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# Assistive Technology Guide for the Occupational Therapy Treatment of Elementary School-Aged Children with Duchenne Muscular Dystrophy

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Assistive Technology Guide for the Occupational Therapy Treatment of Elementary  
School-Aged Children with Duchenne Muscular Dystrophy

by

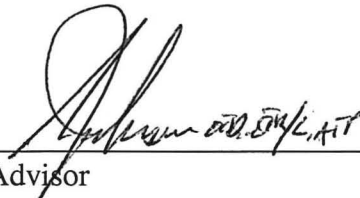
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of the University of North Dakota in partial fulfillment of the requirements for the degree  
of Master's of Occupational Therapy

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This scholarly project paper, submitted by Kara Cook and Jessica McMahan in partial fulfillment of the requirement for the Degree of Master's of Occupational Therapy from the University of North Dakota, has been read by the faculty advisor under whom the work has been done and is hereby approved.

  
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Faculty Advisor

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## CHAPTER I

### INTRODUCTION

According to Steadman's Medical Dictionary (2000), "Duchenne Muscular Dystrophy is defined as the most common childhood muscular disorder with onset usually before age six" (p.557). Duchenne Muscular Dystrophy is the second most common genetic disorder in humans. It is an X-linked recessive disorder, occurring in approximately 1 in 3500 male births, and 1 in about 50,000,000 female births (Webb, 2005, p.385). It is caused by lack of protein dystrophin that affects the skeletal muscles, leading to damage and eventual death of muscle cells. This leads to progressive muscle wasting, which eventually results in severe debilitation (Webb, 2005, p.385).

Children with Duchenne Muscular Dystrophy (DMD) experience difficulty in numerous areas such as gross motor control, range of motion, endurance, balance and postural control, and sensory motor. These difficulties can impact every aspect of their functional capabilities from self-care to schoolwork. Assistive technology (AT) can assist children with DMD to compensate for, increase, maintain or improve their functional capabilities. By using AT, an Occupational Therapist (OT) can help to increase the independence and quality of life in children who are diagnosed with DMD.

Assistive technology (AT) devices are defined as "any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used

to increase, maintain, or improve functional capabilities of individuals with disabilities”(Sanford & Fagan, 2004, p. 1). Assistive technologies range from simple devices (low technology) such as adapted spoons and switch-adapted battery-operated toys, to complex (high technology) devices such as augmentative communication aids, powered mobility equipment, and computers and peripheral devices. Based upon this definition, AT embraces all devices and equipment that can assist young children with disabilities to develop and use their skills to the best of their potential (Judge, 2000). Currently the information regarding the use of assistive technology for children with Duchenne Muscular Dystrophy is limited, especially in regard to an occupational therapy intervention guide. Based on this finding, the purpose of this Scholarly Project was to develop a tool to guide OT’s in using AT in the treatment of elementary school-aged children with DMD.

The guide was organized according to the Ecological Model. The Ecological Model is an individually focused, client-centered framework. According to Dunn, Brown, and Youngstrom (2003), “The Ecology of Human Performance framework is built around the major constructs of person, context, task, and how the dynamic interactions between these three impact performance” (p. 223). This model was chosen for this project because it highlights, although all four constructs are equally important, which expands intervention options. The product focuses on Adapt/Modify which is an intervention approach directed at finding ways to revise current context or activity demands to support performance in the natural setting. The ultimate goal of each intervention strategy is to support the performance needs of the individual.

This chapter concludes with definitions of terminology used throughout the following chapters. Chapter two is a review of the literature containing information on DMD, AT in various contexts, OT and AT, resources for OT, and best practice for intervention. Chapter three explains the methodology used to gather the information for the development of the guide for OT practitioners. Chapter four is the assistive technology (AT) guide for the occupational therapy (OT) treatment of elementary school aged children with Duchenne Muscular Dystrophy (DMD). Chapter five is a summary of the information gained from this project.

### Terminology

The following is the primary terminology the reader will encounter within this document. These terms were compiled out of the following texts; *Assistive Technology: Principles and Practice (2<sup>nd</sup> ed.)*, *Clinician's Guide to Assistive Technology*, and *Occupational Therapy Practice Framework: Domain and Process*.

Accommodation – The act or state of adjustment or adaptation.

Activities of Daily Living (ADLs) – Activities that are oriented toward taking care of one's own body.

Assistive Technology – A broad range of devices, services, strategies, and practices that are conceived and applied to ameliorate the problems faced by individuals who have disabilities.

Augmentative and Alternative Communication (AAC) – Approaches and systems that are designed to ameliorate the problems by person who have difficulty speaking or writing because of neuromuscular disease or injury.



Context – Refers to a variety of interrelated conditions within and surrounding the client that influence performance.

Duchenne Muscular Dystrophy - Duchenne Muscular Dystrophy is a genetic disorder beginning in childhood. It is caused by lack of protein dystrophin that affects the skeletal muscles, leading to damage and eventual death of muscle cells.

High-Technology/Complex Devices – Computerized and electromechanical devices.

Individual Educational Plan (IEP) – The IEP outlines the measurable objectives for each child’s educational program and then describes the services and supports needed to achieve those objectives.

Individuals with Disabilities Education Act (IDEA) – Provides the framework to meet the educational needs of children with disabilities.

Instrumental Activities of Daily Living (IADLs) – Activities that are oriented toward interacting with the environment and that are often complex-generally optional in nature.

Low-Technology Devices – Those devices without mechanical, electrical, or computerized components.

