

Navigating School: A Worthwhile Journey

IEPs, 504 Plans,
Accommodation Considerations, & Tips from Those
who've blazed the trail



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General Principles

- No right or wrong way
- Partnership with school team
- How do we engage our child's school team?
- Start with in-service & educating about what Duchenne IS and IS NOT
- Involve child/ student in 504 Plan development/ IEP meeting when developmentally appropriate – 5 grade?
- Always include child/ student in presentations to peers
- You are not alone...
 - Clinic team resources
 - State advocacy programs – Parent Training Info centers
 - Other parents who've gone before you
 - Men with Duchenne who've graduated

504 Plan vs. IEP – What's the Difference?

504 Plan

- Refers to Section 504 of the Rehabilitation Act of 1973
- Is a **Civil Rights Law**, intended to end discrimination against people with disabilities (not just students or children)
- Two requirements for 504 Plan qualification:
 - Student must have a disability (broad definition of disability applies)
 - Student's disability must interfere with his ability to learn in a general education classroom

Individualized Educational Plan (IEP)

- The Individuals with Disabilities Education Act (IDEA) – 2004 update
- Federal 'special education' law for students with disabilities
- Two requirements for IEP qualification:
 - Student must have at least 1 of 13 specific qualifying disabilities listed in the IDEA.

(Students with Duchenne usually qualify as 'OHI' – Other Health Impaired, sometimes Ortho Disability or Develop Delay)

- Disability must affect the student's educational performance and/or ability to benefit from general ed curriculum

(Inability to 'access' school environment is justification)

Mandates a transition plan for students 16 and over, and a Behavior Plan if applicable

504 Plan vs. IEP – What's the Difference?

504 Plan

- Is a plan for access to learning at school
- Goal is to remove physical barriers to access
- No standard plan format
- Typically created by a team that includes:
 - Parent
 - General & special ed teachers
 - School principal

Individualized Educational Plan (IEP)

- ◆ Is a plan for special education services within the school
- ◆ IEP is a legal document
- ◆ Guarantees fair & appropriate education in the least restrictive environment [mainstreaming to to greatest extent possible]
- ◆ Strict legal requirements about who participates in IEP development:
 - ◆ Parents
 - ◆ At least one general ed teacher
 - ◆ A district representative
 - ◆ School psychologist
 - ◆ Others invited by team
 - ◆ Entire team must be present for IEP meetings

504 Plan vs. IEP – What's the Difference?

504 Plan

Generally Includes:

- Specific accommodations, supports & services for student
- Names of who will provide each student
- Name of person responsible for implementing plan

Individualized Educational Plan (IEP)

Generally Includes:

- Annual educational goals (must be measured)
- Services student will receive & duration/start of services
- A 'present-level' statement
- Accommodations to school/learning environment
- Modifications to academic program
- Plan for standardized testing
- Plan for inclusion in general ed program

504 Plan vs. IEP – What’s the Difference?

504 Plan

- Parents should be notified of any “significant changes” to 504 Plan.
- Notification does not have to be in writing, but most school systems do.
- Generally reviewed annually – and reevaluation is done every 3 years.

Individualized Education Plan (IEP)

- Requests for changes to IEP must be made in writing prior to change. Parents have right to “stay put” while a dispute is resolved.
- IEP team is legally required to review the IEP annually.
- Student must be re-evaluated for service eligibility every 3 years.

