

The Individualized Education Program (IEP): A Blueprint for Ensuring School Success

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An Individualized Education Program (IEP) is a document that outlines the services and accommodations a child with physical, cognitive or other special needs requires to succeed in school. Even if your son with Duchenne Muscular Dystrophy (DMD) has not yet begun to manifest symptoms – or if symptoms are still slight - I would still recommend beginning the conversation with your school about an IEP. There may be services he can take advantage of now that will help lay a solid foundation for the coming years. Your son may be the first child with DMD that his school has enrolled, so it's important to start the process of educating the staff about his disease as early as possible.

The IEP is a collaborative effort between you, his various teachers, a social worker or psychologist, a physical therapist, an occupational therapist and anyone else who comes into contact with your child in school. Remember: even if you are not an educational expert, you are an expert when it comes to your child: no one knows him better.

School staff will write the IEP after assessing your son in various areas. You should have the opportunity to suggest changes to the plan. The IEP should be revisited at least once a year, to make sure it is still addressing his needs.

An IEP for a child with Duchenne Muscular Dystrophy should outline:

- Educational goals
- Information about the disease and its progression
- How the disease affects progress in different curriculum areas
- Accommodations needed for academic subjects
- Accommodations needed for physical and gross motor activities
- Other educational needs, including assistive equipment, software, assessments, etc.

Typical accommodations and services contained in an IEP for a boy with DMD might include modified lesson plans to minimize writing, an emphasis on hands-on learning, extra help for certain types of assignments, adaptive physical education, physical therapy and occupational therapy.

Below is an example of an IEP for a Massachusetts boy, to be used as a guide as you begin to think about these documents.

IEP Recommendations
John Smith
Ridgemont Elementary School
Boston, Massachusetts

Assessment in all areas related to John Smith is requested: Speech and Language, Achievement and Learning, Occupational Therapy, Physical Therapy, Educational, Observation of the Child, Health Assessment, Psychological Assessment and a Home Assessment.

Long Term Goal

Continued academic progress, a level of independence that is comfortable for John and providers, provision of physical activities, maintaining safety (at recess, in the classroom, around the school).

The Vision

John will develop strategies to maintain independence and have as much control over his environment as possible. The team would like to see John make appropriate grade level progress while maintaining safety.

History

John has a medical diagnosis of Duchenne Muscular Dystrophy (DMD). DMD is the most common lethal genetic disorder diagnosed during childhood. It progressively causes loss of muscle function and independence, similar to other types of Muscular Dystrophy. However, Duchenne Muscular Dystrophy manifests in boys because the DMD gene is found on the X chromosome. It affects all races and cultures. Although many cases are genetically inherited, approximately 35% are the result of a spontaneous genetic mutation. DMD affects approximately 1 in 3,500 boys and, each year, approximately 20,000 children are born with DMD worldwide. To date, it has no cure.

Progression of Duchenne Muscular Dystrophy

Typically, DMD is diagnosed in boys between the ages of 3 and 7. Throughout the school year, John's muscles have weakened progressively, affecting many of his physical capabilities.

Many times, the very first signs of DMD involve speech and language delays and other cognitive weaknesses. Physically, John is slower than his peers. He has lost his ability to ambulate and needs a wheelchair. His muscles are very weak and he tires easily. Activities involving the arms, legs, or trunk of the body require assistance or mechanical support. John may still have the ability to use his fingers, although will tire quickly when writing or key boarding for an extended period of time.

As John enters his teen years, life-threatening heart and respiratory conditions will become more prevalent. Major symptoms of heart and lung complications will require the supervision of the school nurse, to include: shortness of breath, fluid in the lungs and swelling in the feet and lower legs.

Currently, Prednisone is being used to try and slow the progression of DMD in John. Prednisone is widely used to treat DMD, however it produces severe physical and physiological side effects, which may affect John's appearance, behavior and academic performance. Physical changes include weight gain and facial changes. Physiological

side effects include difficulty concentrating, sleeping and controlling emotions. There also may be impairment in thinking, reading and coping skills that can lead to depression and/or aggression.

How does this disability affect progress in the curriculum area(s)?

- John may show some cognitive and learning delays.
- John may show some traits similar to those with obsessive-compulsive disorder, sometimes rigid and inflexible in his thinking.
- John's decreased trunk strength and postural endurance affects his sitting posture in the classroom, which may result in reduced attention and increased fatigue during activities.
- John may have difficulty controlling his response and become easily angered, irritable or aggressive.
- John's progressive declining respiratory and cardiac symptoms lead to headaches, mental lapses and sleepiness during the day.
- John's may be unable to participate fully in Physical Education class due to progressive muscle weakness.

What accommodation, if any, is necessary for the student to make effective progress?

The academic team caring for John will be aware that difficulties with language and processing information are not due to laziness, stubbornness or some other character flaw, but are related to cognitive weaknesses.

