

**The Education of Children with Neuromuscular Disease:
A Guide for Teachers and Parents
Revised 2007**

Jonathan Sandoval, Ph.D. and Kristine Strong, Ph.D.

School of Education
One Shields Avenue
University of California, Davis
Davis, CA 95616-8579

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Chapter 1

This guide is intended to serve as a practical resource for educators who have a child with a neuromuscular disease in their school for the first time and for parents of children with neuromuscular disabilities as they participate in the educational process. It was developed to address concerns and questions raised by parents and educators as they work through the process and planning for a child's education.

We assume that most regular/mainstream classroom teachers through coursework in their teacher preparation programs have had only a cursory introduction to children with disabilities and their special education needs and will wish to know more about teaching children with disabilities. Although educators who specialize in special education have had more extensive training concerning children with a wide range of disabilities, children with muscular dystrophy or other neuromuscular diseases (NMDs) represent a very small number of those receiving special educational services. Therefore, even educators in special education programs may not be sure how to work with this group of children. With the mandate to include mainstream educators in the Individual Education Planning (IEP) team process, it is critical to provide information concerning children with disabilities to all educators.

The development of this guide, based on more than five years of research at the University of California at Davis, was made possible by a grant from the National Institute of Disabilities Rehabilitation and Research. During the information gathering and data collection process, a variety of methods was used to learn about the social, emotional, and educational experiences of children with NMD. Twenty children with NMD were observed in their classrooms and at school and eighteen teachers were interviewed about the social needs of the children with NMD in their respective classrooms. Also, over the course of four to six months, fifteen teachers participated in at least three educational consultations concerning the mainstreaming of a child with NMD into their classrooms. Adults with NMD and parents of children with NMD also participated in surveys, in-depth interviews, and focus groups.¹ In addition, the authors also observed numerous other activities related to parenting and educating children with NMD, including observing parent support groups, as well as observing and participating during a summer camp for children with NMD. We have attempted to obtain a broad range of information about children with NMD, their parents, and their teachers in order to gain an understanding of both the needs and potential solutions to address these needs.

Before proceeding, it is important to remember that, first and foremost, children are individuals and must be treated as individuals. Although we will discuss several neuromuscular diseases and their influence on teaching and learning, the focus will be on addressing common needs. Each child may not fit one or more of the generalizations we will make. We do not intend to imply that all children with a given neuromuscular disease will be alike. Like all children, children with NMD vary in

¹ Over 100 parents participated in surveys about their child's social development. A smaller group of five parents participated in a more in-depth interview process (on at least three occasions) regarding their child's development and educational experiences. In addition, four focus groups were conducted which included two groups of educators, one group of parents, and one group of adults with a neuromuscular disease.

scholastic ability, personality, temperament, interests, physical strength, and emotional maturity. They will come from different family circumstances and different cultural groups. Therefore, this guide is just that- a guide. It will provide examples, suggestions, and useful information to be considered while planning and providing an education for a child with NMD.

Because providing equal access to educational opportunities to all children is legally required, Chapter 2 will provide a review of the laws and regulations pertaining to individuals with disabilities, particularly children with mobility impairments. Within this chapter, we will provide a brief history of the laws and regulations pertaining to the education of children with disabilities and how the laws have changed. Specifically, Section 504 of the Rehabilitation Act of 1973 and the newly reauthorized Individuals with Disabilities Education Improvement Act (IDEA) are discussed to give readers a basic understanding of major provisions that are in place to facilitate the education of children with disabilities. A very brief discussion of the Americans with Disabilities Act is also provided to give parents and teachers a basic understanding of what public accommodations are covered under the current laws outside the educational setting for children and other people with disabilities.

In Chapter 3, we will discuss the significance of developing a family-school partnership and how to build productive, collaborative relationships between school personnel and families. For example, we will outline an approach to the parent-teacher conference and how to promote effective communication within this setting. As with any child, familial involvement in the educational process tends to improve the child's progress. By encouraging all concerned parties to participate in the educational experience of the child, the child is better served.

Children have a wide range of educational needs. In Chapter 4, we will outline some academic accommodations for children with NMD and discuss potential ways of creating a more inclusive school environment. We will highlight instructional approaches in this chapter and provide an example of both an Individual Educational Plan (IEP) and a 504 Accommodation plan.

Chapter 5 will cover the social and emotional development of children that occurs within the educational and familial setting. In school, children need to make friendships and gain academic and social competence. Like all children, children with NMD have to learn social skills, deal with various forms of stress, and become comfortable with their self-image in order to gain/retain self-esteem. We will discuss how the educational process can promote the learning of skills children need to succeed socially, as well as academically, and promote a positive self-image for all children.

In Chapter 6, we have provided some basic information about a number of neuromuscular diseases. It is not necessary to know this medical information to provide a child with NMD an equal opportunity to have an equal education. This information is simply provided for individuals who wish to have some basic information about particular neuromuscular diseases. Subtitles are used to separate each NMD description so that a reader who is concerned with a single diagnosis can easily find the pertinent information. This chapter provides a brief overview of as many of the conditions as possible, but it does not cover all neuromuscular disabilities nor does it provide an in-depth discussion of any particular NMD.

While the focus of this guide is on children with NMD and how to improve their educational experience, many of the suggestions in this guide serve multiple educational purposes and will improve the educational experience of all children. If the goal of education is to provide our children with the social, emotional, and academic skills they need to have a quality life, both in the present and in the future, then our goal, as adults, should be to promote opportunities for all children to acquire these skills. The suggestions within this booklet aim to help you accomplish this goal.

Chapter 2 Education Legislation

Prior to the 1970s, children with disabilities, both mental and physical, were educated to the extent authorized by applicable state law. The laws regarding the education of children with disabilities varied widely from state to state. In many locales, children with disabilities were either not educated at all or were educated in institutional settings such as state hospitals or state residential schools. Very few children with disabilities were mainstreamed – educated in classrooms with their non-disabled peers.

This situation began to change in 1972, with the passage of the landmark Congressional act Public Law 94-541: Education for All Handicapped Children Act. The law was recently re-authorized as Individuals with Disabilities Education Act (IDEA, 2004). This legislation is one outcome of the Civil Rights movement of the 1960s. IDEA expresses a preference for mainstreaming children with disabilities as much as possible and avoiding segregation into special education classrooms so that children with disabilities are provided educational opportunities commensurate with the child's abilities.

In addition to the IDEA, Section 504 of the Rehabilitation Act of 1973 protects a broader range of individuals with disabilities in and outside the educational setting. A broader civil rights statute, Section 504 prohibits discrimination against people with disabilities by any federal agency or any other institution or activity that receives federal funding such as school districts. Because Section 504 of the Rehabilitation Act of 1973 was intended as civil rights legislation, “disabled” is more broadly defined than within IDEA.

In this chapter, current trends in the education of children with disabilities will be highlighted and the major provisions of both the IDEA and Section 504 of the Rehabilitation Act of 1973 will be discussed. To illustrate educational plans for a child with NMD, examples of both an IEP and a 504 Accommodation Plan are provided in Appendices A and B at the end of Chapter 4. There will also be a brief discussion of the Americans with Disabilities Act (ADA) and how it protects the rights of disabled people in the public sector.

Trends in the Education of Children with Disabilities

Starting in the 1970s, people within the Disability Rights movement began a concerted effort towards providing equal opportunities for people with disabilities. With the insurgence of this movement came many changes in attitudes, access, and language. Two of the many changes in society have been shifts in educational trends and in the use of language.

With the movement toward equal opportunity and equal access came a demand for a change in terminology, how society talks/thinks about impairment and people with disabilities. During and prior to the 1970s, terms like “handicapped,” “special,” “unfortunate,” and “deviant” were not uncommon terms used to discuss disability and disabled people. This terminology was frequently used to discuss disabled people as a problem in much the same way these terms had been used in the past to discuss race and people of color as a problem. Because the clamor for civil rights is about

recognizing that gross disparities in areas such education and employment are socially constructed rather than based upon “natural” ineptness or inability, changing the language is seen as a first step towards learning new attitudes and changing behaviors.

Today, most parents and some disability rights activists within the United States promote people first language. In other words, they suggest that “person with a disability” is the appropriate terminology because it focuses upon the individual and not the disability. However, there are also disability rights activists who encourage, within the community, the use of terms like “disabled people” to recognize that, while disability is not the individual’s primary focus, it is society’s focus when relating to people with disabilities and, therefore, it is an integral part of the individual experience of being a member of a minority group. The former terminology individualizes the situation while the latter recognizes group experience. Most within the community use these terms interchangeably.

As stated previously, during this struggle for access and opportunity, there has also been a shift in the education of children with disabilities. Prior to the 1970s, children with disabilities were in segregated classrooms, if they were taught at all. Many within the disability rights movement have argued that, in order to have equal opportunities in life, one must have an equal opportunity at an equal education.

This movement has led to a shift in the education of children with disabilities. Over the past two decades, more children with disabilities have been placed in mainstream classrooms. As a result of this shift, educators have developed new ways of providing services in the mainstream classroom that will support children with disabilities. Because of these new trends, children with disabilities now have a greater opportunity to be better educated, to participate in after school activities, to go on to higher education, and to become gainfully employed.

Major Provisions of IDEA

IDEA is a comprehensive law that provides specific provisions for children with disabilities in education. According to the IDEA, a child with a disability is defined as:

(A) ... a child-- (i) with mental retardation, hearing impairment (including deafness), speech or language impairment, visual impairment (including blindness), serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities; and (ii) who, by reason thereof, needs special education and related services.

(B) Child age 3 through 9 --The term “child with a disability” for a child age 3 through 9 may, at the discretion of the state and the local educational agency, include a child-- (i) experiencing developmental delays in one or more of the following areas as defined by the state and as measured by appropriate diagnostic instruments and procedures: physical development, cognitive development, communication development, social or emotional development, or adaptive development,; and (ii) who, by reason thereof, needs special education and related services. (Section 602(3))

The major provisions of IDEA include: 1) free and appropriate public education for all children; 2) nondiscriminatory assessment; 3) development of an Individual Education Plan (IEP); 4) due process; 5) privacy of records; 6) education in the least restrictive environment possible; and 7) discipline under IDEA. This section will briefly discuss these provisions.

Nondiscriminatory Assessment

The nondiscriminatory assessment provision calls for a fair assessment process to determine a child's educational talents and needs. It was created because previous assessment practices had falsely lowered the scores of children due to extraneous factors such as motor weakness, cultural or language differences, or lack of normal exposure to information. These tests were often used to limit the amount and type of education provided to children who were poor, of color, and/or had disabilities. In order to create an equal playing field, tests that discriminate upon the basis of factors such as race, gender or disability are forbidden when assessing the child's academic ability and eligibility for accommodations.

Individual Education Plan (IEP) Development

The Individual Education Plan provision specifies that each child with a disability should have on file an Individual Education Plan (IEP) – see Appendix A following Chapter 4 for a sample IEP. Regulations have specified a general process for the development, evaluation, and updating of an individual plan; however, details vary from state to state. In general, schools establish a multi-disciplinary team consisting of the disabled child, when appropriate (Section 614(d)(1)(B) of P.L. 94-142, now IDEA), parents, teachers, school administrators, school psychologists, special educators, school nurses and others.

For a child with NMD, the IEP team might include all or a combination of the following: the parents and child; the teacher of the child's mainstream classroom; a teacher who specializes in orthopedic disabilities and special education; a resource specialist; a school psychologist; a school administrator; and the school nurse. This team reviews the progress of the child with NMD in the school and attempts to create solutions to problems that occur in the classroom. If a child cannot be helped by modifications or alterations of the classroom setting and/or coursework, he or she may be referred for further study and possible assistance from the special education program.

When further evaluation identifies the child with disabilities and qualifies him or her for special education services, an IEP is developed which addresses the child's educational needs and objectives. The IEP team creates individual goals and objectives for the child's scholastic development as well as services and/or

To Mainstream or Not to Mainstream: Four Factors to Consider

1. Would the child benefit academically from mainstream classroom participation?
2. Are there non-academic benefits (i.e. increased self-esteem or friendships) for the child?
3. Will the child behave well in class, follow directions and not disrupt the learning of other children?
4. Is the cost to mainstream substantially more expensive than special education for the child?

accommodations to support the achievement of these objectives. The school district is responsible for providing accommodations and related services that will appropriately meet the individual needs of the child. Although criteria for qualification for special education services vary from state to state, in general, when a child's achievement and ability to participate fully in school is significantly impacted by the disability, he/she will qualify for special education services.

There are several goals an IEP must cover. It must state the following: 1) services and supplemental aids the school district will provide to help the child in the mainstream classroom, when mainstreaming is determined appropriate by the team; 2) program modifications or supports for school personnel that will involve the child and promote his/her progress in the mainstream curriculum; 3) program modifications that will support participation in extracurricular and non-academic activities within the school; 4) the location, duration, and frequency of services; 5) how the child's progress will be measured when it differs from that of the child's non-disabled peers; and 6) how and when the school will inform parents of their child's progress.

In addition to services, the school is responsible for providing case management or coordination of help for the child. Each school will usually have several people who serve in this role. Often the special education teacher or the school psychologist will help coordinate services and facilitate communication between the school and the home. Due to their increased role in the IEP process, mainstream teachers also frequently assist with the management of services.

Due Process

Although IEPs are intended to be a collaborative approach to a child's educational goals, disagreements can and do occur between the school system and parents of children with disabilities. In the event of a disagreement, the parents of a child with a disability have the right to due process. The first step in the process to resolve the disagreement is mediation. However, if mediation is not successful, a hearing will then be scheduled with the local Department of Education. Mediation and hearings are provided at no cost to parents. However, if a parent wishes to hire an attorney, it is at the parents' expense. This mediation process must be uniform and the school is responsible for informing parents of their due process rights.

Privacy of Records

This provision is the duplication of federal privacy laws pertaining to people with disabilities. It requires that school records are restricted to those who need the information to plan the educational experience for the child. Confidential records cannot be shared with outsiders without the consent of the individual with the disability or, in the case of minors, the parents or guardians. Therefore, school districts should have in place measures to protect the confidentiality of a child's records.

Least Restrictive Environment

According to IDEA, the least restrictive environment (LRE) is defined as: "To the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are not disabled..." (Section 612(a)(5)(A) of IDEA 97). This means that a child with a disability

mainstream teacher must be present at the IEP when a mainstream educational environment is being considered or is included in the child's educational plan; 7) Positive behavioral interventions must be a part of the IEP process for children whose behaviors interfere with their learning or the learning of others; 8) No later than one year before the child reaches the age of majority under state law (18 in most states), the legal rights (if any) regarding special education services move from the parents to the student with a disability. These and other provisions help provide an improved educational experience for children with disabilities.

Discipline under IDEA

Children may be disciplined for minor infractions of school rules, whether they are disabled or not. However, in more serious cases of misbehavior there must be a balance struck between providing a free appropriate public education and providing a safe school environment that permits all children to learn. Children with disabilities are subject to major school disciplinary actions resulting from their inappropriate behavior. Under IDEA, school authorities, usually the school principal may suspend a student with a disability for up to 10 days. During the first 10 days of suspension, schools are not required to provide educational services.

Suspensions may be repeated for new acts of misconduct as long as there is no pattern suggesting the presence of additional disabilities. During any subsequent suspension for less than 10 days, services must be provided that permit the student to advance toward meeting IEP goals and making progress in the general curriculum. Should a pattern develop or when a child is removed for more than 10 consecutive days, a change in placement is likely to occur. If this happens following a suspension, the school must conduct behavioral assessments, develop a behavioral intervention plan, and meet with the child's IEP team within the 10 days following the end of the suspension.

Major Provisions of Section 504 of the Rehabilitation Act of 1973

Section 504, a broad civil rights law, protects individuals with disabilities. It applies to all institutions receiving federal funding, including public schools and institutions of higher education. The intent of Section 504, in terms of education, is to assure that disabled students have the same educational opportunities as non-disabled students by prohibiting discrimination based upon disability. Monitoring compliance for this law, in terms of education, is the responsibility of the U.S. Department of Education/Office of Civil Rights (DOE/OCR). The major educational provisions of Section 504 of the Rehabilitation Act of 1973 include: 1) Non-discrimination against people with disabilities; 2) Comparable education; 3) A 504 Accommodation Plan; 4) Due process; and 5) Institutional accessibility. Many of the provisions within IDEA are repeated within Section 504 and, in terms of education, simply cover a broader group of people with disabilities than IDEA. This section will briefly discuss these provisions.