Occupational Performance – The accomplishment of the selected activity or occupation resulting from the dynamic transaction among the client, the context, and the activity. Improving or enabling skills and patterns in occupational performance leads to engagement in occupations or activities.

Occupational Profile – A profile that describes the client’s occupational history, patterns of daily living, interests, values, and needs.

Outcomes – Important dimensions of health attributed to interventions, including ability to function, health perceptions, and satisfaction with care.

## CHAPTER II

### LITERATURE REVIEW

#### Introduction

Children with Duchenne Muscular Dystrophy (DMD) experience difficulty in numerous areas such as gross motor control, range of motion, endurance, balance and postural control, and sensory motor. These difficulties can impact every aspect of their ability to function in self care activities and school work. Assistive technology (AT) can assist children with DMD to compensate for, increase, maintain or improve their functional capabilities. By using AT, an Occupational Therapist (OT) can help to increase the independence and quality of life in children who are diagnosed with DMD.

Before an OT can consider using AT with a child who has DMD, adequate research needs to be completed in order to gather the most relevant and up-to-date information that can assist in the treatment. The more resources, awareness and knowledge an OT has about the numerous forms of AT, the more the child with DMD will benefit. Currently there is limited research-based information on the subject of DMD and AT however, it is emerging within the field of OT. A review of the literature was completed to define; DMD, AT in various contexts, OT and AT, resources for OT, and best practice for intervention.

## Duchenne Muscular Dystrophy

Duchenne Muscular Dystrophy is a genetic disorder beginning in childhood. It is caused by lack of protein dystrophin that affects the skeletal muscles, leading to damage and eventual death of muscle cells. This leads to progressive muscle wasting, which eventually results in severe debilitation (Webb, 2005, p.385). Duchenne Muscular Dystrophy is the second most common genetic disorder in humans. It is an X-linked recessive disorder, occurring in approximately 1 in 3500 male births, and 1 in about 50,000,000 female births (Webb, 2005, p.385).

### *Physical Progression*

At approximately 3 to 4 years of age, coordination deficits begin to appear such as clumsiness or the inability to walk. Weakness in the hip girdle/proximal lower extremity and paraspinal muscles tends to make walking awkward and difficult (Sayers, 2000). Difficulties walking are exemplified by a sagging of the pelvis as the foot is raised and a concomitant tilting of the body to one side, commonly called a waddling gait (Sayers, 2000). Balance issues often leads to falls and broken bones due to contractures in calf muscles and an extreme posterior curvature of the lumbar spine (lordosis). At age 8, a child with DMD often cannot manage climbing stairs and experiences difficulty rising from the floor unaided. Around the age of 9, children lose the ability to ambulate without the use of assistive devices and may be confined to a wheelchair (Liu, Mineo, Hanayama, Fujiwara, & Chino, 2003). At about 15 years of age, the adolescent becomes unable to sit without support. It is predicted that around twenty years of age, death occurs due to the weakened condition of the respiratory and cardiac muscles; however, life expectancy is

rising because of proactive care along with more aggressive treatments (Liu et al, 2003; Webb, 2005).

### *Cognitive*

An estimated one-third of children with DMD, have some degree of intellectual impairment and they have a higher incidence of learning disabilities than the average child. Although few of the children are diagnosed as seriously cognitively impaired or diagnosed with mental retardation (adapted from [www.mdusa.org/publications/journey/7-3.html](http://www.mdusa.org/publications/journey/7-3.html)).

Doctors now believe that dystrophin abnormalities in the brain may cause subtle and complex cognitive and behavioral deficits (adapted from [www.mdusa.org/publications/journey/7-3.html](http://www.mdusa.org/publications/journey/7-3.html)). Normal brain tissue contains small amounts of dystrophin, a protein complex in brain muscle fiber membranes; however an absence of dystrophin leads to DMD. Though not a form of mental retardation, these deficits can create problems with learning. The most common learning problems are in the ability to receive information, store it in the brain and retrieve it. The problem occurs in three general areas: (1) attention focusing, (2) verbal learning and memory, and (3) emotional interaction (adapted from [www.mdusa.org/publications/journey/7-3.html](http://www.mdusa.org/publications/journey/7-3.html)). Children with difficulty in attention focusing cannot modulate, or regulate their attention (adapted from [www.mdusa.org/publications/journey/7-3.html](http://www.mdusa.org/publications/journey/7-3.html)). This means the child has difficulty focusing his or her attention on something and once they do, he or she then has difficulty letting go of his or her attention.

A child with DMD may demonstrate verbal learning and memory deficits. This means that the brain does not consistently store information that is received verbally the

way they should (adapted from [www.mdusa.org/publications/journey/7-3.html](http://www.mdusa.org/publications/journey/7-3.html)). This can result in difficulty with reading, comprehending spoken language and recalling what is read or heard.

The effects of the brain dystrophin can also create difficulty with an individual's emotional interactions with other people and at times, the individual may appear immature or distant (adapted from [www.mdusa.org/publications/journey/7-3.html](http://www.mdusa.org/publications/journey/7-3.html)). It is important to maximize the child's capabilities and not to ignore learning disabilities if they exist. Because of the unique issues that children with DMD face, their needs should be addressed by creative and innovative intervention strategies, which will be presented later in the literature review and in detail within chapter four.

#### The Needs of Elementary Aged Children with DMD

Although there is still no cure for DMD, families can access various proven activities/interventions to slow the progression and improve the child's quality of life. Activities could include, stretching and low impact sports, which are recommended by physicians to encourage the parents to keep the children active and flexible (Webb, 2005).

