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2ND DECADE



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## 2017 MDF Annual Conference

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Care and a Cure

# HELP FOR DM PARENTS: EDUCATIONAL TOOLS AND RESOURCES AGES 1-21

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# **Getting Early Help and Going to School with Myotonic Dystrophy**

**A Parent's Guide to Understanding Special Education and the Individuals with Disabilities Education Act (IDEA)**

# MDF Vision and Team

## The Guide helps parents with:

- ▣ The basics of IDEA
- ▣ Your child's rights
- ▣ How to manage situations that may arise at school
- ▣ Tips from parents
- ▣ How to work with the school team especially during transitions:
  - from home to preschool,
  - from preschool to elementary school,
  - from elementary to middle school,
  - from middle to high school; and
  - from high school to postsecondary ed or vocational rehabilitation

## The Team

- ▣ MDF Staff
- ▣ Parents/Families:
  - Erica
  - Loraine
  - Ted
  - Penny
  - Sarah
  - Taylor
  - Suzanne
- ▣ Resources:
  - IDEA law, regulations, online tools
  - *MDF Care and Cure Toolkit*

# Guide Content: For all Families

- Basics of the IDEA – what it provides for infants to adulthood
- Highlights key transition points for toddlers to young adults
- Step-by-step in developing an IFSP or IEP
- Tips from parents along the way
- Tools and Resources



# Designed for All: IDEA & Children With Myotonic Dystrophy

The Guide prepares every family whose child qualifies for an IFSP and/or IEP

## Congenital Myotonic Dystrophy (CDM)

- Starts at birth with the home-based IFSP
- Helps parents understand their role, the young child's rights and the state's obligations
- Prepares parents for transition to preschool (and an IEP)
- Tips, tools, resources

## Childhood Onset: DM

- Starts with school-based evaluation for an IEP
- Helps parents understand their role, the child's rights and school obligation(s) incl. limits
- Prepares parents for transitions, for challenges, plans for success
- Tips, tools, resources



# Offers: Tips, Tools, Resources

- Glossary
- Behavior challenges and school
- Compare: IFSP to IEP
- Compare: IEP to Section 504
- Evaluation and Eligibility for IDEA Services
- Independent Educational Evaluation
- Special Considerations for Evaluations
- Standards-Based IEP Goals
- When the Team Can't Agree: Tools for Solving Conflict
- Why Testing Decisions Matter
- Your Legal Rights
- Model letters and forms

**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.

## Parent Insight—The squeaky wheel.

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.

# Helps with: Common Misunderstandings About IDEA & Special Education

- My child's DM means they can't attend a regular school or stay in the regular classroom.

OR

- Special education is a place.

- I have to sign what the first IEP I review.

- The school must provide everything I think my child needs.



- The school decides what my child receives.

- Children with disabilities can't be disciplined the same as other students.

- I need an attorney when I disagree with the school.

# IEP: Walks Parents Through Every Step





# Advice From Parents to Parents

## 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
- ❑ Be a good listener. Ask questions.
- ❑ Share what you know about your child.
- ❑ Be up front if you don't agree with the team. Only compromise in ways that will work for your child and family.
- ❑ Know your rights. You don't have to sign anything until you feel comfortable.
- ❑ Keep good records of all meetings and conversations.
- ❑ Put every request to meet in writing and keep copies of everything.
- ❑ Bring others with you to the meeting(s).

# Explains Why: Understanding Your Child's DM & Services Under IDEA

- Your child's physical condition and symptoms can help inform the services they receive.
- Your medical team can help you educate and advise the school team.
- As your child's medical condition changes, the services and support they receive should shift too.

The Guide provides resources to help support these discussions and decisions.

# Examples of How Symptoms Can Support Decisions About IDEA Services

Symptom	Example of Service/Support
<p>Muscle Weakness</p> <ul style="list-style-type: none"><li>• Nursing, swallowing</li><li>• Pain</li><li>• Crawling, walking</li><li>• Footdrop</li></ul>	<p>Occupational, Physical, Speech Therapy, Therapeutic Recreation</p>
<p>Respiratory System Distress</p> <ul style="list-style-type: none"><li>• Sleep apnea</li><li>• Breathing difficulty, aspiration</li></ul>	<p>Occupational and Physical Therapy, Health, Medical/Nursing Services</p>
<p>Central Nervous System/Cognitive Deficits or Impairments:</p> <ul style="list-style-type: none"><li>• Developmental delays</li><li>• Speech, motor skill issues</li><li>• Apathy/inertia</li><li>• Sleepiness</li><li>• Challenging behavior</li></ul>	<p>Speech/Other Therapy, Cued Language, Assistive Technology, Early Learning/Early Intervention Program, Behavioral Support</p>

# Emphasis on Transitions

- Special Considerations at Every Age/Stage
- Preparing Your Child and Family for a New School
- Working with Your Child's Team

**All transition points from toddlers to teenagers are included!**

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