS.gov, www.hhs.gov/

Wright, Peter W. D., and Pamela Darr. Wright. "Wrightslaw: from Emotions to Advocacy: the Special Education Survival Guide." *Wrightslaw: from Emotions to Advocacy: the Special Education Survival Guide*, Harbor House Law Press, 2017, pp. 115–130, www.fetaweb.com/03/ch12.smartieps.pdf

"Wrightslaw - Transition - Legal Requirements for Transition Components of the IEP by Barbara Bateman." *The Blame Game: Are School and Learning Problems the Kids' Fault? - Wrightslaw*, Developing the Transition Component of the IEP, www.wrightslaw.com/info/trans.legal.bateman.htm



External Resources

This appendix provides a list of online resources that offer additional guidance on issues discussed in this guide and are available for viewing and for downloading. If you do not have Internet access check the local public library or with family and friends to access these resources. Click on the links below.

For additional support, call **415.800.7777** to reach MDF.

Section 1 – Overview of IDEA

Department of Education State Contacts

<https://www2.ed.gov/about/contacts/state/index.html>

Center for Parent Information & Resources – Find Your Parent Center

<http://www.parentcenterhub.org/find-your-center/>

Section 2 – Ages 0-2: The Individualized Family Service Plan (IFSP)

Early Childhood Technical Assistance Center

<http://ectacenter.org/contact/ptccoord.asp>

Statement and Resources on Inclusive Preschool Practices

<https://www2.ed.gov/policy/speced/guid/earlylearning/joint-statement-full-text.pdf>

Section 3 – Ages 3-4: Transition to Preschool

No external resources

Section 4 – Ages 3-12: Developing the Individualized Education Program (IEP)

Individualized Education Program (IEP) Meeting Review Resources

<https://www.parentcenterhub.org/iep-2/>

Roadmap to IDEA 2004: What You Need to Know About IEPs & IEP Meetings

<http://www.wrightslaw.com/idea/art/iep.roadmap.htm>

Section 5 – Ages 4-5: Transition from Preschool to Kindergarten

School Transitions in the Elementary Grades

<https://www.autism-society.org/wp-content/uploads/2014/04/school-transitions-in-the-elementary-grades.pdf>

Section 6 – Ages 6-10: Transition from Kindergarten and to the Early Grades

No external resources

Section 7 – Ages 11-14: Transition from Elementary to Middle School

No external resources

Section 8 – Ages 15-22: Transition from Middle to High School

Sample Transition Individualized Education Program (IEP) with Transition Goals

<http://www.wrightslaw.com/info/trans.legal.bateman.htm>

Transition Guide to Postsecondary Education and Employment for Students and Youth with Disabilities

<https://www.wrightslaw.com/law/osers/transition.postsecondary.guide.2017.pdf>

Career Pathways

<https://s3.amazonaws.com/PCRN/docs/15-0675.CareerPathwaysJointLetterFinal-4-22-2016.pdf>

Section 9 – Ages 18-22: Transition from High School to Postsecondary Education or Vocational Rehabilitation

Transition Guide to Postsecondary Education and Employment for Students and Youth with Disabilities

<https://www2.ed.gov/about/offices/list/osers/transition/products/postsecondary-transition-guide-2017.pdf>

Vocational Rehabilitation Agency

<http://soar.askjan.org/IssueConcern/214>

Service Agencies

<https://acl.gov/programs>

State Independent Living Centers

<https://www.ilru.org/>

Local Independent Living Centers

<https://www.ncil.org/>

Social Security Administration – MDF Guide

<https://www.myotonic.org/toolkits-publications>

The mission of Myotonic Dystrophy Foundation is to enhance the quality of life of people living with myotonic dystrophy and accelerate research focused on treatments and a cure.



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