Orthotic devices such as plastic braces and splints can provide support for weak leg muscles and can also delay contractures and development of scoliosis. It is important that the activity/intervention facilitate ambulation and standing. These two skills are important in the preservation of the child's self-esteem and the ability to remain functionally independent for as long as possible. When walking ceases for children with DMD, they are prescribed a standing program from a physician that may or may not include the orthoses (Kroksmark, 1999). A standing program, at least two hours a day, is

associated with improved lung function and a reduction in the development of scoliosis (Kroksmark, 1999).

Other treatment options include tendon release and spinal fusion surgeries.

“Tendon release surgery is used as a last resort to keep children on their feet as long as possible. Spinal fusion surgery is the only option available to treat scoliosis that develops when the children use wheelchairs full-time” (Webb, 2005, p. 393).

A preferred treatment option that is often overlooked is the use of adaptive equipment, in conjunction with other interventions, which is the focus of this project. It is recommended that adaptive equipment needs to be evaluated and implemented prior to the consideration of therapy and even post surgery to promote maximum independence. There is a wide variety of adaptive equipment to improve the child’s mobility and quality of life. It has been reported that children with DMD successfully use canes, walkers, electric scooters and power wheelchairs to maintain their mobile independence. Other modifications that have been useful are lifts, bars, shower chairs, modified vans, and ramps as aids to assist in self-care activities (Webb, 2005). Assistive technology can increase a child’s independence and provide a means for social participation.

### Assistive Technology

Assistive technology (AT) devices are defined as “any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities” (Sanford & Fagan, 2004, p. 1). Assistive technologies range from simple devices (low technology) such as adapted spoons and switch-adapted battery-operated toys, to complex (high technology) devices such as augmentative communication aids, powered

mobility equipment, and computers and peripheral devices. Based upon this definition, AT embraces all devices and equipment that can assist young children with disabilities to develop and use their skills to the best of their potential (Judge, 2000).

The impetus for the growing use of AT arises from the passage of the Technology-Related Assistance for Individuals with Disabilities Act (Tech-Act) of 1988. This Act expanded the availability of AT services and devices for persons of all ages with disabilities (Judge, 2000).

Although there are many benefits to AT use by children who have disabilities, one chief benefit is that AT provides a means of enabling mastery or control over the child's environment, including enhanced exploratory play and independence in activities of daily living. Copley and Ziviani (2004) conducted two comprehensive studies of AT applications in schools and found that facilitation of independence was among the most frequently cited benefits identified by parents and teachers. A commonly reported benefit contributing to self-determination is the ability to make choices and direct one's own care with the use of augmented or alternative communication. Other outcomes include enhanced social interactions, increased motivation and self-esteem. Another area that has improved with the use of AT is skill acquisition and enhancement such as: handwriting, motor skills, reading, visual attention and perception, and math skills. Reported cognitive benefits associated with AT use include understanding of the cause and effect relationship, increased attention span, and problem solving abilities. Parents and teachers have recognized the capacity of AT to offer children new opportunities, reveal their potential and provide them with the tools to realize that potential (Copley, & Ziviani, 2004).



## *Assistive Technology at School*

Schools are active environments and present a wide range of challenges to all members of the learning community. Children with DMD often have learning problems or other conditions that can interfere with participating in a traditional school setting. The support provided by AT can be a way to level the learning, living, and playing field (Beigel, 2000). Assistive technology makes significant differences in the quality of life and education for children with disabilities. Assistive technology provides access to general curriculum materials and enables children to show what they know and what they are learning.

The 1997 revision of the Individuals with Disabilities Education Act (IDEA) provides that, if a child with a disability requires AT devices, services, or both in order to receive a free and appropriate public education, the public agency must ensure that they are made available to the child. These services can include: special education, related services or as supplementary aids and services. IDEA specifically identified AT as a special factor that must be considered by each individualized education plan (IEP) team. IDEA requires that AT devices, services and training be provided to children with disabilities by the public agency serving them at no cost to the parents. The results of a traditional assessment within the school setting may lead to the recommendation for a device geared toward specific school tasks as opposed to a tool to facilitate independent functioning of a child in multiple environments. Assistive technology is not only important in the school setting, but also within the child's home.

### *Assistive Technology at Home*

In the home, AT devices can: (1) increase safety and independence in self-care activities, (2) allow for participation in instrumental activities of daily living (IADLs), (3) promote play and leisure opportunities, (4) facilitate communication and interaction with family and friends, (5) improve mobility, and (6) enhance environmental control. By using AT, a child can remain independent longer therefore increasing quality of life.

It is important to recognize that the home not only is a physical place, but also is an extension of the self, expressing identity, providing independence and security, and representing participation and belonging. As a result, it is necessary to understand the meaning of home, the objects contained in the home, and their relationship to the client and his/her everyday occupations before introducing changes to the existing structure or function of the residence (Sanford & Fagan, 2004).

### *AT Challenges*

#### *Funding*

Finding and paying for AT at home remains one of the biggest obstacles to acquiring needed devices and services. This may be due to: (1) the high cost of equipment, (2) the restrictive or vague eligibility criteria imposed by potential public and private sources of funding, (3) lack of knowledge about finding funding options, or (4) locating and accessing third-party payment sources (Judge, 2000). Without financial alternatives to help families obtain these assistive devices, young children with disabilities are limited or denied the opportunities to engage in play, learning, communicating, and interacting with family and friends.