Non-Discrimination

Students who are considered "disabled" under Section 504, but not under special education laws are entitled to "reasonable accommodation" of their disability. Children

with many medical conditions such as asthma, diabetes and neuromuscular disease, may not easily fit under IDEA due to the act's limited definition of who is defined as disabled. While a child may not be covered under IDEA, if he or she is defined as an individual with a disability within Section 504, the child is entitled to the accommodation of his/her disability under the Rehabilitation Act.

Under Section 504, disabilities or "handicapping conditions" are defined in much broader terms than IDEA. Section 504 defines a "qualified individual with disabilities" as any person that "(i) has a physical or mental impairment which substantially limits one or more major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment" (Section 104.3 of P. L. 93-112). A "substantial limit of one or more life activity" is usually defined as difficulty in walking, seeing, hearing, speaking, breathing and/or learning. Students with NMD are considered as having substantially limited life activities when their daily work and classroom tests show a pattern of failure despite conscientious effort, and when their achievement is below the instructional range of the classroom, as demonstrated by achievement tests, daily work, and classroom tests. As a result, students with NMD who are not covered under IDEA are usually covered under Section 504 of the Rehab Act.

Comparable Education

Under Section 504, as under IDEA, children are guaranteed the right to a free appropriate education in the least restrictive environment. An appropriate education under Section 504 means that a child with a disability receives an education with reasonable accommodations within the mainstream classroom and curriculum that is comparable to that of non-disabled students.

504 Accommodation Plan

A 504 Accommodation Plan, like an IEP, is developed that specifies the types of modifications and alterations needed in order to address the child's educational needs (see sample plan, Appendix B at the end of Chapter 4). The types of services offered might include adjusting class schedules, providing extra time on and/or modifications of tests (e.g. an exam in large print, double-time on tests), and/or using adaptive equipment. Like an IEP, this plan is developed with the child with the disability (when appropriate), the parents, the child's mainstream teacher, a school administrator, and sometimes specialists who can be consulted regarding appropriate modifications.

Due Process

Similar to IDEA, Section 504 also requires districts to provide impartial hearings for parents or guardians who disagree with the school district's evaluation findings, educational placement, and/or provision of services. Parents have the right to timely notification, the right to inspect records, the right to participate in a hearing with legal or other representation, and the right to appeal. As with IDEA, parents should be informed of their rights and responsibilities under Section 504 of the Rehabilitation Act by the school.

Institutional Accessibility

Section 504 has detailed regulations regarding building and program accessibility. The district must provide physical accessibility within the school and classroom as well as at extracurricular venues (such as sports and theater venues) and activities (such as field trips, after-school clubs and programming). Building modifications may be needed in order to provide physical access, such as wheelchair ramps or elevators, Braille/large print signage, a sound and light fire alarm system. These modifications are required to offer access for all individuals with disabilities who wish to enter the school including students, employees, parents, and the general public.

Americans with Disabilities Act of 1990

Another major piece of legislation affecting children with NMD is the Americans with Disabilities Act (ADA). The ADA was signed into law on July 26, 1990 and was intended to prohibit discrimination on the basis of disability in employment, to update some provisions within the Rehabilitation Act of 1973, and to prohibit discrimination by private companies and in privately owned public venues. The law contains requirements for new construction, for alterations or renovations to buildings and facilities, and for improving access to existing facilities of private companies providing goods or services to the public. Beyond physical accessibility, the ADA also provides for reasonable accommodations in communication, policies, and procedures that exist within public and state venues such as shopping malls, public libraries, state parks, and schools.

Although most people believe this legislation deals primarily with accommodating employees with disabilities, the ADA is civil rights legislation affecting all aspects of life. Like the Rehabilitation Act of 1973, the ADA defines a person with disability as someone with a physical or mental impairment that substantially limits one or more major life activity such as walking, talking, seeing, hearing, breathing, learning, has a history of such an impairment, and/or is thought to have such an impairment.

The ADA specifies that buildings be accessible to individuals with disabilities. The provisions specify architectural adjustments such as ramps and elevators, accessible transportation (e.g. a wheelchair accessible public transportation), accessible bathroom facilities, or visual/auditory fire alarm systems. These modifications make it possible for individuals with disabilities to access public, employment, and educational venues independently. While these provisions were established for academic settings through the Rehabilitation Act, the ADA provides updated codes for architectural modifications and expands access for people with disabilities into the public sector. By providing these types of accommodations within a school setting, children with disabilities gain more independence and have the opportunity to socialize with their peer group without adult interference. This, in turn, increases socialization skills and improves the child's self-perception and quality of life.

The law states that employers and, by extension, school personnel, must make reasonable accommodations for an individual with a disability. Reasonable accommodations in school make existing facilities used by people without disabilities readily accessible to and usable by people with disabilities. Such accommodations may include but are not limited to: the modification of a work schedule; the acquisition or modification of equipment (e.g. adaptive computer hardware/software); the provision of

books and information in accessible formats (i.e. books on tape or in electronic format); and the provision of American Sign Language interpreters and/or closed captioning. School personnel are not required to lower quality or quantity standards as an accommodation; nor are they obligated to provide personal use items such as wheelchairs, glasses or hearing aids. However, schools are expected to provide accommodations that level the playing field in terms of participation and access to the public venue.²

The decision as to what constitutes an appropriate accommodation must be based on the particular facts of each case. In selecting the particular type of accommodation to provide, the principal test is that of effectiveness, i.e. whether the accommodation will provide the opportunity for a person with a disability to achieve the same level of performance and to enjoy the same benefits as those achieved by an average, similarly situated person without a disability. In addition, the school is not required to make an accommodation if it would impose an "undue hardship" on the operation. An "undue hardship" is defined as an "action requiring significant difficulty or expense" when considered in light of the size and resources available to the institution in question. For example, "undue hardship" for a school district would be based upon the size and available resources of the particular school district. For example, an economically disadvantaged urban school district would be looked at differently than a suburban school district that is not economically disadvantaged.

Conclusion

Children and their parents have rights under the law and schools must be prepared to grant children with disabilities an equal opportunity to access an equal education. At the same time, there are limits on what the schools can and do provide. An equitable process has been provided to satisfy the needs of individuals and the institutions that serve them. However, to work effectively, everyone must be aware of both the letter and the spirit of the law.

References

National Information Center for Children and Youth with Disabilities and the Federal Resource Center for Special Education. (2003). IDEA '97 Training Material. Revised text-only online version. <http://www.nichcy.org/Trainpkg/toctext.htm> [30 June 2004]

² While the ADA does overlap with the Rehabilitation Act and IDEA, the ADA, within the educational setting, strictly pertains to providing access to the public and school employees not to the education of children with disabilities.

Chapter 3 Creating and Maintaining Family/School Partnerships

Introduction

In addition to being a good idea and a sound educational practice, the Individuals with Disabilities Education Improvement Act mandates the involvement of the child and parents in the educational programming of students with disabilities. The extent of parent and child participation in educational planning varies widely from case to case. For example, some children will be more capable of participating in their educational planning than others due to their age, maturity level, and understanding. Parents, due to a variety of factors, may be more or less involved with the day-to-day school process. Nevertheless, a critical element in addressing the needs of any child consists of forming a healthy family-school partnership, and this will be an important forum for problem solving and support when addressing the needs of a child with NMD.

This chapter begins with a discussion of the benefits of family-school collaboration and an outline of the ways that both schools and families can develop an effective partnership. Drawing from our research and that of others, we will outline common concerns of parents, teachers, and individuals with NMD. By being aware of these anxieties, schools and families can work together so that all parties can get what they need. Next, we will present a strategy for promoting family involvement. Finally, the reader will find tactics for effective communication and a family-teacher mainstreaming checklist and conference form to assist the family and the school in developing ways to have successful communication and planning.

Benefits of Family/School Partnerships

Families and schools benefit from forming partnerships that are both supportive and instrumental in developing appropriate educational plans for the child. Effective family-school collaboration can lead to improved communication, resolution and prevention of problems, as well as improved services for the child. Given the ever-changing nature of neuromuscular disabilities, crucial components in providing a productive educational environment for the child include effective communication and problem solving techniques.

Turnbull and Turnbull (1990) have identified the multiple benefits of family-professional partnerships for families. The benefits for families of children with disabilities include: access to information concerning the child's disability and adaptive technology that the child may use; an increased awareness of the rights and responsibilities of a parent of a child with a disability; access to different techniques used to teach different skills; and access to resource information (i.e. vocational rehabilitation, Independent Living Centers (ILC), support groups or sexuality resources) available to them and their child concerning a wide variety of issues.

Schools also benefit from these partnerships. Schools gain insight into the child's development, behavior, and needs, as well as obtaining support in teaching the child new skills by including the family of a child with a disability in the educational plan. Establishing rapport and trust can also prevent communication breakdowns and

potential difficulties. When schools and families can communicate frequently and work toward solutions rather than simply rehashing what the problems are, disagreements can be avoided.

Children with NMD present a unique challenge to families and educators because their disease is progressive. As a result, educational, social, emotional, and physical needs will continue to change and vary, requiring ongoing communication between home and school. For example, there will be times when children with some neuromuscular disabilities are experiencing more or less illness as a result of acute flare-ups and/or a decline in symptoms that affect classroom functioning. Because of these fluctuations, communication between the child, parents, and educators is essential in order to ascertain how a child is doing physically, educationally, and emotionally, so that appropriate expectations can be set.

Promoting Communication and Collaboration

A collaborative approach that includes the child, teacher, and parents is a critical element in inclusive settings (Stainback & Stainback, 1992) and is certainly important in any educational setting. Understanding the common concerns of parents who have a child with neuromuscular disabilities will also be helpful when developing a school-home partnership. In a study conducted by the authors (Strong & Sandoval, 1998), parents, teachers, and adult individuals with neuromuscular disabilities were interviewed in focus groups. Figure 1 represents some of the concerns expressed in these focus groups when they discussed their interactions in a school setting. Collaborative relationships and open communication tend to help allay these common concerns.

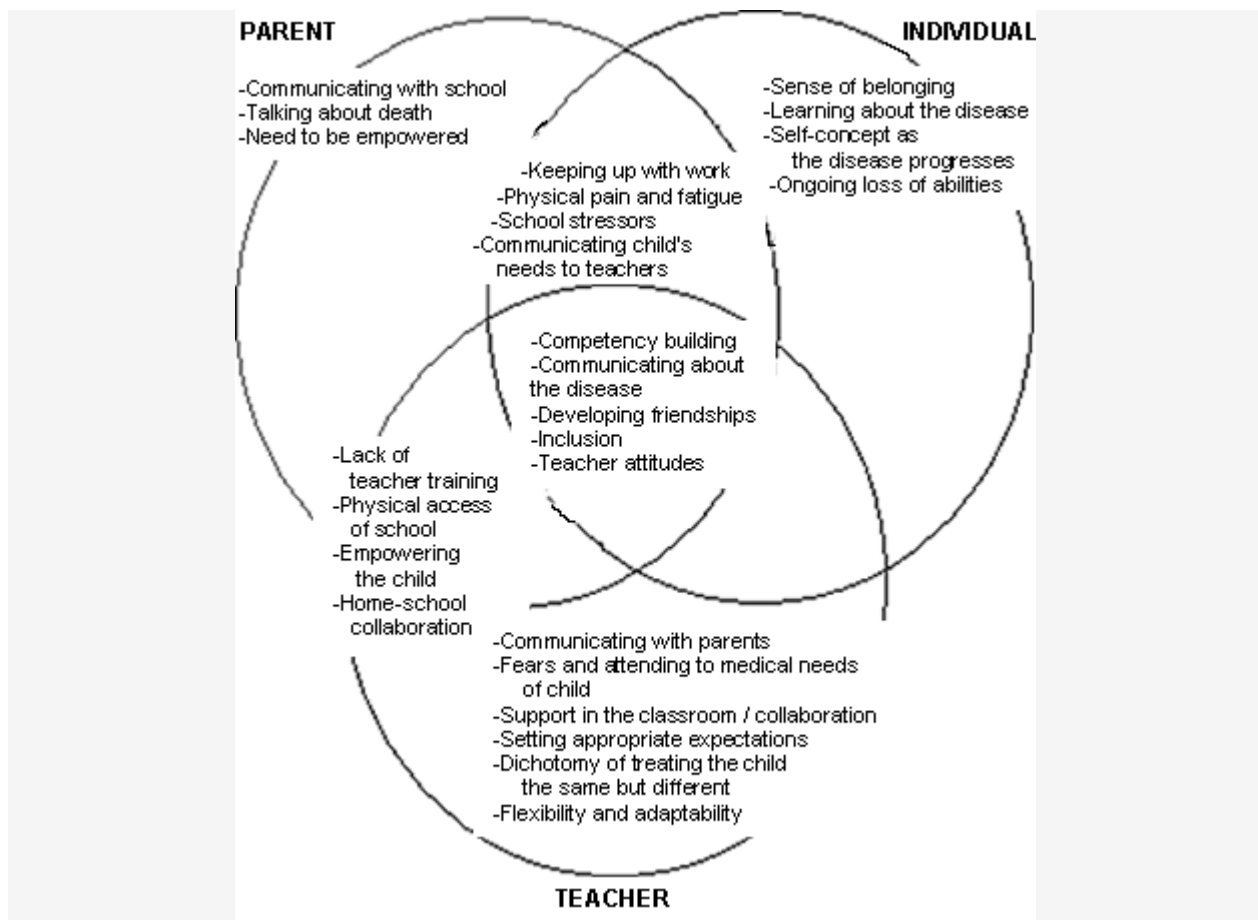


Figure 1. Understanding the Three Perspectives: A Map of Concerns

Open communication and collaborative efforts help alleviate concerns the child, parents, and teachers tend to have when interacting with one another in the school setting. For example, one of the concerns of teachers is the fears or misconceptions they have about the child's disability. Direct interaction between the child, parents, and

teachers can produce collaborative solutions to accessibility issues while providing growth opportunities for each, and increasing the child's confidence in their ability to articulate their needs. At the same time, this collaborative effort increases the parents' sense of trust in the school and in their child's self-efficacy abilities. With each interaction, all parties gain valuable information and skills as well as an increased sense of trust in one another. This, in turn, increases each individual's sense of competency in his or her role.

Furthermore, active problem solving will most likely lead to decreased anxiety in the child, parents and teachers by offering them a tangible way of dealing with concerns. Aldwin (1994) points out that active problem solving, as a form of coping, can be a critical process leading to healthy outcomes for individuals dealing with illness. As a result, by facilitating active problem solving by the family, the school is providing an opportunity to improve the child's quality of life. It will also promote appropriate teacher attitudes and, by example, increase the inclusive behavior amongst the child's peers.

Promoting Child Involvement

As stated in Chapter 2, legislation mandates that children with disabilities be involved in the educational planning process to the extent that they are capable of participating. Like all other children, students with disabilities vary in their abilities, maturity level, and understanding of planning short and long-term goals. While some students may be able to participate at an early age in a substantive way in the IEP or 504 Accommodation Plan process, others may only be involved marginally until they are older and, still others, may not have the skills to participate at all. Each child should be brought into the process when and where they are ready to participate.

Inclusion of the child in the process should be done for several reasons. First, the law mandates it. However, there are other, more important reasons, to include children with disabilities in the design and implementation of their educational plan. The following are just some of the many benefits for all concerned parties and include examples of how this participation might be encouraged.

Involving the child in the process will help him or her develop abilities they will need later in life such as effective communication skills, short-term and long-term planning techniques, problem solving proficiency, and self-efficacy. These skills are already a part of the educational process for children without disabilities but tend to be limited or left out of a disabled student's educational experience. And yet, the "empowerment" of students with disabilities is frequently cited in journal articles and conference papers by members of organizations like the Association of Higher Education and Disability (AHEAD) as a major on-going problem. The sooner a person with a disability takes control of the decisions which affect his or her life, the more empowered the individual becomes. By bringing the child into the educational planning process, the child is empowered to make decisions affecting her or his future while learning valuable life skills.