- Speak clearly and concisely and repeat the information to ensure he grasped it.
- John should not be pushed to his maximum fatigue level or overexerted during any gross motor and fine motor output activities.
- John requires a classroom setting where additional staffing is provided to support his learning and physical needs.
- Encourage John to vocalize what he's writing as he writes.
- Provide praise/positive reinforcement, particularly in his areas of difficulty.
- Modify length and complexity of written assignments.
- Model that there are many different ways of completing tasks and getting the "right" answer.
- Teach keyboarding skills.
- Provide a warning to John that he will be called upon to provide a verbal response. This warning will provide him with additional time to formulate oral expression and decrease initial sound repetition (dysfluencies).
- John will work with a school counselor on frustration management.
- John will have access to assistive technology (calculator, tape recorder).
- John will be given the opportunity to leave earlier and arrive later than his class when transitioning to different classrooms, with adult supervision when needed.

- John will be given the opportunity to leave school early with parents depending on his fatigue level.
- John will have access to: notes for test taking, scribe, number line, multiplication chart, math reference sheet and oral test.
- John will be given a full assistive technology assessment. The recommendations will be given to parents and to the team. Implementation of the accepted recommendations will include training of the teacher's aide and will begin with renewed IEP.
- John will have the option to use project-based learning activities versus the written assignment whenever possible.
- The classroom teacher will promote active, hands-on assignments.
- Writing output will be limited whenever possible.
- Allow frequent breaks and allow John to work in various positions.
- To promote independence and conserve energy, teach John to use tools (staying close to the door, written work)
- John will be provided with multiple choice type questions to help with impairment of inferential thinking and comprehension skills.
- Opportunities for creative expression will be accepted in lieu of specific assignments
- Help with math and reading will be provided.
- Homework will be condensed, extra time for assignments; verbal reports may be given instead of written.
- Long complex assignments will be broken down into smaller segments.
- Allow John to explore music and art options as part of his curriculum and allow these activities to have credit toward his grade.

Physical and Gross Motor Accommodations

- John will be able to use other areas of the recess grounds for outdoor activities, with 1-2 peers, weather permitting. (regardless of the class schedule, John will have an area located outside for recess, where he can do the activity of his choice).
- Allow John the opportunity to stretch either prior to PE class or after PE class, with his teacher, aide and/or a peer. This should be worked out with John and the classroom teacher.
- John will use modified PE equipment.
- John will participate in adaptive physical education provided by the school. (skills will be appropriate for his physical ability).
- John will work with PE teacher to participate in other activities during the normal PE time, such as taking notes, using the timer or making presentations.
- John requires a wheelchair for transportation. A peer or adult will be provided at all times to push John until a motorized wheelchair is obtained.
- John will be given verbal cues to maintain posture.
- A stable chair: an assistive chair that enables John to sit at his desk will be provided. A chair will decrease fatigue while sitting, provide

independence out of the wheelchair, will increase lung capacity and decrease overall muscle weakness due to poor positioning.

- Physical therapy will teach John and his aide to transfer him correctly from wheelchair to assistive chair.
- John will transfer himself from wheelchair to a new sitting chair at his desk in the classroom, and back again.
- Physical therapy will include stretching and maintaining tone.
- Physical therapy provided 60 minutes per week.
- John will participate in one 30 minute adaptive PE/week.
- PT and OT goals to be modified and goals to be amended.
- John will participate in two 30-minute OT sessions/week.
- John will participate in two 30-minute speech/language development sessions/week.
- John should be kept out of school during cold and influenza epidemics.
- School nurse will monitor John health during school year and report to appropriate physician changes noted.
- School nurse will implement emergency care if needed.

Other Educational Needs

- John will be given organizational tools, such as graphic organizers, the use of tape records, calculators, use of classroom computers whenever possible.
- John will be given the opportunity to work with a school counselor whenever needed.
- John will receive an assistive technology assessment.
- John will be introduced to Kurzweil 3000 software for reading and writing assignments.
- John will utilize Dragon Naturally Speaking 9 software. This program allows John to speak directly into a microphone attached to a headset and have his work typed for him.
- John will utilize Inspiration software to assist him in the visual organization of his writing.
- John will have a keyboard slant to use.
- John will be provided with multiple choice type questions to help with impairment of inferential thinking and comprehension skills.
- John will be provided with a chair that offers support of his entire body while using the computer. His feet must touch the ground and support given to enable him to utilize the keyboard fully when needed.

Kurzweil 3000 software will allow John to write, edit and read assignments with decreased fatigue. The Dragon Naturally Speaking 9 software will reduce the amount of written work for John, thus, decreasing his hand fatigue. Inspiration will help John organize, create and modify his written assignments. It will also allow John to type his ideas one time and transfer them from a graph or web into an outline and into a word document without having to retype any information. Inspiration will reduce the amount

of written work for John, thus decreasing overall fatigue. A keyboard slant will improve wrist positioning and the keyboard will be closer to his visual field.

An IEP Amendment proposal will be done in September 2008, at which time the above recommendations can be evaluated and amended if needed.

Evaluation of additional supportive equipment to be provided to John is currently ongoing.