Funding under IDEA and the Tech Act is available for use in supplying technology related needs but with shrinking budgets and limited resources, it is increasingly difficult for funding sources to process all the requests for assistive devices (Judge, 2000). As a result, the application process may require substantial energy expenditure and advocacy in finding a source for funds. Although financial resources are often scarce, funding does not limit a child's need for AT. Funding is available from a variety of public and private sources. Professionals need to become stronger advocates and assist families in becoming resourceful and actively involved in accessing funding mechanisms for needed AT (Judge, 2000).

Historically, OT practitioners and other prescribers of AT, have not demonstrated cost-effectiveness of high- or low-tech devices (Schouten, 2003). Because of the limited amount of outcome based research supporting the use of AT, the AT that is often provided for children with disabilities, may not necessarily be the best choice for that child.

#### *Assistive Technology Abandonment*

Schouten (2003) states that high numbers of persons discard the technology recommended to them, wasting precious health care resources; therefore, reimbursement agencies became unwilling to pay for technology. The abandonment of AT happens for various reasons, ranging from children outgrowing particular devices to professionals determining what they think is appropriate as opposed to listening to child and family preferences. Other reasons for technology abandonment include lack of meaningful training on how to use the device and/or lack of ongoing team support; sophistication of the device to the extent that it confuses the family, the child, and professionals; lack of

access to and information about repair and maintenance; and lack of motivation to use the device or do the task for which it is intended (Judge, 2000). Problems associated with abandonment or lack of implementation of AT maybe a direct outcome of ineffective assessment and intervention processes. To avoid the problem of technology abandonment, professionals must involve families in all aspects of AT decision making (Judge, 2000).

There are several strategies that professionals and families can employ to ensure success and prevent AT abandonment. The key to success when implementing any strategy is for professionals to empower families to capitalize on technological options for their children. Using a family-centered approach, professionals are encouraged to reassess their roles and responsibilities and develop effective help giving behaviors and attitudes that promote family competencies and decision making capabilities in all aspects of the selection and provision of AT. Family-centered AT practices should be understood from the perspective of how this approach can be used to produce a higher level of success in the use of AT for young children. The family-centered approach suggests that when parents are in control of the assessment and intervention process, decisions about the appropriate selection and use of AT will be made that increase the likelihood of the functional use of technology in the natural environments of the child (Judge, 2002). It is essential that the OT discuss family strengths and resources that will be beneficial in selecting and implementing AT devices or systems that accommodate the needs of both the family and the child.

### *Professional Training*

Lack of suitable training for personnel constitutes a major barrier to effective AT choice and implementation. The implementation of AT devices, modifications, and low-tech adaptations can be challenging with personnel who may not be comfortable with AT devices, a change of staff, or a general reluctance to explore alternatives.

Though emphasis in the area of AT training has increased over the last few years, it is evident that professionals as well as families need additional training in this area. Until technology training is significantly improved, young children with disabilities may often continue to be mismatched with devices that do not meet their communicative, educational, and independent learning need (Judge, 2000).

Assistive technology is intended to facilitate health and functioning and is a contextual factor of the physical environment; lack of resources to purchase AT constitutes a barrier. Lack of trained personnel to assist in choosing and obtaining AT constitutes a barrier within the social environment. Finally, a personal history of perceived failure with AT may hinder the future of AT (Scherer, Coombs, & Hansen, 2004). Therapeutic AT services may be conducted in structured settings that do not represent natural conditions under which a child with DMD will be expected to use a device. Therefore when the device is used in the natural context the child and family may experience unanticipated difficulties.

### *Financing Assistive Technology*

There are several programs that can provide financial assistance to access AT. These programs include; Medicaid, CHAMPUS, school systems, third party payers, private sources and persona financing. These are presented in more detail within this section.

#### *Medicaid*

The Medicaid program has a durable medical equipment category that covers some devices if that device is considered medically necessary and a physician's authorization is obtained. In addition, AT services are covered under federal Medicaid law. The Early and Periodic Screening Diagnosis, and Treatment (EPSDT) program for children from birth to age 21 requires that states cover regular and periodic exams for eligible children. This program specifically states that any medically necessary services or durable medical equipment prescribed by EPSDT must be provided even if that service is not covered in that state's Medicaid program. This includes assistive devices that may have been excluded under the regular Medicaid program (Judge, 2000).

#### *CHAMPUS*

The Civilian Health and Medical Program of the Uniform Service (CHAMPUS) provides funding for AT to dependents of active duty members or to retired members if it is deemed medically necessary. CHAMPUS contracts with various health insurance companies to administer this program which provides medically necessary equipment and AT services (Cook & Hussey, 2002).

### *School System*

Local school districts are required by law to provide AT for children with disabilities if it is shown to be necessary to allow the child to receive an education in the least restrictive environment. The need for AT devices and services must be included in the IEP. Once the AT need is determined by the IEP committee, the school system must actively pursue funding to obtain the device for the child.

### *Third Party Payer*

The consumer may have private health insurance that will cover AT equipment and related services. Individuals who have private health insurance are provided with or can obtain the details of their plan, which stipulates whether any rehabilitative therapies are covered. Rehabilitation engineering services usually are not provided for under any private health insurance plan. Some plans also cover a portion of the cost of durable medical equipment. Funding by private health insurance companies is based on a medical diagnosis and justification of medical necessity (Cook & Hussey, 2002).