These skills can facilitate other learning that makes it easier for a child to transition into an independent adult. For example, some children with disabilities need the assistance of a care attendant throughout their lives. This person (usually more than one) provides the individual with daily care needs such as help with bathing and

toileting. During childhood, the parents may provide some or all of this assistance or they may manage the child's care attendants. For someone who requires care attendants to function independently, managerial type skills are necessary in order to have a higher quality of life. While it may be required for the parent to take responsibility for this when the child is young, the child should at least begin to take on some of these managerial tasks as he or she matures. By promoting the child's decision-making processes at an early age, one is encouraging the learning of valuable life skills through the empowerment of the child. By providing the gradual training of these abilities over time, rather than all at once, the child has the opportunity to become effective at various skills he or she needs in order to live a happy and productive life.

Beyond what the child may learn from being part of the process, she or he also brings a specific and needed perspective to the table. This viewpoint is needed because it is the child's life that is being planned and, therefore, the child's life goals that need to be placed at the forefront of the planning process. This is especially true once the student reaches the age of fourteen and a transition plan that takes into consideration the child's personal wishes/goals for the future must be implemented. While they may not be able to help with specific long-term plans at a younger age, children will be the first ones to know they are having problems in a certain area and/or may think of solutions to problems that work and are cost effective, but that adults might not consider. By providing the child with another opportunity for experiential knowledge, the parents and educators might learn as well.

Promoting the child's involvement requires listening to the child, because it is his or her life that parents and educators are helping plan and shape. Like non-disabled children, children with disabilities should be consulted and involved in their educational process. For this to happen, both parents and educators need to practice active listening with regard to what the child is communicating about their needs and goals for the future. For example, a child may wish to become a scientist when she or he grows up. By actively listening to the child's needs and goals, both parents and educators can facilitate learning that is both appropriate and necessary for attaining the child's goals while, at the same time, providing for the child's needs.

As with all children, some are quick to communicate their needs and goals while others are not. Knowing how the child communicates his or her needs and goals (verbally and non-verbally) is what makes for successful active listening. By encouraging the child to communicate, e.g. whether they understand something or what they want to learn, both parents and teachers are persuading the child to become a more effective communicator while also learning something of the child's abilities, habits, learning styles, and goals for the future.

As the child gets older, he or she will be able to not only articulate his or her needs but also solutions to problems in a more effective manner. By practicing active listening techniques, both parents and teachers are modeling for the child advanced communication skills that will help the child transition into the adult world. The earlier this process is utilized, the more time the child has to become adept at communicating and the more effective the child will become at utilizing various communication techniques.

Child involvement in the educational planning process also requires encouraging the child to be an active participant in his or her education. This can be done in a

variety of ways. The educator might ask the child to explain how a specific piece of assistive technology (such as adaptive computer software that the child uses) works. The child might be made responsible for relaying information between the parents and the teacher. Or, the child might participate in all aspects of his or her educational process from IEP/504 Accommodation Plan meetings to training educators in wheelchair repair to learning in and outside the classroom.

By having the child participate in his / her educational plan in a more direct manner, the child becomes a valuable resource for information and ideas rather than just a problem in need of a solution. Inclusion of the child in the process also sends a message to the parents that the educational system is actively empowering the child as well as educating her or him. In the process, it is modeling, for parents, who tend towards over-protectiveness, more appropriate and productive behavior with regard to their child.

Promoting Parental Involvement

Although formal conferences can offer focused discussions, informal communication amongst all parties may be even more important in creating an on-going collaborative effort. Beyond this, most parents prefer informal and more frequent communication with their child's teacher and school. Turnbull and Turnbull (1990) point out that, similar to individualizing instruction for children, an individualized approach to parental involvement is also important. A good first step consists of asking parents how they would like to participate in their child's education.

Providing a variety of ways that the parents can both directly and indirectly participate will encourage different parents to contribute in various ways. Some parents may prefer to participate indirectly, such as in helping with classroom materials, whereas other parents may choose to contribute directly, such as in assisting in the classroom on a regular basis. Recognizing that families have different responsibilities and social activities to which they must also attend will help one remember to be flexible and, in turn, will help in finding a good "match" or "fit" for parental involvement.

While society has changed with regard to gender roles, many within the educational system still assume that the mother is the primary care giver of the child and hence assume that she will be the primary actor in the child's educational development. Today, many children are raised within complex family networks (i.e. single parent households or multiple households with multiple sets of parents). Recognizing how all family members in the child's life can play a role in his or her education is key to effective family involvement.

Educators should take into consideration the type of familial network within which the child is growing up and should encourage all interested parties within the familial network to participate in the child's educational development. This could mean involving grandparents or significant others in educational activities or providing a role for siblings in the process. Each family, like each individual, is unique. Appreciating that uniqueness will make more opportunities for family contribution possible.

Knowing the family's preferences for certain modes of communication and offering multiple ways to keep up on-going communication can also promote parental involvement. As suggested before, asking parents when it is best for them to meet and

meeting when they are available encourages their attendance at conferences. If it is more feasible for parents to meet via conference calling or using e-mail, then these options should be discussed. Providing the option of writing in a "communication notebook" can also increase communication and provide frequent and timely information. This method of communication can be particularly helpful when a child has chronic medical conditions, such as NMD, which change frequently, and/or when teacher and parent's work schedules make it difficult to communicate on the phone or in person.

Another forum for including parents in the educational process includes offering home visits. Scheduling a home visit can often alleviate the pressure of a more formal conference. By cultivating an active interest in the child's and the family's needs, by offering to visit the home, educators have an invaluable opportunity to develop parental participation and enhance trust while, at the same time, gaining the opportunity to learn more about the child outside a school setting.

Parent-Teacher Conferences

In addition to case management, conferences or meetings also offer a forum for problem solving and communication. Most parents of students with disabilities are willing to and do attend meetings with educators. However, parents often report that they are not satisfied with these interactions. Parents of children with disabilities state that meetings with school officials are often confusing, disorganized, and too technical (Turnbull & Turnbull, 1990). Parents also feel as if the needs of their children are being ignored or take a back seat to the financial concerns of school officials.

Although parental input is mandated by IDEA, many parents assume a passive role in conferences and appear to be intimidated by technical jargon and test scores. Educators and parents can take several steps to improve the quality of conferences, an essential step in establishing a positive, trusting relationship between the home and school.

Educator's Contribution

To improve the quality of conferences educators can:

1. *Plan the meeting.* Before the meeting, educators can identify objectives and develop an agenda by compiling a list of issues that all concerned parties have expressed. This means educators should ask parents for input about issues that they would like addressed at the meeting so that the agenda reflects their input. Parents should be consulted to determine what dates and times at which they are able to attend. Follow-up reminders to parents about the conference will also increase the likelihood that they will attend the meeting. Arrange for refreshments and for childcare when it is needed.
2. *Structure the environment to promote communication.* The meeting place should be comfortable and arranged to promote communication. It should also be wheelchair accessible if any of the participants in this meeting needs this accommodation. It should be a quiet, distraction free space so that everyone can participate equally. Providing conference material in alternative formats (i.e. large print or on tape or provide a reader or interpreter) for anyone present who needs such accommodation

(whether it is the child, parent, or school staff member who has a disability) acts as an implicit message that everyone's input is wanted and needed.

3. *Conducting the conference.* There are many simple ways to promote open and effective communication that will allow everyone in the meeting to participate and understand the proceedings. Some of these strategies include: 1) Start on a positive note by discussing the student's strengths; 2) Present concerns about the student's performance in a clear and concise way using examples and avoiding jargon; 3) Give parents and the child the opportunity to discuss issues and concerns from their perspectives. Both parents and the child should be encouraged to bring a list of questions, comments, and concerns to the meeting; 4) Listen attentively to the parents' and the child's comments, questions, and suggestions; ask questions, when necessary, to clarify what has been said; 5) Affirm the inherent dignity in all parties involved and strive to maintain a climate of justice and freedom of expression marked by respect for each individual participating in the meeting.
4. *Evaluate the conference.* After each meeting (either in person or by mail), ask parents and the child if the meeting addressed the issues they wanted to discuss, whether they had sufficient time to present their opinions, whether they were satisfied with how the meeting was conducted, and whether or not they were satisfied with the outcome of the conference. Encourage all parties to suggest improvements in the meeting process.

Parent's Contribution

Parents can also make meetings more productive. They see their child in a variety of settings and are in close communication with their child's physician. To prepare for a conference, parents can:

1. *Plan for the meeting.* Write a list of questions and/or concerns you wish to raise at the meeting. Schedule the meeting so that you will have ample time to discuss each item on the agenda without interruption.
2. *Bring information to the meeting that might be needed by educators.* For example, be prepared to update school personnel on the child's medical status and behavior at home. Alert the school to changes in the family status that may be affecting the child's schoolwork, such as divorce or death. Bring past medical and school records that the school may not have, particularly if you have recently moved to a new school district.
3. *Participate actively.* Ask questions if anything is not clear or if you have a particular concern or need information about a particular topic related to child development. Point out both consistencies and inconsistencies in the child's behavior at home and at school. Suggest solutions to problems that arise and, perhaps, provide examples of how a particular solution might work. Pass on information about resources that you may have found that could be helpful to teachers and / or other parents of children with disabilities such as websites or listservs, books, or local groups and organizations.
4. *Evaluate the conference.* Let the school know if you have further questions or if there are topics that were not covered during the meeting. Let them know what was satisfactory and what was not satisfactory about the conference.

When Parents and Educators Disagree

While the goal is to foster and maintain a good working partnership with parents of children faced with NMD, there are circumstances that sometimes occur which make this difficult. Educators and parents should be informed of their options if communication between the school and the family breaks down. It is in the best interest of the child for the school and the family to work towards reaching an agreement about a child's education.

Turnbull & Turnbull (1990) argue that communication breakdowns result from faulty systems, not faulty individuals. When communication is approached in a systemic way, schools and families can develop effective ways of collaborating. For example, implementing a regular team meeting that includes all key participants in a problem-solving format can provide ongoing communication. In addition, when parents can establish trust with one or two individuals in the school, problems can be solved as needed, and parents can exercise their right to be involved in their child's education.

When a disagreement persists after efforts to resolve the problems have been tried at the school, two options are available to parents and educators: 1) Schedule a *mediated conference*, in which an outside, unbiased party serves as a mediator in a conference situation in order to encourage open communication between educators and parents that promotes resolution; or 2) Invoke *Due Process* rights, which allow either parents or educators to initiate a due process hearing to resolve disputes about a child's educational program. Both parents and educators have a right to appeal and contest each decision made by a placement team. In due process, an impartial hearing officer will conduct a hearing in order to make a decision about the issues in question.

Conclusion

The Individuals with Disabilities Education Improvement Act mandates the involvement of the child and parents in the educational programming of students with disabilities. Beyond the legal requirement, it is also sound educational practice. Both the school and the family benefit from forming working partnerships. However, ultimately the child benefits the most from these collaborative efforts by receiving a better education.

Appendix A

Suggestion/Outcome Table for Successful Parent Involvement

Activity/Suggestion	Outcome
Whenever possible, provide food and child care (when needed) during parent meetings.	Increases participation and establishes a clear message that family involvement is important.
Provide a variety of parent involvement activities that include both indirect and direct ways of participating.	Parents can choose the activities that they feel the most comfortable with and that match their strengths.
Provide specific activities in which extended family members participate.	Increase participation and broaden support to the child by including extended family, such as grandparents, siblings, and/or significant others.
Suggest homework activities that promote family involvement in the child's education.	Increase family awareness of what the child is doing in school and promote support for the child.
The school can offer parenting classes which focus on educating parents about disabilities, educational rights, how to help their child with homework, and about effective parenting practices.	Promote parent knowledge about educational rights, child development and increase parental awareness of effective ways to work with their child.
Offer curriculum review workshops that focus on specific educational objectives and methods of instruction.	Promote parental understanding of achievement and curriculum.
Encourage frequent parental communication and let parents know that they can request a conference at any time.	Prevent potential problems from developing and increase awareness of both parents and teachers regarding the development of the child.
Include parents when planning the parent-involvement activities for that school year.	Develop a parental involvement program that reflects the priorities and strengths of the parents in your school.
Train a parent facilitator who can provide a liaison between the home and school and who can develop training and education meetings for parents.	A parent representative can provide an effective link between parents and schools, can involve hard-to-reach families, and can often target areas that are important to parents.

Appendix B

Checklist for Parent Teacher Conferences

PARENT-TEACHER CONFERENCE CHECKLIST
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- ❑ Build rapport by having informal and formal talks where a common understanding can be developed.
- ❑ Develop a working relationship that will promote open and frequent communication and collaboration.
- ❑ Obtain and provide information about the child's educational progress, strengths, and needs.
- ❑ Share concrete information that will help the teacher/parent work with the child to promote as many opportunities for success as possible.
- ❑ Work toward solutions rather than focusing on problems.
- ❑ Develop a clear action plan and follow-up plan when needed.
- ❑ Discuss ways of continuing ongoing communication, such as, a notebook that goes back and forth from home to school, home visits, and telephone calls as needed.
- ❑ Learn about resources available to the child, as well as the key people involved in the child's school/home who can provide support.

Appendix C

PARENT-TEACHER CONFERENCE OUTLINE

Date: _____ Time: _____
 Teacher: _____ Other Staff: _____
 Goals of the Conference:

Child's Strengths and Abilities:

Update Academic Progress/Identify Needs:

Update Physical Needs/Health and Medical Information:

Parent Concerns:

Physical Access in Classroom:

Adaptive Equipment/Technical Assistance Needs:

Recess/Lunch/Social and Extracurricular Activities:

Action Plan:

Teacher:
 Parent:
 Other:

FOLLOW-UP DATE: _____

Chapter 4

Academic Equity for Children with NMD

Children with NMD, like all other children, need a variety of services to support their education. As has been stated elsewhere in this guide, all children are unique and, therefore, require different things to accomplish the same goals. All children require the least restrictive environment in school in order to attain the maximum success in academics. Children with NMD are no different in this respect.

Because all children are different, the services that are needed and provided to a child by the educational system will depend upon the specific needs of the student. While one child may need a more structured environment to succeed, for example, another child may thrive with less structure and more leeway to explore. Further, both of these children's needs may change over time. Attaining the goal of instructing all children in the educational system requires providing for all children's needs.

The needs of children with disabilities vary from child to child, just as they do with all children. Some children may need physical modifications to the school to provide wheelchair access. Others may need adaptive equipment such as a computer, adaptive computer software such as voice recognition software, books in alternative formats or adapted pencil grips to provide a level playing field. Others may use a service dog as an accommodation. In addition, some students may require adaptive teaching strategies because recent research links learning disabilities with certain neuromuscular diseases. Some children may use a combination of a wide variety of accommodations. In this chapter, both the educational needs of children with NMD and the range of possible services and modifications to address these needs will be explored.

Academic and Environmental Assessment and Accommodation

One of the major traps educators frequently fall into is focusing on correcting or fixing the disability rather than educating the child. For example, educators frequently spend more class time working on walking, talking or reading ink-based texts than teaching the skills required for the child's grade level (i.e. math, science, grammar or literature) in a format that is accessible. (Cheu and Tyjewski, 2001; Hehir, 2002; Crescendo, 2004). As Thomas Hehir, Director of the School Leadership Program at the Harvard Graduate School of Education, notes in "Beyond Inclusion," "Considerable evidence points to unquestioned ableist assumptions that are handicapping the education of children with disabilities and resulting in educational inequities" (March 2003). Ableism is a term used by academics and activists to describe the societal prejudices that exist towards people with disabilities. Like racism, ableism frequently affects the way a child with a disability is (or isn't) taught within the educational setting. Just as, historically, the educational system had lowered expectations of children of color, children with disabilities are frequently provided fewer opportunities due to prejudicial views held by educators (Hehir, 2002). If educating the child is the goal, then encouraging the student with a disability to use the skills and modes of expression that are the most effective and efficient for the child will produce a more well- educated child. For example, promoting rather than discouraging, the use of adaptive technology

(computers, spell check or books on tape) and alternative forms of learning and communication (oral examinations, multimedia reports, sign language or computer technology), while teaching the student the age appropriate material, will give the student the opportunity to perform up to his or her potential.