504 Plan vs. IEP – What's the Difference?

504 Plan

- Services provided at no charge.
- Allows for Assistive Tech use.
- State does not receive additional funding for Section 504
- IDEA funds cannot be used to serve students with 504 Plans
- For compliance issues, contact: Office of Civil Rights (OCR), Denver CO

Individualized Education Plan (IEP)

- Students receive these services at no charge
- Funds Assistive Technology, when needed.
- Services are supported by state's federal IDEA funds (40%)
- For compliance issues, contact: State Department of Education

Steps to the IEP

- Engage with you child's school team (in-service, meeting, etc)
- Request is made that child be evaluated (by you, by teacher, by PT)
- Child is evaluated by multi-disciplinary team
- You can ask for a copy of the evaluations prior to the meeting
- Eligibility is decided based on evaluations
- Child deemed 'eligible'
- IEP meeting scheduled
- You are a member of the team; you can invite others to join you
- Request a draft prior to the meeting
- IEP meeting held and IEP written
- Come prepared with questions, concerns, ideas, and proposed goals
- 'present level' statement – describes your child, drives the goals
- Your signature on the IEP or 504 only means that you attended the meeting. You did not sign a contract.
- Services provided
- Progress measured operationally, through measurable goals (agreed upon by the team)
- IEP reviewed (at least annually)

Recommended School Accommodation Considerations

Physical Therapy

Stretching

Range of Motion exercises

Muscle cramp massage

Safety training (on stairs & playground)

Hallway safety

Accommodating activities of daily living (ADL's) to changing physical needs (toileting, lunch time/cafeteria safety, etc)

Adapted/modified Physical Education

Physical Education (Adapted)

Being physically active is absolutely critical in DMD. It is also important that students remain included in the general education classroom for PE. The modification of most activities can be done through consultation with the Physical Therapist, with the goal of this student's PE curriculum being recreation, rather than increased strength & endurance.

Weight lifting, push ups, pull up, abdominal crunches, and other muscle-building exercises WILL NOT improve strength and may actually be detrimental.

Recommended School Accommodation Considerations

- **Occupational Therapy**
- Most students with Duchenne will eventually benefit from:
 - * an **Assistive Technology Evaluation**
 - * **Occupational Therapy consultation** for body positioning, seating, and gross and fine motor function
 - * assistive devices such as manual or power wheelchairs
- May also require:
 - * modified written assignments
 - * computer technology that maximizes fine motor strength or utilizes voice command/dictation typing systems

Recommended School Accommodation Considerations

School Accommodations

An additional set of text books

If the school has multiple levels, the student should have access to an elevator.

student's physical needs should be taken into consideration when designing his class schedule (classrooms should be close together to minimize distance walked throughout the day, etc).

Preferential seating in the classroom

An Emergency Evacuation Plan with student's physical needs considered:

- * School personnel should be assigned to accompany him during emergency
- * 'Safe Room' should be established with the local fire department

Field trips and school events should consider:

How far will students have to walk from the bus to the front door?

Is the field trip destination accessible for wheelchairs?

Is there a wheelchair lift on the bus?

Have chaperones been informed of this student's needs? Etc.

General Principles

- No such thing as ‘one size fits all’, depends on the student & the school system
- Partnership with school team – and YOU play a key role
- Even more, the student with Duchenne plays the central role
- Involve child/ student when developmentally appropriate – 5 grade?
- IEP Goals to consider adding:
 - Self-advocacy goal
 - Socialization
 - Community mobility (for high schoolers)

Legal Rights by Precedent

- Private school tuition must be covered by the public school district if the public school district fails to provide an appropriate education (Forest Grove)
- The school system does not have to reimburse private school tuition if the child is placed in private school before eligibility is determined (Schaeffer v Weast)
- The school system has to provide a RN if the child needs one to attend school (e.g. student uses a vent) (Cedar Rapids)
- Parents who prevail in disputes over services are not entitled to recoup expert witness fees (Arlington v Murphy)
- Parents can represent themselves in school hearings (Winkleman v Parma City)

Say What? – Speaking the same Language

- **IEP – Individualized Educational Plan**
- **FBA – Functional Behavioral Assessment**
- **AT - Assistive Technology**
- **FAPE – Free & Appropriate Education**
- **PTI – Parent Training & Information center**
- **OCR – Office of Civil Rights in Denver (IDEA)**

Thank you!