### *Private Funding Sources*

Private funding sources have historically supplemented public funding sources for AT. These sources include community groups (e.g., Shriner's, Elks, Nights of Columbus), special interest groups (sororities and fraternities), and non-profit service organizations (e.g., March of Dimes, Muscular Dystrophy Association). Most private funding will assist in the purchasing of devices if other sources of funding have been unsuccessful, however these organizations usually have specific guidelines and eligibility guidelines (Olson & DeRuyter, 2002).

### *Credit Financing*

Credit financing provides another option for families who are not eligible for other third-party payment programs. A variety of loan financing programs operate in some of the state Tech Act projects that provide low or no interest loans to help buy AT equipment (Judge, 2000).

### *Occupational Therapy and Assistive Technology*

“Assistive technology is still an emerging field of practice for OT’s (Schouten, 2003; p. 1).” Occupational therapists have a significant role to play in the AT process. Whether a children’s primary disability is motor based, sensory based, cognitively based, or communication based, having an OT involved in the process can keep the information gathering and decision-making process focused on functional outcomes (Struck, 2003). Occupational therapy practitioners understanding of their clients daily occupational needs, abilities, and contexts make them ideal collaborators in the design, development, and clinical application of new or customized technological devices (Webb, 2005).

### *Therapist Preparation*

In order to provide appropriate AT services, therapists need the skills and knowledge to competently address AT needs and the services to support them. Occupational therapists need to become certified in the use of AT through the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA).

According to RESNA.org (n.d.), the credentialing program for assistive technology service providers promotes an entry level of expertise in the field of assistive technology. It further provides a standard for recognizing qualifications and validating broad-based knowledge. These standards



aim to enhance service provision to people with disabilities seeking technology applications to maximize their function. Earning a RESNA credential provides recognition for attaining the necessary knowledge and experience to provide safe and effective service to persons with a disability. The Assistive Technology Practitioner (ATP) and Assistive Technology Supplier (ATS) credentials promote quality assurance for the consumer, instill pride in the service provider, and promote a standard level of professional practice for the field. (p. 3)

The ATS is primarily involved in the sale and service of commercially available AT devices. The ATP is primarily responsible for identification of the client's functional abilities and limitations and the potential technology applications to meet those needs. The ATP may also be involved in providing instruction on a particular device on an individual basis to meet the user's needs (Olson & DeRuyter, 2002).

#### *Service Delivery*

The OT provides a broad range of services in the application of basic and complex adaptive technology. These services include: evaluation, recommendation, justification of need, advocacy, awareness of funding resources, fabrication, customization, training, integration, and follow-up.

In the area of evaluation, Occupational therapists create a successful match between the individual and AT devices. The process begins by the completion of an occupational profile and an analysis of occupational performance. The therapist then analyzes the characteristics of the AT devices, the activity demands, and the context in which devices will be used (Buning, Hammel, Angelo, Schmeler, & Doster, 2004). In making AT decisions, the connection of the children with the tool or strategy will depend on the anatomical, neurological, psychosocial, and sensory motor considerations that

impact that connection both from a children perspective and an environmental perspective (Struck, 2003). The OT needs to conduct interviews with parents, teachers, and the children in order to determine what the children needs in the way of AT. It is also important to keep the teacher involved throughout the intervention process in order to assure that the AT is used within the school context.

Occupational therapists incorporate both basic AT devices and complex AT devices in their interventions. Consideration of context, activity demands, and client factors are critical to successful outcomes. Context is defined as a variety of interrelated conditions within and surrounding the client that influence performance. Activity demands are the aspect of activity, which include the objects, space, social demands, sequencing or timing, required actions, and required underlying body function and body structure needed to carry out the activity. Client factors are those factors that reside within the client and that may affect performance in areas of occupation. The above definitions were adapted from (Occupational Therapy Practice Framework: Domain and Process, 2002.).

When choosing AT, the OT needs to also consider the activities that a person chooses to engage in hold purpose and meaning to an individual. When a person is unable to participate in meaningful activities or occupations, AT may be used as a support. Assistive technology may unlock human potential and optimize human performance throughout the lifespan and across contexts and allow individuals to assume or regain valued life roles. Within OT service delivery, AT application can enhance an individual's personal control, communication, mobility, independence, work, leisure activities, and social participation. Technology is a valuable tool for OT's to use in

assisting individuals with moving toward their highest level of independence and with the process of adaptation to disability (Buning, Hammel, Angelo, Schmeler, & Doster, 2004).

Occupational therapists can be instrumental in supporting academic staff by periodically checking, training and retraining as needed so that AT is effectively used and seen as valued tools for academic achievement. This support role would call for each OT, not just a specialty OT, to take an active part in continuing professional development in AT that is based on the needs of the children they see throughout their schools (Schouten, 2003). The OT contributes a unique perspective incorporating the functional performance of the total human body.

Occupational therapists also need to develop strategies and funding mechanisms to pay for the needed technology and services; a strategy for measuring child and family outcomes; and family and contextual factors such as culture, economic status, and geographical location and their impact on both attitudes toward and utilization of AT and AT services (Long, Huang, Woodbridge, Woolverton, & Minkel, 2003). Understanding the complexity of services system involved with children with disabilities and special healthcare needs is critical in making sound decisions that have a meaningful impact on the lives of children with DMD and their families. Providers need the knowledge regarding funding to assure that AT related plans can be implemented, yet many currently lack this knowledge and there are few training programs available that focus on these issues. It is imperative that therapists understand the responsibilities of the Medicaid system, the early intervention system, and/or the educational system, and how these systems interrelate regarding funding of AT and AT services.