As stated in Chapter 2, each child's individual needs will be assessed and documented through the IEP team process or through a 504 Accommodation Plan. As with many disabilities, neuromuscular disabilities present a wide range of possible educational needs. Therefore, an individualized assessment will be useful in the

Types of Educational Placements

- **Regular (mainstream) Classroom with Modification**
Regular classroom curriculum and placement on a full time basis with modifications and accommodations to address individual needs.
- **Resource Specialist Program (RSP)**
Small group instruction for a portion of the child's school day with a special education teacher – an educator specializing in teaching children with disabilities.
- **Special Day Class (SDC)**
Instruction, either full or part time, in a small self-contained classroom with children having different disabilities. The class is taught by a special education teacher who is helped by an instructional assistant.
- **Orthopedic Disabilities Special Day Class (ODSDC)**
Sometimes still referred to as OH, or Orthopedically Handicapped, Special day classes of this nature are small self-contained classrooms comprised strictly of children with orthopedic disabilities (mobility impairments). It is taught by a special education teacher who specialized in teaching children with orthopedic disabilities.
- **Home Instruction**
Child receives instruction at home under the parents' supervision with coordinated by a home instructor from the school district who will oversee the program and meet with parents and child weekly.

development of an appropriate educational plan. Educational assessments can include testing in the areas of achievement, intelligence, communication, social-emotional development, self-help or adaptive behavior, and fine and gross motor skills. The identification of a child's unique strengths during this process will be an important element in the assessment of, as well as in the identification of educational needs. By identifying the strengths as well as the needs of a child, educators are better equipped to support the child's educational process.

As stated previously, children with NMD are usually educated in regular (mainstream) classrooms with accommodations and/or support services, such as occupational therapy and/or adapted physical education. Some accommodations that may be part of a child's IEP/504

Accommodation Plan may include:
1. Providing extra time to complete

assignments, homework and/or exams, 2. Using a multimedia approach to learning, 3. Stating behavioral and/or learning expectations before starting a lesson, 4. Providing reading materials in alternative formats, 5. Providing adaptive computer hardware and/or software, and/or 6. Making the facility wheelchair accessible. As stated before, each child is unique and some may need all of these accommodation and others may only need a few. Many of these accommodations have been shown to benefit children both with and without disabilities, such as utilizing a multimedia approach to learning. Therefore, an accommodation, that is provided because one child in the classroom needs it, may actually contribute to the educational growth of the entire class.

The goal in assessment and provision of accommodations is to provide the child with the least restrictive environment in which to obtain the academic skills the child needs to succeed in life. Therefore, children with NMDs and other disabilities should be encouraged to use the skills and techniques that work best for them. In this way, the child's abilities are being accentuated and she or he will be more inclined to succeed because they are being included within the classroom.

Valuing Diversity: Inclusive Learning

This section discusses types of programming that will promote inclusion within the classroom. How a school system functions profoundly impacts how children are educated. Many schools today are incorporating diversity components into their curricula. Other schools are creating what are known as inclusive school communities (Stainbeck and Stainbeck, 1992). Both types of programming have been shown to increase opportunities for all children to develop self-esteem, accept diverse groups of people, and thrive both academically and socially.

These goals are attained through a commitment to the valuation of diversity and difference that is an integral part of the child's education. Children learn about diversity and its value throughout the curriculum. For example, while teaching a component on health and the human body, a discussion of different body types could be included that helps children understand that diverse body shapes can all be "healthy." Or, a discussion of a historical event might include several different perspectives of that one event (for example, the revolutionary war as seen by the revolutionaries, by the British, and by Native Americans). In this way, children are learning multiple skills at one time. They are learning in health class, for example, how to be healthy and that looking different is normal. This in turn provides the child with the building blocks of self-esteem related to body image and promotes the acceptance of different types of bodies as normal. Providing different perspectives on the same event in history not only teaches the child about the event, but also instills the idea that different people can see the same event in very different ways. This, again, promotes the acceptance of different opinions and cultures as a normal part of human existence.

By encouraging the valuation of differences, educators can offer an opportunity for children to learn more while covering the required curriculum. Although disability and other types of cultural awareness programming can be taught separately during a Disability Awareness Week or by studying African American literature and history during Black History Month, segregating it from the core curriculum

Disability Awareness Programs

Disability awareness programs often include several adults or young adults with disabilities who talk about their experiences as disabled people and can offer creative and fun ways for children to learn about disabilities. An awareness plan may include:

- Information about particular disabilities
- Age appropriate literature that has characters with disabilities
- Guest speakers with disabilities
- Diversity programming that shows how people are alike and different as general concepts
- Offers discussions of proper use of adaptive technology, service animals, etc.

sends a specific message to the students that diversity is not an integral and important part of society. As is discussed in the following chapter, these subtle messages tell children that it is acceptable to segregate peers who are different from the norm. By incorporating diversity programming into the curriculum, educators not only provide children with a well-rounded education, but also communicate the normalcy of diversity in everyday life.

This type of teaching values difference. However, many of these programs also recognize and respect the fact that people learn in different ways and that a one-size-fits-all approach to education does not provide the best education for all people. As a result, instruction is provided in a way that meets the needs of each student. This can be done in several ways. For example, an educator might use text, pictures, and hands-on material to help students learn multiplication tables. A multimedia approach to educating, like the one suggested above, repeats the information in several different formats. This not only reinforces the lesson, but also offers several different ways to learn the same information. Another example is reading along silently while someone else reads aloud. Because they have been given different approaches to receiving the same content more children learn the material. This method of teaching keeps the material fresh and interesting for all members of the classroom, while providing accommodations for those who need them. Although training and professional development may be needed to implement this type of classroom environment, the increased educational and psychosocial opportunities for all children make this a cost effective tool to increase excellence in education.

Accommodations that Promote Success in School

The child's unique learning profile will determine the types of modifications needed and these should be spelled out in the IEP or 504 Accommodation Plan. The following is a more detailed explanation of the kinds of alterations that may be required. As stated previously, every child is different and while some of the following accommodations may work for a particular student, other adaptations will not.

Physical Environment

The physical environment may need to be modified to allow the child access to the classroom, playground, or other areas in the school. Accessibility is critical when providing each child with an equal opportunity to learn and develop. Ramps may need to be installed in the school, as well as the widening of doorways to allow wheelchair access, and the modification of door handles to allow someone with limited use of their hands to open them independently. Adapted equipment may also need to be installed in bathrooms such as grab bars for transferring, wheelchair accessible sinks, and the lowering of paper towel and soap dispensers. Prior to the start of school, someone trained in making public spaces accessible can help identify the changes that need to be made at the school to allow access for the child and bring the school up to code. The school district will be responsible for seeing that the recommendations are followed so as to provide physical access and fulfill the legal mandate.

Types of Designated Instructional Services (DIS)

- **Speech and Language Therapy**
A credentialed practitioner provides speech therapy. His or her job is to assist the child in improving his or her speech and language skills.
- **Psychological Services**
Counseling and consultation provided by a credentialed school psychologist to address the mental health needs of students.
- **Occupational Therapy (OT)**
A trained professional provides OT to assist the child's development of functional skills to adapt to their physical disability.
- **Physical Therapy (PT)**
A trained professional provides PT to assist the child's development of gross motor skills (i.e. large muscle movements) and ambulation.
- **Adaptive Physical Education (Adaptive PE)**
A physical education instructor who specializes in Adaptive PE teaches the child various sports and recreational activities such as goal ball, wheelchair basketball, and track and field.
- **Health Services**
Health services are medical and personal care needs that are provided by the school nurse, a trained technician, or a care attendant. These types of services may include such things as assistance when eating, catheterization, giving child prescribed medication, and other personal care or medical needs the child either cannot or should not provide for themselves.
- **Instructional Assistant/Care Attendant**
A part or full time aide who assists the child in participating in educational activities (i.e. note taker or reader) in the regular (mainstream) classroom, and/or a care attendant who assists with physical care needs (i.e. helping with transfers in and out of the wheelchair or assisting with personal care needs).

Classrooms should also be arranged to promote physical access and independence. An important first step in promoting independence for children who use wheelchairs includes changing desks and tabletops to appropriate heights. Other classroom modifications that may be needed include arranging desks in the classroom so that the child in a wheelchair can move about the classroom without difficulty; adaptive seats for children who need additional support in order to sit for long periods in a chair; and/or making science lab equipment (e.g. sinks or workstations) wheelchair accessible.

Medical and Health Issues

Children with NMD may also experience health difficulties as a result of muscular deterioration. Respiratory complications may occur because of poor upper body support, and chewing and swallowing problems may occur in some types of NMD. Some children may require suctioning during the school day to prevent respiratory infection or they may

have specialized needs when eating. When a child has medical or health needs which require specialized physical health care services, a credentialed school nurse or other qualified, designated school employee can provide a complete evaluation of the child's needs. Collaboration and consultation with the child's physician will be a critical part of the assessment. Following this appraisal, a care plan will then be developed, which then becomes a part of either the 504 Accommodation Plan or IEP. The school nurse and/or other appropriate staff may need training to provide this type of support so that the child's education, health, and well being will not suffer.

Other environmental precautions may also be needed due to the increased susceptibility of children with NMD to health risks. Some children with NMD have immune systems that put the child at greater risk for disease and infection; therefore, necessary precautions include frequent hand washing by the child, teacher,

and classmates, as well as the use of protective gloves when administering anything orally. Again, if this protocol is needed, it should be a part of the child's IEP or 504 Accommodation Plan.

In addition to a specific care plan for the child regarding medical interventions, children with NMD may also need curriculum modifications in their 504 Accommodation Plan or IEP to accommodate frequent or prolonged absences from school because of illness or surgery. Parents and teachers will need to communicate frequently when the child's health needs change and result in absences. This may be done in a variety of ways, some of which have been discussed in the previous chapter.

Learning Disabilities

Students with and without physical impairments have learning disabilities. However, certain cognitive disabilities have been linked with specific neuromuscular diseases, particularly Duchenne muscular dystrophy (DMD). Although these issues have not been fully explored by researchers, enough information exists to confirm that children with neuromuscular diseases frequently have learning disabilities, cognitive impairments, and some behavioral problems. As a result, if children show evidence of any educational problems, or have a physical disability that is associated with a cognitive impairment, parents should arrange for an evaluation by a developmental neuropsychologist. These learning disabilities usually can be improved through special instruction in a mainstream classroom. Further, having a particular neuromuscular disease that has been associated with a cognitive impairment does not necessarily mean that every individual with that disease will have a learning disability. The research only indicates that these students are at an increased risk for cognitive deficits, and thus should be evaluated if any learning problems develop.

There are a number of traits that identify a student with a cognitive impairment. For example, if a child appears to have problems with schoolwork, cannot focus or complete tasks, or has difficulty making friends, he or she may have a learning disability. Often, despite dedicated work in school, the student will seem to make no progress or will act frustrated with certain material. For instance, "Jake," a boy with DMD, could not read his third grade texts, but could comprehend the material when his parents read the books to him. Also, he had auditory processing problems, which kept him from remembering more than a few directions at once. His parents learned to write longer lists of instructions, instead of directing him verbally. Individuals may have difficulties with many subjects depending on the disability, including English or math. If an evaluation shows that a student has a problem, the teacher can adopt specific strategies to help the child learn. First, the evaluation should show the specific issues a child has, and what the professional developmental psychologist believes to be the best approach to improve the student's education. The IEP should include information about this recently observed cognitive impairment and parents and educators may want to hold a conference to decide what action to take. This program might also incorporate specific instructions for the educators of the child, such as using multi-modal strategies or lecture notes. If possible, children should remain in a mainstream classroom with their peers.

In particular, recent studies associate DMD with specific cognitive impairments. Other neuromuscular diseases also may be correlated with learning disabilities, but the

most comprehensive research focuses on DMD. Scientists have discovered that people with this impairment have an average IQ of around 80, but individual scores range from very low to very high. However, the IQ scores do not represent global learning issues, and for many individuals with DMD, does not appear to affect the brain at all. Children with DMD are born without the protein dystrophin in their tissues, including in their muscles and brains. Our brains normally process words as phonemes, or clusters of sounds. However, in children with DMD, a higher proportion of individuals process verbal information differently, or not as well. Consequently, approximately one-third of students with this disability display signs of cognitive impairment that influence IQ scores, specifically affecting their short-term memory, reading comprehension, ability to process verbal data, and occasionally their emotional state. The most significant and common issue for these individuals consists of problems with verbal short-term memory, which can cause difficulties in many aspects of education. For instance, a child with DMD may have difficulty remembering and following long verbal instructions, learning new vocabulary, and comprehending texts. Also, when the individual experiences phonological processing deficits, and thus cannot discriminate and process speech sounds as well, he or she often has a problem reading. These issues resemble dyslexia, a learning disability where a student struggles to differentiate speech sounds, and attention deficit disorder (ADHD), a behavioral problem that includes hyperactivity and distractibility. Younger children often experience greater difficulties related to these cognitive impairments because of the importance of early verbal development, but can improve with the aid of teachers. In addition, the absence of dystrophin affects emotional interactions in some children, described as emotional immaturity or a lack of connectedness with others. However, educators can also assist with this issue.

Other neuromuscular diseases have also been connected with learning disabilities. For example, research connects some children with hereditary motor sensory neuropathy and hereditary spinal cerebellar ataxia to a specific cognitive impairment. Although intelligence test scores were normal, detailed examinations showed that these individuals have problems with spatial construction. Students with facioscapulohumeral dystrophy and limb-girdle syndrome also appear to have some type of learning disability, but studies have not determined the specific nature of this impairment. However, not all individuals will exhibit any of these deficits, and others will be affected in different ways. Further, other neuromuscular diseases such as Becker's muscular dystrophy and spinal muscular atrophy do not seem to be linked with any specific learning disabilities. In addition, children may have learning disabilities or behavioral problems unrelated to neuromuscular diseases.

Parents and educators should adapt their approaches to teaching and giving instructions if a student in their class has a learning disability. For example, teachers could shorten and simplify verbal instructions, and write information on handouts or on a blackboard when lecturing. The instructor may also wish to repeat statements, particularly if they included a large amount of information. This will help children who have problems remembering verbal information understand and remember instructions and facts. All students will also benefit from multi-modal techniques of imparting data, such as combining audio, visual, and tactile forms of information. School texts recorded on cassette tapes or compact disks may assist individuals who have difficulty comprehending written material as well as verbal material. In addition, instructors might

place children who cannot focus as well as others in the front of the classroom, where the instructor can pay greater attention to the student and he / she can concentrate more easily. Those with short-term memory problems or issues related to ADHD should keep a written daily assignment planner, and learn organizational techniques. Teachers should consider restructuring any lessons or educational strategies (e.g. testing, long lectures or lengthy reading assignments), that might prove more difficult for individuals with these learning disabilities. However, the educator should not make lessons less challenging for the student. Instead, the goal of these adaptations should be to allow the child to learn in the best environment possible for him or her. Most importantly, both teachers and parents must remember that, although many children with DMD possess these disabilities, they do so to varying degrees, and some may not be affected at all. As a result, every student should be treated as an individual, not as someone with a potential learning impairment.

Curriculum

Modification to classroom instruction and curriculum is perhaps one of the most critical forms of adaptation, and is performed to promote independence and the opportunity for success within the classroom. The classroom teacher can adapt or change activities so that students with disabilities can successfully participate in the curriculum. One way of modifying instruction is through the use of cooperative learning groups.

Cooperative learning structures can facilitate learning while, at the same time, promoting a supportive social network with classmates. In addition, specific modifications to materials and curriculum can increase achievement and completion of work. Children with NMD who may become fatigued faster than other students or who have difficulty sustaining attention for long periods may need shorter assignments or extended time to complete assignments so that breaks can be taken. The goal of the learning activity will be the same for all students; however, the outcome or product may be altered for those with disabilities by reducing the amount of written work, by providing more time to get the same amount of work done or by providing additional organizational support. For example, an outline of the topic to be written about might be given to the student in advance to help facilitate the completion of the assignment in a timely fashion.