## Best Practices for Intervention

According to the Occupational Therapy Practice Framework (OTPF), best practice occupational therapy is the use of a client-centered approach where the client's needs, wants, and desires are used to create an occupational profile (AOTA, 2002). The profile guides the development and delivery of various levels of preparatory, purposeful, and occupation based interventions that enable the client to return to those occupations outlined in the profile (Amini, 2005).

The first and most important step when determining the need for an assistive device is to form an AT team. Potential members of an AT team include the child with DMD, the child's family, teachers, teaching assistants, therapists, school nurses, rehabilitation engineers, and social workers. The main question for the team is to determine what the child with DMD needs to do to perform their roles now and in the future. The process of selecting an appropriate device is as follows:

1. It is important to initiate the assessment by talking with family, caregivers, teachers, and others who interact with the child regularly. If the child with DMD is able to communicate, it is important that he or she is given the opportunity to express his or her needs or preferences.
2. Team members should consider the context in which the technology is needed by observing the child with DMD in all settings where he or she will be using the device.
3. Complete a functional needs assessment taking into consideration the child's physical and cognitive abilities and limitations to evaluate the

child's cognitive and physical functioning and identify their activities of daily living.

4. Evaluate the child's positioning, developmental needs, strength and endurance, and functional features of the device before making a recommendation.
5. Sociocultural factors may affect the implementation and use of the device, and may include: the family's educational level and knowledge of the disability, emotional readiness, roles, the extent to which independence is important to the family, goals and expectations for using the device, and the families financial resources (Isabelle, Bessey, Draga, Blease, Shepherd, & Lane, 2002).

Once the appropriate assistive technology equipment is chosen, it will then be implemented into the child's treatment plan. A periodic assessment of the child and the equipment will be completed to ensure that the AT equipment is being used properly, that the child has not outgrown the equipment, and to perform any maintenance necessary to the AT device. By performing these periodic assessments, outcomes may be determined.

Outcomes are the clinical end-results of patient care for individuals, families, and communities. In measuring specific outcomes, OT's document the value of service delivery, and justify the need for devices and services in terms of improved patient care and cost. Outcomes measurement also provides manufacturers and third-party payers with information concerning the difficulties and successes associated with AT device use, documentation about device durability, longevity, and insight into discontinuation and replacement. Thus, outcomes research becomes essential to identifying the greatest

benefits of AT, and cost effective ways of providing services. Outcomes measurement with children offers a unique set of challenges. Children with DMD grow, mature, and develop quickly, and as they do, their needs for assistive devices and services change. They may physically outgrow their AT device, or surpass it developmentally. Thus, within the realm of AT, there are limited empirical studies documenting the impact of AT on children.

### Conclusion

The literature review has presented both clinical reasoning and empirical research indicating the importance of AT devices and services to children with DMD's ability to master various skills, communicate, and physically and cognitively engage in exploration of their environments. The use of AT may give children with DMD opportunities that they otherwise would not have. When children with disabilities use properly selected AT devices, proper positioning, and electronic aids to daily living (EADLs), they have increased access to the world around them. They are able to communicate with others, play, and physically and cognitively explore like their normally developing peers. Their ability to be active is crucial to their cognitive, physical, social, and psychological development. This development, facilitated by AT devices, gives children with disabilities a strong foundation to participate successfully in their natural environments (Isabelle et al., 2002).

Upon completion of the literature review, the information was compiled into a guide, designed for the OT, to maximize treatment intervention with AT.

The purpose of this project was met in the development of an assistive technology (AT) guide for the occupational therapy (OT) treatment of elementary school aged children

with Duchenne Muscular Dystrophy (DMD). The development of the assistive technology (AT) guide for the occupational therapy (OT) treatment of elementary school-aged children with Duchenne muscular dystrophy (DMD) was based on a thorough literature review. The literature indicated that AT can assist children with DMD to: compensate for, increase, maintain, or improve their functional capabilities.

The AT guide contains general information about AT, which is separated into three sub-categories: AT in the home, in the school, and in the community. The guide provides specific AT techniques for elementary school-aged children with DMD based on the contexts in which children participate. The product also contains a list of resources that are available for OTs who require further information. Due to the limited evidence-based research on the OT treatment of DMD using AT, this guide will provide OT practitioners with an easy to use manual on different AT interventions to implement within various contexts

This product was organized using the Ecological Model and the areas of occupation in the Occupational Therapy Practice Framework: Domain and Process. The product focuses on Adapt/Modify which is an intervention approach directed at finding ways to revise current context or activity demands to support performance in the natural setting. Some areas of this product are repetitive since some of the AT and modifications are used within more than one context in which a child with DMD participates.

## CHAPTER III.

### ACTIVITIES/METHODOLOGY

The process of developing an AT guide for the provision of occupational therapy with elementary school-aged children with Duchenne Muscular Dystrophy (DMD) began with an extensive review of current literature. The topics researched included: DMD, AT in various contexts, OT and AT, resources for OT, and best practice for intervention. The literature review included searching sites such as the Harley French Library, the Muscular Dystrophy Association internet site, various internet sources and educational text books. After reviewing the literature it was determined that there is a lack of information regarding the use of AT devices in the OT treatment specific to elementary school-aged children with DMD.

The next step was to develop an outline to identify issues found within the literature review. The product was organized using the Ecological Model and the areas of occupation in the Occupational Therapy Practice Framework: Domain and Process. According to Dunn, Brown, and Youngstrom (2003), "The Ecology of Human Performance framework is built around the major constructs of person, context, task, and how the dynamic interactions between these three impact performance" (223). This model was chosen for this project because, although all four constructs are equally important, the model highlights context. The guide was organized based on the three



main contexts in which an elementary school-aged child with DMD is involved in. The three contexts include AT in the home, AT in the school, and AT in the community.

The guide is then organized into specific Assistive Technology techniques/categories for elementary school-aged children with Duchenne Muscular Dystrophy based on the areas of occupation affected. The areas of occupation in the home that were discussed include activities of daily living (ADL), leisure/play, and social participation. The areas of occupation in the school include education, leisure/play, and social participation. The areas of occupation in the community include leisure/play, social participation, and the instrumental activity of daily living (IADL) of community mobility. The product also contains a list of terminology and a list of resources that are available for occupational therapists that require further information.

## CHAPTER IV

### PRODUCT

The development of the assistive technology (AT) guide for the occupational therapy (OT) treatment of elementary school-aged children with Duchenne muscular dystrophy (DMD) was based on a thorough literature review. The literature indicated that AT can assist children with DMD to: compensate for, increase, maintain, or improve their functional capabilities.

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Assistive Technology Guide for the Occupational Therapy  
Treatment of Elementary School-Aged Children with Duchenne  
Muscular Dystrophy



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## Introduction

This occupational therapy guide was developed to provide a resource with general information on the use of assistive technology as an intervention for elementary-school aged children with Duchenne Muscular Dystrophy.

The AT guide contains general information about AT, which is separated into three sub-categories: AT in the home, in the school, and in the community. The guide provides specific AT techniques for elementary school-aged children with DMD based on the contexts in which children participate. The product also contains a list of resources that are available for OTs who require further information. Due to the limited evidence-based research on the OT treatment of DMD using AT, this guide will provide OT practitioners with an easy to use manual on different AT interventions to implement within various contexts.

This product was organized using the Ecological Model and the areas of occupation in the Occupational Therapy Practice Framework: Domain and Process. The product focuses on Adapt/Modify which is an intervention approach directed at finding ways to revise current context or activity demands to support performance in the natural setting. Some areas of this product are repetitive since some of the AT and modifications are used within more than one context in which a child with DMD participates.

Assistive technology (AT) embraces all devices and equipment that can assist young children with disabilities to develop and use their skills to the best of their potential. Currently the information regarding the use of assistive technology for children with Duchenne Muscular Dystrophy (DMD) is limited, especially in regard to an occupational therapy intervention guide. By using assistive technology, an occupational therapist can help to increase the independence and quality of

life in children who are diagnosed with Duchenne Muscular Dystrophy.

### Best Practices for Intervention

According to the Occupational Therapy Practice Framework (OTPF), best practice occupational therapy is the use of a client-centered approach where the client's needs, wants, and desires are used to create an occupational profile (AOTA, 2002). The profile guides the development and delivery of various levels of preparatory, purposeful, and occupation based interventions that enable the client to return to those occupations outlined in the profile (Amini, 2005).

The first and most important step when determining the need for an assistive device is to form an AT team. Potential members of an AT team include the child with DMD, the child's family, teachers, teaching assistants, therapists, school nurses, rehabilitation engineers, and social workers. The main question for the team is to determine what the child with DMD needs to



do to perform their roles now and in the future. The process of selecting an appropriate device is as follows:

1. It is important to initiate the assessment by talking with family, caregivers, teachers, and others who interact with the child regularly. If the child with DMD is able to communicate, it is important that he or she is given the opportunity to express his or her needs or preferences.
2. Team members should consider the context in which the technology is needed by observing the child with DMD in all settings where he or she will be using the device.
3. Complete a functional needs assessment taking into consideration the child's physical and cognitive abilities and limitations to evaluate the child's cognitive and physical functioning and identify their activities of daily living.
4. Evaluate the child's positioning, developmental needs, strength and endurance, and functional features of the device before making a recommendation.

5. Sociocultural factors may affect the implementation and use of the device, and may include: the family's educational level and knowledge of the disability, emotional readiness, roles, the extent to which independence is important to the family, goals and expectations for using the device, and the family's financial resources (Isabelle, Bessey, Draga, Blease, Shepherd, & Lane, 2002).

Once the appropriate assistive technology equipment is chosen, it will then be implemented into the child's treatment plan. A periodic assessment of the child and the equipment will be completed to ensure that the AT equipment is being used properly, that the child has not outgrown the equipment, and to perform any maintenance necessary to the AT device. By performing these periodic assessments, outcomes may be determined.

Outcomes are the clinical end-results of patient care for individuals, families, and communities. In measuring specific

outcomes, OT's document the value of service delivery, and justify the need for devices and services in terms of improved patient care and cost. Outcomes measurement also provides manufacturers and third-party payers with information concerning the difficulties and successes associated with AT device use, documentation about device durability, longevity, and insight into discontinuation and replacement. Thus, outcomes research becomes essential to identifying the greatest benefits of AT, and cost effective ways of providing services. Outcomes measurement with children offers a unique set of challenges.

Children with DMD grow, mature, and develop quickly, and as they do, their needs for assistive devices and services change. They may physically outgrow their AT device, or surpass it developmentally. Thus, within the realm of AT, there are limited empirical studies documenting the impact of AT on children.