Providing alternate methods for students to demonstrate an understanding of a concept can also facilitate learning. There are many ways to adapt instruction to meet the needs of individual students. For example, some alternate approaches that can be used to allow students to demonstrate their skills and knowledge include assigning team projects, oral reports, and/or computer-assisted learning assignments. The acquisition of the specific skill or knowledge should remain the goal, while the assignment may provide an alternative way of acquiring and assessing those abilities of the disabled student.

Expectations

Often, teachers and parents are unsure of when to challenge their child and how to do it. For a student with NMD, fatigue can play a role in academic output, and there may be times that the child will make more or less progress in the curriculum depending

on the course of his / her muscular dystrophy. This fluctuation in performance can be confusing to both parents and educators. A child who is fatigued may be inaccurately perceived as not trying hard enough or being lazy. It will be important to evaluate which times of day the child is most alert and able to do academic tasks, as well as when the student needs a break. Keeping a record of when a child is normally more alert may help in determining when a student is more receptive to the education process.

There are several ways in which teachers and parents can evaluate a child's progress and develop appropriate methods for achieving expected outcomes. The use of an academic portfolio can provide concrete and specific examples of a child's development. In addition, frequent and more informal assessments of the child's improvement can provide the teachers with information about how the child is functioning in the classroom and curriculum. These types of informal assessments have also been found to be beneficial to children without disabilities, because they provide children with concrete examples of their continuous progress acquiring skills, which can boost their self-esteem. They can also be used as a kind of early warning system to show when a child may be developing problems in a particular area. In this way, educators will have the opportunity to help the child before he/she becomes discouraged.

Assistive Devices

Adaptive equipment and assistive technology can have a profound impact on a student's functioning in the classroom. Recent advances in technology, especially in the area of computer technology, have promoted independence for many individuals with disabilities. The well known physicist, Stephen Hawking, is one example of an individual with NMD who uses an augmentative computer communication system that allows him to communicate and be successful in his chosen profession. If needed, funding is available for children with disabilities, such as NMD, to attain this type of equipment. Therefore, every child with NMD who may benefit from technology should be assessed.

The goal of assistive technology is to promote access to the curriculum and school environment, as well as to increase independence. Areas to consider for assistive technology include: communication, mobility, self-help, and activities of daily living, fine and gross motor skills, as well as cognitive or learning requirements. When the IEP team determines a need, a referral to a qualified assessor can be made to gather important information about the child's assistive technology needs.

Assistive technology experts can help the teacher, parents, and child find ways to promote learning in the classroom. Assistive devices can include simple modifications, such as a calculator, an adaptive spoon or other eating utensil to promote independence in feeding, or an adaptive pencil grip which can reduce fatigue when writing. They can also be very high-tech such as computerized speech technology. Additional devices might include: an adaptive switch to help the student turn on and off electrical equipment; a voice activated or modified computer to assist in communication and in written work (e.g. *Dragon Naturally Speaking* or *Scan Read*); software programs which promote organization and achievement and facilitate written effort (e.g. *WYNN Wizard* or *Quick Fire*); and physical equipment, such as a hand rail, a manual or power wheelchair, an adaptive chair or desk, and even adaptive play equipment, such as a

powered mobility toy. Again, each child will be different. While *Dragon Naturally Speaking*, for example, may work for one child, it may not work at all for another. This is why assessments should always be done in collaboration with the child. When choosing assistive technology devices, it is important to include the student in the evaluation and decision making process. In addition, it may help to offer choices and opportunities to "test drive" or try out the device to evaluate how useful it may or may not be to the student. Although not all manufacturers of adaptive technology allow sampling of the product, many will provide a sample if asked. Trying out a variety of equipment and devices allows teachers and students to find the best "match" for the child's specific educational needs. Once a decision has been made, the piece of equipment can become a part of the child's educational tools just as pencils and books are scholastic tools. Keep in mind, the teachers, parents, and student will need to be trained in the proper operation of the technology. For example, teachers and staff will need instruction on the appropriate use and care of the child's wheelchair. Instruction on the proper use, care, and safety measures of a particular piece of technology may be given by the student, the parents, a school staff member or by an outside training person (such as an assistive technology expert or durable medical equipment provider).

Physical Education

Physical education, (PE), is often a daily educational activity in elementary school. Children with motor difficulties will frequently need modifications and assistance when participating in a PE program. Alternative activities can be provided to the student when involvement in the PE activity for that day is not appropriate. Some students may have a doctor's exemption from the PE requirements, if participation is not possible due to health reasons. However, many students with NMD will be able to join with accommodation, such as giving them a non-physically demanding role like scorekeeper. Other students may be able to participate in the activity, but with modified equipment or an alternative way of contributing. For example, when playing baseball the child with NMD may be able to hit the ball on a stand and maneuver her/his wheelchair to the bases. Adapted PE teachers can consult with the child's classroom teacher or PE teacher and can provide direct instruction to the child with a physical disability. As in most instances, an important step consists of including the student in the planning and decision making process concerning physical education activities. It is critical that the child has an opportunity to participate and be a part of the activity in any manner possible. Brainstorming ways to adapt the activity and include the child should be an ongoing part of the educational process.

Peer Support

Peers can provide social support and assist in specific ways in the classroom. Peer encouragement can offer a cultural/social means of help to students both with and without disabilities. For example, new students with and without disabilities often need help adjusting to a new classroom and school and can benefit from other students' assistance. This form of support offers students an opportunity to help others and provide social support to them. Students with and without disabilities should be encouraged to be a part of the peer support team. By being both a recipient and a giver of aid, students learn the value of cooperation and social responsibility.

Teachers can play an important role by encouraging appropriate peer support. For example, the teacher may split the class into teams that have to utilize their collective skills in order to complete a task or to win a learning game. When classrooms view peer support as a “norm” or a natural part of the classroom experience, helping others becomes a normal part of the day. For example, peers can assist in getting materials that are difficult for other students to reach or they can help another student learn a concept that individual is having a hard time grasping. Educators can also use this approach to create collaborative learning projects for the class that utilize cooperative efforts for completion. In this way, the instructor can encourage socialization, cooperative learning, networking, and social responsibility amongst the students.

Conclusion

Children may need a variety of support approaches during the educational process. Every child needs the least restrictive environment in order to succeed in an academic setting. Children with disabilities are no different. Some may need many accommodations to equalize the playing field, while others may need very few. By focusing upon the goal of educating every child, while assessing the individual needs of each child, all children are served better and have an equal opportunity at an equal education.

Appendix A
Example of an Individual Education Plan

INDIVIDUAL EDUCATION PLAN

Student: Joey Cartwright
Address: 1234 Starbright Lane
Phone: (555) 555-5555
Birth Date: December 4, 1989
Parent/Guardian: Jill & John
Cartwright

IEP Meeting Date: September 1, 1998
Purpose of IEP: Initial placement
Grade: 4 Age: 9
Teacher: Ann Rose
School: Eisenhower Elementary

Team Members Present:

Jill & John Cartwright	Parents
Mrs. Rose	Teacher
Mrs. Fuentes	Principal
Mrs. Johnson	Resource Specialist Teacher
Mr. Allen	Adaptive P.E. Teacher
Mrs. Holden	School Psychologist
Joey Cartwright	Student

Educational Services/Instructional Individual Responsible for the Service Placement

Regular (mainstream) education classroom	90%	Classroom teacher
Resource Specialist Services		RSP teacher
Consultation to classroom	10%	
Adaptive Physical Education		A.P.E. teacher

Date services will begin:

September 1, 1998

Duration of services:

One year.

Instructional minutes:

300 school day minutes

Time in the regular (mainstream) education program:

270 minutes in regular (mainstream) education

Justification for the educational placement: William has benefited from participation in the regular (mainstream) curriculum. Consultation from R.S.P. with regular (mainstream) classroom modification was determined to be the most appropriate and least restrictive program for William.

PARENT/GUARDIAN APPROVAL (INITIAL AND SIGN BELOW):

____ I have participated in the development of the IEP, received a Parent's Rights copy, and had my rights as a parent/guardian explained to me.

____ I consent to my child's participation in the Special Education program and/or related services.

____ I do not consent to my child's participation in the Special Education program.

____ I consent to all components of the Individualized Education Program with the exceptions noted (attached). I understand those components that I consent to may be implemented so as not to delay provision of services to my child.

____ I consent to my child's dismissal from Special Education.

____ I understand that my child does not qualify for Special Education at this time.

Signature: _____ Date: _____

Signature: _____ Date: _____

Current Level of Educational Functioning	Annual Goals	Instructional Objectives	Measured by:
<p><u>Motor/Physical Education</u></p> <p>Strengths: 1. Can throw a ball five feet 2. Independent with wheelchair 3. Plays wheelchair basketball</p> <p>Needs: 1. Develop skills in team sports in adaptive P.E. and extracurricular activities</p>	<p>1. Participate in team sports during P.E. and extracurricular activities weekly.</p>	<p>1. Hit a ball with an adapted bat and T during softball games in P.E. and extracurricular sports. 2. Independently negotiate bases during a softball game.</p>	<p>1. Adaptive P.E. teacher will observe during P.E. team sports and evaluate use of adaptive bat and T and ability to negotiate bases during a softball game.</p>
<p><u>Reading</u></p> <p>Strengths: 1. Can read 3rd grade text well. 2. Can answer main idea comprehension questions at 3rd grade level.</p> <p>Needs: 1. Weak phonological skills. 2. Weak reading word vocabulary. 3. Weak 4th grade reading comprehension.</p>	<p>1. William will read beginning 4th grade materials with fluency. 2. William will comprehend beginning 4th grade reading materials.</p>	<p>1. Given a word followed by a series of four words, William will select the word that rhymes with the first word given. 2. Given a list of non-sense words, William will visually and auditorially blend the letters by reading the words they make. 3. When given a list of 50 sight words at the beginning 4th grade level, William will read the words correctly 9 out of 10 times.</p>	<p>1. Resource specialist will evaluate rhyming skills, phonological skills, and sight words using the Woodcock Johnson Revised and the Rhyming Phonological Awareness Assessment Measure.</p>

Current Level of Educational Functioning	Annual Goals	Instructional Objectives	Measured by:
<p><u>Written Language</u></p> <p>Strengths: 1. Uses computer skills to write book reports. 2. Writes complete sentences using four words.</p> <p>Needs: 1. Weak sentence construction and punctuation. 2. Weak skills in story writing.</p>	<p>1. William will write a short story with accurate sentence structure and punctuation.</p>	<p>1. Given a group of sentences, William will correctly punctuate with periods, question marks, comas, and capitalization.</p> <p>2. Given five sentences, William will identify the nouns, verbal, and adjectives.</p> <p>3. Given a subject, William will write a story containing a beginning, middle and end.</p>	<p>1. Resource specialist and classroom teacher will evaluate written language using a portfolio assessment. The Woodcock Johnson Revised will also be used to evaluate written language skills.</p>

Current Level of Educational Functioning	Annual Goals	Instructional Objectives	Measured by:
<p><u>Self-Help/Adaptive Behavior</u></p> <p>Strengths: 1. Uses wheelchair for mobility independently. 2. Self-care skills are also independent.</p> <p>Needs: 1. Transferring self from wheelchair to other chair when needed.</p>	<p>1. William will transfer from his wheelchair independently when needed</p>	<p>1. During toileting William will transfer partially to the toilet with assistance from the school aide. He will learn how to use the assistive devices in the bathroom to assist himself. 2. William will transfer independently to the toilet with minimal assistance from the school aide. 3. William will transfer to other types of furniture as needed with minimal assistance.</p>	<p>1. The occupational therapist will observe transfers and evaluate ability to use devices and assistance from others.</p>
<p><u>Social-Emotional</u></p> <p>Strengths: 1. Friendly and liked by classmates.</p> <p>Needs: 1. Learning how to be assertive. 2. Joining in play with other children.</p>	<p>1. William will develop social language skills that will increase his ability to be assertive.</p>	<p>1. William will ask his teacher or classmates to assist him when needed each day. 2. William will invite another student to participate in a game or to play daily. 3. When given a hypothetical situation of when he might need assistance, William will state two possible ways that he could be assertive.</p>	<p>1. Classroom teacher and school psychologist will observe William during school and interview him regarding ways to be assertive and ways to join in play at school.</p>

Appendix B
Example of a 504 Accommodation Plan

504 ACCOMMODATION PLAN

Name: William Jones

School: Martin Luther King Elementary

Birth Date: Oct. 23, 1990

Teacher: Mrs. Hanson Grade: 3rd

Age of child: 8 1/2

Disability: Becker's Muscular Dystrophy

A student study team/support team has identified both strengths and needs for William:

STRENGTHS

NEEDS

Cooperative and friendly

Extra time needed to complete tasks

Knowledgeable in science

Math is three months behind

Smart creative thinker

Reading is 8 months behind

Very adept with a computer

Spends time alone during recess

Feeds the class pets

Fatigues quickly during P.E.

Good sense of humor

Becomes distracted, especially when fatigued in the afternoon

William's needs have been determined by this team to significantly impact his/her learning and ability to participate in the school curriculum and activities, and therefore, this team recommends a 504 accommodation plan. The team suggests the following modifications in his/her regular (mainstream) class, lunchroom, and/or schoolyard to accommodate his/her needs.

- Provide a structured learning environment that includes:
Structure written assignments using graphic organizers and story charts. Use comprehension wheels to facilitate book report writing. Provide opportunities for frequent practice of newly learned materials. Provide frequent and specific feedback about William's progress.
- Provide the following architectural modifications for accessibility:
No structural modifications are needed at this time.
- Provide instruction in organization strategies:
Teach William study skills that will help him complete class work and homework. Provide him with a daily study schedule at home and at school with specific instructions on what work to complete for that day.
- Give the student additional time to complete assignments:
Provide William with adequate time to complete class work and homework.
- Provide the following materials/adaptive equipment to assist learning:

Provide William with access to the classroom computer for writing assignments when possible. Provide an adaptive pencil grip to help reduce fatigue when writing.

- Select modified textbooks and workbooks:
Provide William with reading materials that will challenge him and develop his reading skills.
- Tailor homework assignments:
Modify homework using a combination of team projects and homework daily progress reports. Provide William with a homework folder with the daily progress report.
- Use a one-to-one peer or cross-age tutor:
Use a cross-age tutor twice weekly during the third grade class reading time and utilize one-on-one peer reading within the classroom.
- Home-school communication:
Meet monthly to review progress and discuss further modifications. When William demonstrates adequate progress, the team meetings can take place as needed.
- Modify test delivery:
Provide William with more time to complete tests. He can take the tests in the reading room to reduce distractions.
- Use behavioral management techniques:
Provide frequent feedback to promote work completion.
- Modification of non-academic times such as lunchroom, recess, and P.E.:
Consult with adaptive P.E. teacher regarding appropriate modifications for regular (mainstream) classroom P.E. Provide William with alternative activities during P.E. when he is fatigued. Begin a science club during lunch recess for third and fourth graders twice weekly. Provide alternative games and activities during recess, such as computer games and board games.
- Adjust class schedules:
No adjustment is needed at this time.
- Other:
Provide staff with in-service on muscular dystrophy to increase awareness of this disability and provide teachers with an opportunity to learn about helpful classroom modifications.

PARTICIPANTS' SIGNATURES:

Appendix C

IEP-Individual Transition Plan

Student's Name: Timothy Smith

Date of Meeting: 01/02/02

Projected Transition Date/Graduation: 7/02/03

Team Members Present:

Mrs. Gibson – Itinerant OH Teacher

Mr. And Mrs. Smith -- Parents

Mr. Ray – High School Counselor

Timothy Smith -- Student

Ms. Fields – School Psychologist

Mr. Hamm – Regional Center Rep.

Ms. McNeil – Dept. of Rehabilitation

Mrs. Roberts – Program Specialist

Mr. Lott – Math Teacher

Long Range Plans (Desired Post-School Outcomes):

- Instruction: Research skills on a voice activated computer and learn to use voice - activated software.
- Community Experience: Transition to adult services—Independent Living Services to access community resources.
- Employment: Interest in Math for College Major
- Daily Living Skills/Functional Vocational Evaluation Activities: Teach self-advocacy for working with personal aides.

Activities to Support the Above Outcomes:

Activities	Responsible Persons	Time-line	Completion Date
<p>1. Instructional: Timothy will maintain college eligibility in school and will be aware of needed University requirements. Timothy will use voice activated word processor to research colleges on the internet.</p>	<p>Student, Family School, Counselor</p>	<p>1/02 – 1/03</p>	
<p>2. Community Experience: Timothy and his family will coordinate with the Regional Center and the Dept. of Rehabilitation to secure independent living services, including personal assistants.</p>	<p>Student, Family, Regional Center, Dept. of Rehab.</p>	<p>By 18th birthday</p>	
<p>3. Development of Employment and Other Post-School Living Objectives: Timothy will continue to pursue interests in math, and will attend the annual regional math conference. Timothy will apply to 4 year Universities.</p>	<p>Student, Family Math Teacher, School, Counselor</p>	<p>1/02 – 5/02</p>	
<p>4. Daily Living Skills/Functional Vocational: Timothy will work with educational aides and personal aides, communicating with them effectively.</p>	<p>Student, Aides, Teacher, Regional Center</p>	<p>1/02- 1/03</p>	

Student Participation:

Document how student's input, interests, and preferences were obtained:

Student participated in the transition planning and shared interests and goals.

Individual rights have been provided at least one year before becoming a member of the majority age (18): yes

Appendix D

Example of a Blank 504 Accommodation Plan Form

504 ACCOMMODATION PLAN

Name: _____ School: _____

Birth Date: _____ Teacher: _____ Grade: _____

A student study team/support team has identified both strengths and needs for
_____:

STRENGTHS

NEEDS

[Child's Name] needs have been determined by this team to significantly impact his/her learning and ability to participate in the school curriculum and activities, and therefore, this team recommends a 504 accommodation plan. The team suggests the following modifications in his/her regular (mainstream) class, lunchroom, and/or schoolyard to accommodate his/her needs.

- Provide a structured learning environment that includes:

- Provide the following architectural modifications for accessibility:

- Provide instruction in organization strategies:

- Give the student additional time to complete assignments:

- Provide the following materials/adaptive equipment to assist learning:

- Select modified textbooks and workbooks:

- Tailor homework assignments:

- Use a one-to-one peer or cross-age tutor:

- Home-school communication:

- Modify test delivery by:

- Use behavioral management techniques:

- Modification of non-academic times such as lunchroom, recess, and P.E.:

- Adjust class schedules:

- Other:

PARTICIPANTS SIGNATURES:

Appendix E

MAINSTREAMING CHECKLIST

- ❑ Physical arrangement of classroom (i.e., desk and equipment placement) allows for access to materials.
- ❑ Physical arrangement of classroom allows for access to peers.
- ❑ Emergency plan has clear procedures for addressing the evacuation of a person with a disability (i.e. an extraction point for people who use wheelchairs that are on a floor other than ground level). The child should be made aware of these procedures so they may act appropriately during a drill.
- ❑ Training for school staff regarding the disability, inclusion, guide/service dogs, wheelchair safety, and other health and educational issues is provided as needed.
- ❑ Fatigue – how to identify it, how the child and teacher can recognize and communicate this need, and how to address it in the school day.
- ❑ Share IEP information and discuss accommodations necessary for the child. Consider 504 Accommodation Plan when appropriate.
- ❑ Consider a peer support system in the classroom (i.e. a buddy system or cross-age tutor) when appropriate.
- ❑ Recess and lunchtime have alternative activities that the child and peers can engage in (i.e. computer games, adaptive equipment, etc.) that will promote peer interactions and the development of friendships through common interests and abilities.
- ❑ Adaptive equipment and assistive technology needs are evaluated and requested through Low Incidence Funds via the IEP when needed to address educational goals.
- ❑ Informal or formal conferences are scheduled on a regular basis to ensure ongoing communication and collaboration.
- ❑ Teacher-child talks take place frequently, either informally or formally to promote communication and to give specific feedback on what is working well and what needs improvement.

- ❑ Increase social access to peers by planning group activities, team projects and other social and educational interactions that will encourage students to form support networks.
- ❑ Accessible transportation is provided to and from school and planned for when organizing class field trips.
- ❑ Special Education Personnel are available to teachers and parents to share expertise and information regarding classroom modifications and adaptations.
- ❑ Adapted physical education services are considered when necessary.
- ❑ Curriculum modifications to consider: 1) Modifying assignments and tests so that they accomplish the same goal and accommodate for fatigue or other condition related to the disability (i.e. shortening written assignments, providing oral exams and reports, providing extra time to complete the task, etc.); 2) Utilize assistive technology such as computer writing programs, text-to-speech software, speech-to-text software, etc.); 3) Institute and encourage team or cooperative learning networks; 4) Provide and encourage frequent and specific feedback on academic work.

- **Appendix F**

YEARLY TRANSITION CONFERENCE

- Educational, health and medical information is shared with next year's teacher by the child, parents and school staff during the spring transition meeting.
- A scheduled observation of the child, in her/his current classroom, by the teacher instructing the child the following year should be done. This observation will help the new educator to get to know the child's strengths and weaknesses as well as familiarize them with the accommodations the child requires.
- A teacher-child conference is held with next year's teacher so that the child can communicate any needs, wishes, and to establish clear and open communication with the teacher before the beginning of the school year.
- Resources are shared with next year's teacher, such as successful classroom modifications, adaptive equipment, and agencies that might provide information, and people who can be available to him/her when needed.

Chapter 5 Addressing Social and Emotional Needs

All children have unique social needs that impact their daily lives. Some children have to be the center of attention, while others prefer to be alone, and still others fall somewhere in-between. As they grow, children learn socially acceptable behavior along with what their personal preferences for social interaction are. Most children begin learning what is considered socially appropriate behavior in the home.

Parents and siblings, through modeling behavior in interactions with others and through specific interactions with the child, teach the child what the family considers appropriate behavior. For example, if siblings give in to the child every time she or he screams, the child is being taught that the appropriate way to get what he or she wants is to scream. While different children might desire different things, the interaction is teaching the child that this is the appropriate behavior to get what he/she wants. The same is true of other types of social activities including resolving conflict, gaining attention and making friends. Children learn by observing others.

These lessons learned at home continue to be learned within the educational setting. As the child's world expands to include more and more varied social situations, the child learns what society feels is appropriate behavior in each circumstance. As the child grows, she / he learns about himself / herself as well – the types of social interactions preferred, the most comfortable types of interactions with people, and the type of people he / she would prefer to be around.

A major developmental task for children is to establish mutually satisfying relationships with other children. School is where this happens most frequently. Negotiating peer interactions in school, on the playground and in other relevant social environments is a daily task for all children. Successful negotiation leads to the development of friendships and a sense of belonging, two critical elements of psychosocial well-being.

Children also have a variety of stressors in their lives, as well as a variety of coping mechanisms and varying levels of coping ability. Stressors that affect the family often become stressors for the child. For example, financial difficulties, problems with siblings or parents' work stresses can frequently become stressors for a child that may or may not be reflected in the child's behavior at home or at school. All children deal with some amount of stress, some more than others, and each child may handle stress in a different way. While some students might handle the divorce of parents rather well, others will be completely

incapacitated by this event. Some might withdraw or seek time alone. Others might lash out. Still others may not change their outward behavior at all. Each child may handle the situation differently. This may be for a multitude of possible reasons including type of familial support, the child's personality and the maturity level of the child. Different children will require different amounts or types of help to handle the stressors that arise in the child's life.

Just as social interactions are learned, the way a child handles (or doesn't handle) stressors is also learned. These skills are first learned within the home environment in much the same way social behaviors are learned. Some students will

come to school equipped with a set of coping mechanisms already established and will simply build on these skills in the educational setting. Others will not be as well prepared or have what are frequently considered inappropriate coping mechanisms (e.g. bullying, fighting or passive aggressive behavior). They will have to improve their skills or learn different coping strategies to use while in school. These skill levels and skill sets, in combination with the child's personality and what has been learned as appropriate social behavior, are what makes each child's emotional and social needs unique.

Children with disabilities are no different. They learn what is considered appropriate social behavior through their interactions with others around them and have a variety of personalities and preferences for social interaction. They also have a range of stressors in their lives and learn to handle them the same way other children do (observation, modeling, and social interactions). And, like non-disabled children, disabled children will come to the educational setting with different levels and types of coping skills.

The difference between children with and without disabilities, in terms of behavior, frequently consists of the information that has been relayed to the child, not the way it has been taught. In other words, children with disabilities frequently get different messages from society indicating what socially appropriate behavior is and how to cope with various situations. For example, those around the disabled child might accept certain behavior, such as throwing things to get attention that would not be accepted from a non-disabled child. While positive reinforcement of appropriate behavior (or negative reinforcement of inappropriate behavior) might be used to teach the non-disabled child what is appropriate, refraining from correcting this same conduct in the disabled child gives the message that what is being done is socially acceptable. This training, in combination with the messages children receive about how society feels about people with disabilities, creates added and unnecessary stressors for children with disabilities and tends to create different outcomes for them socially.

Just as non-disabled children learn how society feels about them, disabled children learn that they are considered different and "wrong." They discover this cultural attitude through a variety of social experiences. When they have to ride a different school bus than their non-disabled peers, when doctors discuss treatment to "fix" or alter them, when they watch TV and do not see disabled persons, when video games do not include disabled characters, they receive the message that this culture feels that people with disabilities are "defective," "less than," and a problem (Davis, 1995; Longmore, 2003; Shapiro, 1993). Non-disabled children receive these same messages as well. When they see children with disabilities in a "special" classroom or riding a different bus, for example, they are being taught that disabled people are different and "different" in this society is not considered culturally acceptable. Therefore, all children are being taught culturally specific messages about disability and what is an appropriate response to disability.

Different children react to these cultural messages in different ways depending upon a variety of factors. Both disabled and non-disabled children tend to internalize these cultural messages in much the same way that other social messages are internalized. While non-disabled children may experience affirmation of their status in society from these situations, children with disabilities have their lack of status in the

population affirmed. Although everyone in society receives the same basic cultural messages, not all people will accept or respond to these social norms in the same way. While some may readily accept societal beliefs, others will not and, frequently, how a child is taught to think about societal norms affects the child's responses and behaviors.

As children of other minority groups who frequently receive negative messages about themselves may experience stress, children with disabilities may consciously or unconsciously experience stress related to cultural messages. This experience can cause depression and a host of behaviors or desires that may not be readily viewed as problematic by the larger society (e.g. an African American girl who desires blue eyes and blonde hair or a deaf child who desires to communicate as hearing people do). These desires are the way some children show that they have internalized the larger social problem of discrimination and prejudice. Others may exhibit self-doubt when it comes to new social environments. Still others may be more aggressive, try to please everyone or display signs of depression. Still others may become involved in social activism, the arts, athletics or some other outlet that allows them to express themselves and handle the situation in another way.

In this chapter, we will examine some of the ways adults can help children with disabilities learn the social skills they need in society and we will suggest ways to alleviate some of the social inequalities that exist in most schools across this country. While all children need to learn appropriate social behaviors and how to deal with stress, these aspects of a child's developmental process are frequently ignored or are not a part of a disabled child's educational experience (either in or outside the classroom). The following are some suggestions to help the disabled child learn to socialize with her or his peers, to cope with stress, and to deal with discrimination when it occurs.

The following suggestions are specifically related to children with NMD. They are not a complete set of suggestions nor will they necessarily work for every child in every situation. Like all children, children with NMD are unique individuals from unique backgrounds with unique sets of skills and experiences. These are simply a few ideas that may elicit other thoughts and solutions that may work for the unique situation that the student with NMD is encountering.

Promoting Social and Emotional Development

For children with NMD, emotional growth may be particularly demanding because the progressive nature of the disability may create added frustrations. The development of adaptive coping skills and the provision of social support is critical for these children in order for them to have a high quality of life.

Emotional development is paramount over almost all other aspects of growth in childhood. We can see children grow up physically and observe their growing mental capacities, but they are also gaining self-control and skill in interacting with others. As stated in the introduction, these skills are needed and learned by all children, including children with NMD. While the stressors may be different for disabled children with NMD, these children still

need to develop the skills that will help them live in society.

As a group, children with chronic illnesses and physical disabilities are at risk of experiencing social-emotional difficulties. In a review of the clinical literature, which has principally focused on myotonic muscular dystrophy, Livneh & Antonak (1994) report that children with muscular dystrophy experience psycho-social reactions to their social environment including: (a) codependency related to the over protectiveness of parents; (b) social isolation due to negative attitudes of peers and shame about their physical appearance; (c) negative body image and self-concept; (d) feelings of helplessness due to increasing dependency on others; (e) anxiety over impending death; (f) depression;

Potential Stressors for Children with NMD

- ❖ Coping with medical appointments and interventions and frequent absences from school
- ❖ Coping with lack of physical access within the school and the community
- ❖ Coping with changes in physical abilities due to the progressive nature of the disability, such as going from walking unaided to using a walker to using a wheelchair
- ❖ Coping with changes in self-help skills due the progression of the disability, such as being able to dress without assistance to needing some assistance to needing someone to complete the task
- ❖ Coping with prejudicial beliefs of adults and peers
- ❖ Coping with people not understanding or believing the child has a disability – for some children their NMD (or aspects of the condition, such as fatigue or pain) are not visible
- ❖ Coping with fatigue and/or pain
- ❖ Coping with completion of schoolwork while dealing with pain, fatigue, etc.
- ❖ Coping with familial attitudes such as grieving, towards their disability
- ❖ Coping with their own mortality (some forms of NMD shorten lifespan)
- ❖ Coping with a lack of opportunities to interact and form relationships with peers

and (g) anger toward parents and peers without disabilities. The research on children with myotonic muscular dystrophy does not necessarily reflect the psychosocial experiences of all children with NMD. However, when adults with Charcot Marie Tooth disease were interviewed about their school and social experiences, many reported that they became more introverted in school and that their relationships with peers were negatively affected by their introverted behavior (Goldfarb & Shapiro, 1991).

This picture is not necessarily as bleak as it may appear. Although research with children with chronic illnesses and physical disabilities indicates that, when, along with unequal opportunities, there are inadequate levels of social support from family, peers, and teachers, the children may experience more depressive symptoms. When children with disabilities or chronic illnesses experience adequate levels of social support and a more inclusive environment, they exhibit significantly fewer symptoms of depression. In one study, 153 mothers of children (ages 4 to 16) with a chronic physical illness or disability (including juvenile diabetes, juvenile rheumatoid arthritis, chronic obesity, spina bifida, and cerebral palsy) were asked about the behavior of their children and the family environment.

Those children with physical disabilities or chronic illnesses who had little family support and little peer support had more problems with disruptive behavior. Those with little peer support had more problems with depression and anxiety (Wallander & Varni,

1989). Teachers, parents, and peers play a critical role in the promotion of equal social opportunities, social support and the acquisition of coping skills for all children.

As stated previously, all children experience stress and children with disabilities are no exception. While disabled children have to cope with the same types of stressors as their non-disabled peers, they also have to contend with stressors specifically related to being a person with a disability in a discriminatory society. For example, a child may not only have to deal with the financial stress that paying for a field trip could place upon the family, but also may have the anxiety and frustration of knowing that, even if the trip is paid for, he/she still may not be able to go because the trip has not been made accessible by the school (lift-equipped transportation not provided, dietary needs not being met or the venue not being accessible). These types of stressors combined with being in a situation of having to take on adult responsibilities (understanding and explaining the NMD to others, being responsible for medication or the use and care of high-priced adaptive equipment) create a unique situation for children with disabilities. While, on some level, society expects people with disabilities to be perpetual children (Shapiro, 1993), children with disabilities have to take on some fairly adult responsibilities and frequently are not provided the opportunity to learn the skills needed to successfully accomplish the tasks without undue stress. Later in this chapter, we will come back to the issue of teaching children how to cope with the types and levels of stress experienced by adults.

Not only is it essential to recognize the types of stressors a child might be dealing with, it is also important to understand the development of coping abilities and the need for social-emotional support for children. As stated before, stress impacts individuals differently depending on many factors, including differences in coping ability and the availability of social support from friends, family, and the community. Furthermore, coping ability develops within a broader context of emotional development. In order to better understand the experiences of children with NMD, it will be helpful to consider their emotional needs within the context of normal development as well as within the context of disability.

Child Development

According to western psychology, one of the significant emotional tasks of childhood is the development of a sense of mastery. According to Erikson (1963), in young children and children in middle childhood these tasks of development include the growth of autonomy, initiative, and industry. Children need to cultivate a sense of confidence in their ability to initiate their own actions and ideas as well as in their ability to tackle major societal tasks, such as schoolwork and the development of friendships. Children with NMD live within the paradox of losing physical independence while at the same time needing to develop self-reliance and mastery. Because of this paradox, parents and

Teaching Strategies

Teaching strategies that can be used include the use of behavioral techniques, such as the use of reward plans, contracts, and social praise. Reward plans or reinforcement plans can be developed to target specific social skills. Frequent rewards, such as frequent praise or a reward chart help children become more aware of their new skills. Reward systems should provide frequent feedback to reinforce successful behaviors.

teachers will need to be sensitive to issues related to independence, and provide opportunities to experience mastery and self-reliance.

To change the environment, parents and teachers need to shift their focus from one that impedes certain children's success to one that promotes the achievement of all children by encouraging the interconnectedness of individuals within society. Individuals within this society interact in collaborative ways in many instances. Couples tend to collaborate on decision-making processes whether deciding about buying a house or deciding how to handle the in-laws. Co-workers assist each other to successfully complete a project for a client. Children work together to build a fort out of discarded items or to create imaginary worlds in which to play. However, teachers usually emphasize competition and self-reliance within the classroom and avoid interdependency. This emphasis must be shifted in order to help children with and without disabilities develop into capable adults. There are several ways educators can shift the focus of skill acquisition within the classroom.

Modeling

Another way to promote interdependency within the classroom is through modeling. Educators can ask students to help with specific tasks, can create team projects, and can give positive reinforcement to children who attempt to aid their classmates. By focusing upon interdependence inside the classroom, children learn how to interact in socially responsible ways and discover that every person in the classroom has something to offer.

Classroom environments that focus upon interdependence rather than competition and self-reliance are naturally more inclusive of difference and diversity because they utilize and rely upon the strengths of each individual in the class. Children who have this paradigm modeled for them in the classroom and at home are more likely to accept differences and do not feel threatened by them because competition with others is not the focus of their social interactions. Because the environment is inclusive and promotes the idea that everyone has something to contribute, all children, both disabled and non-disabled, gain a sense of self-worth and become more confident in their abilities. By creating an environment that values interdependency, children with disabilities will feel more included because helping and needing help become the norm rather than the exception within the classroom.

Research conducted by the authors indicates:

- Children with NMD have fewer opportunities to interact with their peers
- Children with NMD experience more solitary play and activities than their peers
- Children with NMD engage in fewer social interactions with peers
- Children without disabilities engage in fewer social interactions with their disabled peers

Outside the Classroom

Outside the classroom, this shift in values can be promoted through a variety of techniques.³ For example, by providing accessible activities such as board games, an accessible jungle gym, computer or video games for all children at recess, children both with and without disabilities can choose from a wider range of activities. Asking the child with the disability what types of social interests or hobbies in which she or he would like to participate might be a good way to begin the inclusion process. The more choices children have in play, the more opportunities they have to socially interact and learn from one another. The more children with and without disabilities interact, the more likely they are to create friendships and positively reinforce one another's social skills.

Of course, modeling and positive reinforcement outside the classroom by adults is also important. For instance, when preparing field trips, teachers can provide this focus on interdependence by considering accessibility issues such as accessible transportation and accessibility of the venue or activity. When this is not done as part of the planning process, children receive the message that difference is not valued, and that children with disabilities do not belong in social settings. Children will act according to what they have been taught; children with disabilities will lose self-confidence and feel stigmatized and children without disabilities will avoid and alienate their disabled peers. Including these aspects of the field trip in the initial planning process (rather than as addenda or not including them) normalizes these facets of life, and consequently reinforces the value of each individual. As access, interdependency, and the valuing of difference become the norm, children with and without disabilities will become more adept at articulating these values to their peers, family members, and people within the community. As children reach adolescence, they will be more inclined to accept themselves and others as unique individuals with both strengths and weaknesses.

Adolescent Development

According to Erikson, the key tasks of early adolescence are forming identity and developing broader social roles (1963). Part of this process is accepting one's unique strengths and weaknesses. According to Elkind, this requires "the establishment of a stable and resilient personal identity" (1978:159). This period is also associated with social conformity, an intense interest in being accepted by one's peer group, and establishing both social and psychological independence from one's parents. Of course, cognitive abilities and skills are being broadened as well.

For youth with physical disabilities, such as NMD, adolescence may present unique challenges. While some adolescents with NMD may need to rely more on personal care attendants, they also require greater independence both socially and psychologically, just as their non-disabled peers do. Like other teens, it is important to provide opportunities for adolescents with NMD to engage in a variety of social activities. More diverse and expanded public responsibilities, such as leadership opportunities and community involvement, should be available for all students to explore and educators and parents should encourage teens to engage in a variety of activities.

³ Access to extracurricular activities offered by the school is a requirement under IDEA and the Rehabilitation Act of 1973. Therefore, access to social activities such as lunch, recess, the school newspaper or chess club is required by law.

These opportunities are important for the development of the cognitive, social, and emotional skills needed for coping and adjustment to the transition from childhood to adolescence and on to adulthood. These types of prospects also provide teens with leadership skills that can transform into job expertise and give adolescents the opportunity to begin creating social networks.

Students with NMD should be encouraged not only to participate in the community and to accept leadership opportunities, but also to participate in social activities such as school dances, school sporting events and dating. These opportunities provide teens with the chance to socialize with peers in an atmosphere that is less supervised and controlled, giving them the independence they need to grow into adulthood and providing necessary stress relief. Like their peers, teens with disabilities need these types of outlets to gain independence from their parents, to learn adult socialization skills, to retain and gain friendships and to relieve stress. Making sure school sponsored events are held in accessible venues is one way that educators can let students with disabilities know that they are welcome and model for students without disabilities that inclusion, not exclusion, is a valued norm in the community.

Developing and Promoting Skill Sets

As stated previously, children and adolescents with disabilities frequently experience extra stressors due to a variety of factors. Some of these additional pressures a child with NMD might experience are: 1) discrimination within the school and community towards people with disabilities; 2) coping with responses from educators and peers because of frequent absences for medical appointments; 3) responding to prejudicial or discriminatory comments of adults and peers; 4) pain and/or fatigue management; and 5) dealing with the family's response to disability. These and other strains are common extra stressors for children with disabilities. They are also

Although children with NMD are more at risk for having difficulties forming healthy peer relationships, they do not appear to have more problematic behaviors, such as aggressive or disruptive actions. Children with NMD tend to be more solitary and tend to experience social activities on the periphery, rather than within the social group. Children with NMD tend to have more internalized social and emotional difficulties, such as depression and low self-esteem, and are often not targeted for interventions because they frequently do not cause problems in their classroom.

pressures that are not experienced at a young age by most people and, therefore, the skills to cope with these adult strains are often not taught to children. Consequently, recognition that some children are experiencing these levels and types of stress may not occur to the adults and, in turn, coping mechanisms to handle adult stress are not promoted within primary and secondary education.

The coping demands and stressors that children and adolescents with NMD face can be viewed in two different ways. Like the view of child development that focuses upon physical ability, independence, and competition, these extra stressors can be viewed as simply problematic and, circularly, stress producing. Or, they can be seen as an impetus to teach adult coping skills to children

so that they can deal with adult levels and types of stress. These are abilities that not

all children may need. However, beginning to teach children these techniques at an early age does two things: 1) it gives all children an opportunity to acquire skills that they can use when the need arises; and 2) it allows children who do need these abilities to acquire them in a non-stigmatizing manner. If the objective is to help children, then the most productive approach to the situation is to acknowledge the presence of these extra stressors and to teach children effective ways of managing stress and coping with societal pressures that result.

Recognition

One of the biggest obstacles for children with disabilities who are learning healthy coping skills is the lack of recognition of their worldly experience by society, family, educators, and peers. For example, if a child with a disability is called “retard,” the child’s experience of the event should be acknowledged. This is similar to a child of color dealing with a racial epithet and should be recognized as verbal abuse and prejudice in the same manner. By doing this, the situation is acknowledged and the children who are using epithets can be corrected.

While diversity programs can help alleviate this issue within the classroom, children with NMD will also be experiencing this type of behavior from adults and children in their everyday experiences. Unfortunately, children with disabilities often do not report these incidents to adults for many of the same reasons that physically abused children don’t report the abuse – because they don’t know how to, they are afraid of the response they’ll receive or because the response in the past from adults and peers has been negative. By not trivializing these very negative encounters, one is recognizing the child’s feelings and communicating to the child that he/she is a person with whom they can safely discuss negative experiences.

Brainstorming: Becoming a Critical Thinker

While recognition and empathy are good starting points, ultimately, the child has to learn how to handle situations when they occur. Brainstorming is an effective adult coping mechanism that can be taught to a young child in order to prepare him or her to deal with a situation before it happens or to plan for the next time it does happen. For example, the child may come to an adult because an epithet (like “moron”) or a derogatory comment (such as, “Your parents should have put you out of your misery.”) was directed by an adult at the child. First, the adult should acknowledge that what happened to the child was discriminatory and praise the child for having the courage to report the incident to an adult. Second, the adult should listen to the child. Some children will simply want consolation and recognition that the person was acting inappropriately. Depending upon the child’s age, personality, and maturity level, this may be all the support the child needs or wants. Other children may want more support or may need help figuring out how to respond if this happens again. To help alleviate feelings of frustration or loss of a sense of self-worth, allow the child to discuss the situation and help him/her brainstorm possible responses to the experience. These discussions can be one-on-one or in a group, depending entirely upon the child’s preference. Questions can be asked of the child to help him / her to articulate the desired end result. For example, with the above scenario, one might ask the child what he/she would like to accomplish with a response (e.g. education or correction of the

adult, self-empowerment) or how she or he would have liked this experience to conclude.

Different options should be explored and a discussion of the pros and cons in different situations can help a child learn how to analyze events and come up with multiple ways of dealing with a incidents. With the above example, a child might think to respond with a sophisticated joke, or by telling his/her parents, or simply by walking away. Depending upon the child and the circumstance, each of these responses could be appropriate and could empower the child in a potentially disempowering situation.

The same type of technique could be used to help the child learn to problem solve with more tangible, physical forms of discrimination such as inaccessible bathrooms or information in non-accessible formats. While young children may need assistance in learning how to advocate for changes in the environment, children should participate in the brainstorming process to come up with solutions. This is a natural part of the IEP/504 Plan procedure, but can be used in and outside the classroom environment as well. For children who need it, shadowing an adult might also help the child develop the skills to both articulate the situation and suggest solutions. Learning these abilities as children will not only help the child develop effective coping skills, but will also empower the child by making him or her a more effective agent for change and provide him or her with leadership expertise that will help later in life.

Active Listening

Behavioral changes in children with NMD, as in other children (e.g. becoming more or less outgoing or paying less attention in class) are potential signs of stress or depression. However, they can also be signs that the student is just not interested in school that day. As with any individual, the best way to find out is to ask. Depending upon the child, this could be done in a variety of ways. For example, one may simply ask, "What's up?" or "Are you feeling OK?" or "How's it going?" The point of asking should not be to get an answer but rather to provide an opportunity for the individual to express him/herself. By asking the question and showing genuine concern, you are letting the individual know that you are concerned and would like to help if you can.

If you ask a question, be prepared to actively listen to the response. Every person is different and, while some may verbalize what is going on, others may use different forms of communication such as body language or facial expressions to convey what they mean. Some children may also not be able to articulate clearly what is occurring while others may be very coherent. Ask questions when you aren't certain about what the child is saying or make "I statements" such as, "I think you're saying that.... Am I understanding you correctly?" This will not only help you figure out how best to help the child, but also let the child know you are paying attention. While not all children may have the skills to effectively articulate what is happening, most children will know if an adult is really listening. As a result, utilizing active listening techniques can be a way of ensuring continual honest and open communication between adults and children.

Networks of Support and Mentorship

There will be times when a child does not wish to speak to an authority figure. Therefore, alternative resources such as a support group, organizations created by and for disabled people or specifically for disabled teens and teen chat-rooms are examples

of venues that the child should have at his or her disposal. Providing a child with access to adults and other children with disabilities creates opportunities for mentorship and access to others who may be able to provide guidance and support. While integration should be the goal for all children with and without disabilities, providing opportunities for children to identify with a particular group of people can allay feelings of isolation.

Educators should be aware of various programs and organizations (local, regional and national) that children and families can utilize for support and networking, as well as places for gathering information. For example, a child interested in sports may be given contact information for local sports and recreation activities and facilities or national organizations, like Disabled Sports USA, that the child might join or contact for more information.⁴ There may also be local mentoring programs such as Big Brothers Big Sisters of America for children with and without disabilities in which the child can participate. Also, having the contact information for larger organizations such as the Parent Project Muscular Dystrophy, Muscular Dystrophy Family Foundation, the World Association of People with Disabilities, and the American Disabled for Attendant Programs Today will provide families and children with the opportunity to network and gather information and assistance in a non-medical environment.

Body Image and Other Issues

Depending upon the type of disability and when it was acquired, the child or adolescent with a disability may also experience stress that is related to adjusting to his or her disabled body, to the nature of the disability (if it is progressive, for example), to her or his own mortality or to the way she or he has internalized society's perceptions of people with disabilities. As with everything else, children will respond differently in different situations. Therefore, to more effectively help the student approach each child based upon the specific personality and maturity level of the child, rather than from perceptions of a particular disability.

Body Image

We are a society that is overweight (CDC, 2004) and is increasingly more disabled (Shapiro, 1993). However, the images we portray of the "normal" or "correct" body type is that of the supermodel or pro-athlete. Consequently, many children in this culture have problems with the way their body looks in relation to society's portrayal of it. For children with disabilities, this problem is compounded by the consistent message in mainstream media that the disabled body is an unwanted, worthless, and problem body (Davis, 1995; Longmore, 2003; Shapiro, 1993).

Diversity programming that includes not only cultural differences, but also a discussion of the value of different body types can help alleviate some of the stress caused by the barrage of imagery most children experience. This type of curriculum will provide an opportunity for all children in the classroom to attain a healthier self-image and a respect for difference. As stated previously, this will lessen the likelihood of bullying and name-calling due to differences in body type and will promote a more positive environment for all children. This programming could be complex or basic

⁴ See Appendix A for a list of some national organizations and programs.

depending on the needs of the group of children. Learning to appreciate and accept different appearances can help lessen the likelihood that children will develop problems related to a poor self-image.

Including images of successful disabled people can help children with a disability have a positive self-image and can promote a different view of disability among their non-disabled peers. Examples such as Christopher Reeve, Ray Charles, Helen Keller, and Franklin Delano Roosevelt can provide children with a different perspective of disability that includes adjectives such as capable, and strong. Inclusion of this type of programming will promote self-esteem and a positive self-image in all children, teach children to value difference, and help eliminate negative social behavioral problems exhibited in childhood (e.g. bullying, teasing, depression).

Invisible Disabilities

Like most other disabilities, neuromuscular disabilities can be invisible, where the person with a disability will not “look” impaired. Symptoms such as fatigue and pain are not visually discernable. This can be a problem for the disabled person, since people in general assume all is well when the problem isn’t visible. For example, a person’s complaint of fatigue may be written off as an exaggeration or a complete fabrication. Denying and ignoring a very real condition contributes to a lowering of the disabled person’s self-esteem, creates distrust among the parties involved, and unnecessarily increases stress levels for the individual with the disability.

As family members and educators of a child with NMD, it is essential for the child’s well being that you help reduce stress where possible. Simply believing the child when he or she states something regarding his or her experience of disability is one of the easiest ways to decrease anxiety for the child. By believing the student you are validating the child’s experience. This provides an opportunity to provide support or assistance.

Pain/Fatigue Management Skills

The problem of pain and fatigue is related to the issue of invisibility. Some children with NMD will experience pain and/or fatigue that is related to the impairment. As stated previously, believing the child when she or he complains of fatigue or pain will help reduce stress. Depending upon the age, personality, and maturity level of the child, he or she may not be able to clearly explain what is being felt. Therefore, one might create a method for the child to articulate the amount of pain or fatigue that is being experienced. For example, a pain scale like the kind physicians now use (1 being minimal pain and 10 being maximum pain) might help the child describe the type and extent of the pain being experienced. Providing this type of tool for the child can help evaluate the situation and learn basic management skills for pain and fatigue.

This articulation can also help you, as the educator, examine the situation and create an environment that is more conducive to learning. For example, by learning when the child usually experiences fatigue, one can prepare the child’s schedule so that the child’s education occurs when the child is least likely to be exhausted. Like all children, there will be good and bad days and sometimes the child will not be following his or her particular norm. Therefore, some flexibility within the classroom routine may help alleviate stress for both you and the children in your classroom.

Family members can also utilize this information to plan, for example, when homework is done or when a family outing might take place. Encouraging the child to keep a record (or keeping a record yourself) of changes in levels of fatigue and pain can be used to discuss concerns and medical treatment with doctors. Many children with progressive disabilities can feel confused, helpless or out of control because of the increasing loss of functions. Providing a means for the child to become more aware of his or her body and how it functions can help him or her feel more in control of the situation and less helpless. Because this approach focuses upon the individual's norm, rather than a societal norm, it also is a subtle way of affirming the child's experience while providing him or her with techniques to manage his or her life.

Managing Care Attendants and Assistants

Some children with NMDs will need the assistance of a care attendant. As stated in the previous chapter, care attendants assist with personal needs, such as feeding or personal hygiene, while assistants, such as note takers or readers, provide a specific service. This situation can be perceived in two very different ways, either as evidence of the child's inability to be independent or in a more empowering light. The assistant or care attendant is, for all intents and purposes, the child's employee; his or her job is to provide services for the individual with a disability. As was noted earlier in this chapter, redefining the meaning of independence and promoting interdependence among the children results in more children mastering the abilities they need to succeed in life. Given that a child who needs a care attendant or assistant will continue to need this assistance in adulthood, beginning to teach the child basic management skills will benefit the child.

One of the simplest ways to encourage this empowered position and help the child learn good management skills is to treat the attendant or assistant as the child's employee. To do this, address the child when something needs to be done and encourage the child to instruct the attendant as to what should be done and when it should be done. For example, the child may have a care attendant who assists with eating and the class' lunch period is moved to an earlier time. As the educator, you alert the class to this change in schedule early in the day. The child should let the care attendant know of the change in schedule. Some children may be able to do this on their own, while others will need to be encouraged to notify the attendant. If the care attendant is not in the classroom, a brief reminder to the child to let his or her attendant know that there has been a change in schedule is a way of empowering the child making the child aware of his or her duties in that particular working relationship.

By giving the child the responsibility of taking care of this small business related task, you are providing the child with the opportunity to acquire basic management skills and effective communication processes, and empowering the child. Some children will be capable of handling managerial tasks at an earlier age than others and each child should be encouraged to take on as much of this business relationship as he/she is capable of handling. A teenager may be able to start managing the bookkeeping or scheduling of care attendants as well as the hiring and firing of these employees. Bringing the child into the managerial process in stages the child has the opportunity to learn these skills gradually and with less stress than if the tasks are not taken over until adulthood.

This gradual building of skills does more than relieve the undue stress that may occur later in life if the individual had not learned these things as a child. It is also a way for the child to be independent and gain and retain self-esteem because it puts him/her in charge of his/her own future. Often, when a child is dealing with an adult, there will not be any choices. Parents decide for the child when to go to bed and teachers tell him/her what to read. Although all children experience these moments of non-choice, children without disabilities have opportunities to make small decisions for themselves that disabled children may not have. They can decide to some extent when and what they eat. Generally speaking, children without disabilities are not supervised and regulated to the extent most children with disabilities are and, the more severe the disability, the more likely the child's ability to choose will be decreased by the adults around them. Acknowledging the student as the individual in charge of the care attendant/assistant is a way of empowering the child. This in turn provides an opportunity for increased responsibility while encouraging self-esteem, a sense of self-worth, and self-respect.

Conclusion

All children have unique social needs. They learn to socialize by watching others and from the messages they receive from the people around them and from society as a whole. Children with disabilities are no exception. The difference in behavior between children with and without disabilities is frequently the information that has been learned, not the manner in which it has been taught. While positive reinforcement of appropriate behavior (or negative reinforcement of inappropriate behavior) might be used to teach non-disabled children what is appropriate, the lack of correction of inappropriate behavior with disabled children tells disabled children that what they are doing is socially acceptable. This training, in combination with the messages children receive about how society feels about people with disabilities, creates added and unnecessary stressors for children with disabilities and tends to create different social outcomes.

Like children of other minority groups who frequently receive negative messages about themselves, children with disabilities consciously or unconsciously experience stress related to these cultural messages. These experiences can cause depression and a host of behaviors that may not be readily viewed as problematic by the larger society. While on some level society expects people with disabilities to be perpetual children (Shapiro, 1993), children with disabilities have to take on some fairly adult responsibilities and frequently are not always provided with the opportunity to learn the skills they need to successfully accomplish a task without undue stress. In this chapter, we have outlined just some of the ways educators and parents can help the child learn the skills necessary to deal with the responsibilities that are expected of them while, at the same time, alleviating or helping the child avoid undue and unnecessary stress caused by society and the environment.

Appendix A

Contact Information for National Organizations and Programs

Ability OnLine is a free internet community where children/youth with disabilities/illness and their parents can meet others like them, make friends from all over the world, share their hopes and fears, find role-models and mentors, and feel like they belong.

Ability OnLine
1120 Finch Avenue West, Suite 104
Toronto, Ontario
M3J 3H7 - Canada
416-650-6207
1-866-650-6207
<http://www.ablelink.org>

American Disabled for Attendant Programs Today (ADAPT) is a grassroots activist organization that focuses on promoting services in the community instead of warehousing people with disabilities in institutions and nursing homes.

ADAPT – American Disabled for Attendant Programs Today
201 S Cherokee
Denver, CO 80223
303-733-9324
<http://www.adapt.org/>

Big Brothers Big Sisters of America is the oldest and largest youth mentoring organization in the United States with a proven track record of having a direct, measurable, and lasting impact on children's lives.

Big Brothers Big Sisters of America
230 North 13th St.
Philadelphia, PA 19107
215-567-7000
<http://www.bbbsa.org>

Disability Resources on the Internet is a nonprofit 501(c)(3) organization established to promote and improve awareness, availability and accessibility of information that can help people with disabilities live, learn, love, work and play independently.
<http://www.disabilityresources.org>

Disabled Sports, USA offers nationwide sports rehabilitation programs to anyone with a permanent physical disability. Activities include winter skiing, water sports, summer and winter competitions, fitness and special sports events.

Disabled Sports, USA
National Headquarters
451 Hungerford Drive, Suite 100
Rockville, MD 20850
301-217-0960
<http://www.dsusa.org>

Families of Spinal Muscular Atrophy is the largest international organization dedicated solely to:

- Eradicating spinal muscular atrophy (SMA) by promoting and supporting research
- Helping families cope with SMA through informational programs and support
- Educating the public and professional community about SMA

<http://www.fsma.org>

Learning Disabilities Online is a national educational service of public television station WETA in Washington, D.C. It is operated in association with the Coordinated Campaign for Learning Disabilities and is made possible by generous support from Lindamood-Bell Learning Processes®. LD OnLine offers online services and produces video programs dedicated to improving the lives of children and adults with learning disabilities and ADHD.

<http://www.ldonline.org>

Muscular Dystrophy Association (MDA) is a voluntary health agency — a dedicated partnership between scientists and concerned citizens aimed at conquering neuromuscular diseases that affect more than a million Americans.

<http://www.mdausa.org>

Muscular Dystrophy Family Foundation provides adaptive equipment and emotional support to individuals and families affected by one of over forty neuromuscular diseases covered under their program.

Muscular Dystrophy Family Foundation
2330 North Meridian Street
Indianapolis, Indiana 46208-5730
317-923-6333
800-544-1213
<http://www.mdff.org/>

National Dissemination Center for Children with Disabilities (NICHCY) is a center that provides information to the nation children and youth with disabilities.

National Dissemination Center for Children with Disabilities (NICHCY)
P.O. Box 1492
Washington, DC 20013
(800) 695-0285 · v/tty
(202) 884-8441
<http://www.nichcy.org/>

National Organization on Disability (NOD) The mission of NOD is to expand the participation and contribution of America's 54 million men, women and children with disabilities in all aspects of life by raising disability awareness through programs and information.

National Organization on Disability (NOD)
910 Sixteenth Street, N.W. Suite 600
Washington, D.C. 20006
202-293-5960
TTY: 202-293-5968
<http://www.nod.org/>

Parent Project Muscular Dystrophy (PPMD) is a not-for-profit organization founded in 1994 by parents of children with Duchenne and Becker Muscular Dystrophy.
<http://www.parentprojectmd.org>

Winners On Wheels provides an innovative learning environment that promotes academic, social, and emotional development so children who use wheelchairs can gain life skill and experiences that will launch them toward productive, independent, and enjoyable lives.

Winners On Wheels
302 East Church Street
Lewisville, TX 75057
800-969-8255
<http://www.wowusa.org/>

World Association of People with Disabilities (WAPD) advances the interests of people with disabilities at national, state, local and home levels. They also link people with disabilities and their allies to current leading edge information via the various mediums of communication.

World Association of People with Disabilities (WAPD)
4503 Sunnyview Dr., Suite 1121
Post Office Box 14111
Oklahoma City, Oklahoma 73135
405-672-4440
<http://www.wapd.org/>

Wrightslaw Parents, advocates, educators, and attorneys come to Wrightslaw for accurate, up-to-date information about special education law and advocacy for children with disabilities. You will find articles, cases, newsletters, and resources about dozens of topics in the Advocacy Libraries and Law Libraries.
<http://www.wrightslaw.com>

Chapter 6

Chapter 6: Characteristics and Medical Management of Neuromuscular Diseases

Examples of Neuromuscular Diseases and Prevalence

Neuromuscular diseases are disorders of the neuromuscular system which includes four components:

- Anterior horn cells located in the spinal cord,
- Motor and sensory fibers of the peripheral nerves between the spinal cord and body muscles,
- Skeletal, cardiac and smooth muscle fibers, and
- Junctions between the muscle and nerve fibers, the myoneural junctions.

Diseases may be inherited (hereditary) or acquired. Hereditary disorders are x-linked recessive, autosomal recessive and autosomal dominant.

Examples are shown in Table 1. Over 200 neuromuscular diseases have been reported.

Table 1. Examples of Childhood Onset Neuromuscular Diseases

Affected Component	Etiology	
	Hereditary	Acquired
Muscle	- <i>Muscular dystrophies</i> Becker's Duchenne Emery-Dreifuss Facioscapulohumeral Limb-Girdle Myotonic (Steinert's) - <i>Metabolic myopathies</i>	-Polymyositis -Dermatomyositis
Peripheral nerve and Motor nerve roots	- <i>Hereditary Motor & Sensory Neuropathies</i> Charcot-Marie-Tooth Dejerine-Sotta's disease - <i>Friedreich's ataxia</i>	-Physical injury -Accompanying disease, such as diabetes -Guillain-Barré syndrome
Myoneural junction	- <i>Hereditary myasthenia gravis</i>	-Myasthenia gravis -Botulism -Lambert-Eaton syndrome
Anterior Horn Cell	- <i>Spinal muscular atrophy</i>	-Poliomyelitis and post-polio muscular atrophy syndrome

With the exception of some of the acquired diseases such as peripheral nerve trauma or injury secondary to an accompanying disease like diabetes, most neuromuscular disorders are rare. Table 2 shows the prevalence of some of the hereditary diseases.

Table 2. Prevalence of Some Neuromuscular Diseases

Disease	Estimated Prevalence, per million (Range)	Estimated number in year 2000 in U.S.
Hereditary Motor and Sensory Neuropathies	100 (14 – 282)	28,142
Duchenne Muscular Dystrophy	63 (19-95)	17,729
Myotonic Muscular Dystrophy	50 (9 – 96)	14,071
Becker's Muscular Dystrophy	24 (6 – 27)	6,754
Limb-Girdle Muscular Dystrophy	30 (3-44)	8,442
Facioscapulohumeral Muscular Dystrophy	15 (2 –70)	4,221
Spinal Muscular Atrophy Intermediate and Juvenile	12 (2 – 42)	3,377

General Characteristics of Most Neuromuscular Diseases

It is beyond the scope of this Guide to describe even the more common diseases. Excellent resources for this information are on the web site of the Muscular Dystrophy Association (www.mdausa.org) and the Neuromuscular Disease Center, Washington University, St. Louis (www.neuro.wustl.edu/neuromuscular). Genetic patterns (genotypes) are extensive in many of the neuromuscular disorders. For example, there are at least 11 gene locations for just limb-girdle dystrophy. Fortunately, the clinical characteristics (phenotype) are more homogeneous and can often be clustered. In limb-girdle dystrophy, only one genotype presents with a rapidly progressive and severe weakness with advanced secondary conditions such as contractures and spinal deformity. The others are slowly progressive.

Table 3 reviews the effect of neuromuscular diseases on the various body systems.

Table 3. Effect of Neuromuscular Diseases on Body Systems

BODY STRUCTURE	BODY FUNCTION (IMPAIRMENT)	ACTIVITY LIMITATION (FUNCTION)	PARTICIPATION RESTRICTION
Skeletal muscle	↓ Functional muscle mass ↑ Skeletal muscle fibrosis ↓ Strength ↓ Endurance ↑ Fatigue	↓ Mobility (walking, running, wheeling) ↓ Upper extremity tasks (reaching, throwing)	↓ Educational opportunities ↓ Employment opportunities ↓ Community integration ↓ Socialization ↓ Family functioning ↓ Recreation ↓ Quality of life
Body Composition	↑ Body fat & obesity ↓ Lean tissue	↓ Fine motor tasks (writing, typing, object manipulation)	
Bone & joint	↑ Joint Contractures ↑ Spine Deformity ↑ Osteoporosis ↑ Fractures ↑ Pain	↓ Self care & ADLs ↓ Communication	
Lungs	↑ Restrictive Lung Disease ↓ Pulmonary function ↓ Cough/pulmonary toilet	↓ Ability to undertake tasks	
Heart	↑ Cardiomyopathy ↑ Conduction defects ↓ Cardiopulmonary capacity	↓ Learning & applying knowledge ↓ Psychosocial adjustment	
Gastro Intestinal & Nutrition	↑ Dysphagia ↑ Constipation ↑ Cachexia (late onset)		
CNS	↓ Mental functions ↓ Intellectual capacity		

Although the degree and severity or even occurrence varies, the characteristics of most of these disorders include the primary condition (impairment) of progressive muscle weakness and atrophy and the secondary conditions of obesity, limb contracture, spine deformity, pain, decreased pulmonary function (restrictive lung disease), cardiac disorders and intellectual impairments.

Medical Management of Neuromuscular Diseases

With rare exception there are no specific treatments for the many neuromuscular diseases (such as insulin for diabetes). Treatment is usually restricted to the secondary impairments. These conditions, unless corrected or prevented, usually lead to activity limitation. This loss of function, if not correctly managed, frequently results in participation restriction and reduced quality of life.

References

[A Teacher's Guide to Neuromuscular Disease](#), Muscular Dystrophy Association, 2005.

Carter GT, Ed., Physical Medicine and Rehabilitation Clinics of North America. 1998 Feb;9(1) Full text on nmdinfo.net by permission.

Jones HR Jr, De Vivo DC, Darras BT. Neuromuscular Disorders of Infancy, Childhood, and Adolescence: a Clinician's Approach; 2003, Butterworth/Heinemann, San Francisco.