## Terminology

The following is a definition list of the primary terms that are used in this guide. These definitions have been taken from the following sources: *Assistive Technology: Principles and Practice (2<sup>nd</sup> ed.)*, *Clinician's Guide to Assistive Technology*, and *Occupational Therapy Practice Framework: Domain and Process*.

**Accommodation** - The act or state of adjustment or adaptation.

**Activities of Daily Living (ADLs)** - Activities that are oriented toward taking care of one's own body.

**Assistive Technology** - A broad range of devices, services, strategies, and practices that are conceived and applied to ameliorate the problems faced by individuals who have disabilities.

**Augmentative and Alternative Communication (AAC)** - Approaches and systems that are designed to ameliorate the problems by person who have difficulty speaking or writing because of neuromuscular disease or injury.

**Context** - Refers to a variety of interrelated conditions within and surrounding the client that influence performance.

Duchenne Muscular Dystrophy - Duchenne Muscular Dystrophy is a genetic disorder beginning in childhood. It is caused by lack of protein dystrophin that affects the skeletal muscles, leading to damage and eventual death of muscle cells.

High-Technology/Complex Devices - Computerized and electromechanical devices.

Individual Educational Plan (IEP) - The IEP outlines the measurable objectives for each child's educational program and then describes the services and supports needed to achieve those objectives.

Individuals with Disabilities Education Act (IDEA) - Provides the framework to meet the educational needs of children with disabilities.

Instrumental Activities of Daily Living (IADLs) - Activities that are oriented toward interacting with the environment and that are often complex-generally optional in nature.

Low-Technology Devices - Those devices without mechanical, electrical, or computerized components.

Occupational Performance - The accomplishment of the selected activity or occupation resulting from the dynamic transaction among the client, the context, and the activity.

Improving or enabling skills and patterns in occupational performance leads to engagement in occupations or activities.

Occupational Profile - A profile that describes the client's occupational history, patterns of daily living, interests, values, and needs.

Outcomes - Important dimensions of health attributed to interventions, including ability to function, health perceptions, and satisfaction with care.

## **Assistive Technology**

Assistive Technology (AT) devices are defined as "any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities" (Sanford & Fagan, 2004, p.1). Assistive technologies range from simple devices (low technology) such as adapted spoons and switch-adapted battery-operated toys, to complex devices (high technology) such as augmentative communication aids, powered mobility equipment, and computers and peripheral devices. Using this definition, AT embraces all devices and equipment that can help young children with disabilities to develop and use their skills to the best of their potential (Judge, 2000).

"Assistive technology is still an emerging field of practice for OT's" (Schouten, 2003, p. 1). Occupational therapists have a

significant role to play in the AT process. Whether a student's primary disability is motor based, sensory based, cognitively based, or communication based, having an OT involved in the process can keep the information gathering and decision-making process focused on functional outcomes (Struck, 2003).

The OT provides a broad range of services in the application of technology including evaluation, recommendation, justification of need, advocacy, awareness of funding resources, fabrication, customization, training, integration, and follow-up.

### ***Evaluation***

Occupational therapy practitioners understanding of their clients daily occupational needs, abilities, and contexts make them ideal collaborators in the design, development, and clinical application of new or customized technological devices (Webb, 2005). Occupational therapists create a successful match between the individual and AT devices by completing an occupational profile and an analysis of occupational performance.



OT's then analyze the characteristics of AT devices, the activity demands, and the context in which devices will be used (Buning, Hammel, Angelo, Schmeler, & Doster, 2004).

The OT also needs to conduct interviews with parents, teachers, and the students in order to determine what the student needs in the way of AT. It is important to keep the teacher involved throughout the intervention process in order to assure that the AT is used within the school context.

In making AT decisions, the connection of the student with the tool or strategy will depend on the anatomical, neurological, psychosocial, and sensorimotor considerations that impact that connection both from a student perspective and an environmental perspective (Struck, 2003). The OT contributes a unique perspective incorporating the functional performance of the total human body.

## *Service Delivery*

Within OT service delivery, the application of basic/complex AT can enhance an individual's personal control, communication, mobility, independence, work, leisure activities, and social participation. When designing interventions consideration of context, activity demands, and client factors are critical to successful outcomes. The activities that a person chooses to engage in hold purpose and meaning to an individual. When a person is unable to participate in meaningful activities or occupations, AT may be used as a support.

Assistive technology may unlock human potential and optimize human performance throughout the lifespan and across contexts and allow individuals to assume or regain valued life roles. Technology is a valuable tool for OT's to use in assisting individuals with moving toward their highest level of independence and with the process of adaptation to disability (Buning, Hammel, Angelo, Schmeler, & Doster, 2004).

# Assistive Technology in the HOME



## **Assistive Technology in the HOME**

In the home, AT devices can increase safety and independence in self-care activities, allow for participation in instrumental activities of daily living (IADLs), promote play and leisure opportunities, facilitate communication and interaction with family and friends, improve mobility, and enhance environmental control. By using AT, a child with DMD can remain independent longer therefore increasing quality of life.

It is important to recognize that the home not only is a physical place, but also is an extension of the self, expressing identity, providing independence and security, and representing participation and belonging. As a result, it is necessary to understand the meaning of home, the objects contained in the home, and their relationship to the client and his/her everyday occupations before introducing changes to the existing structure or function of the residence (Sanford & Fagan, 2004).

## ***Accommodation***

Accommodation addresses the fit between the task environment and the assistive device. How will the child with DMD use the assistive device to perform functional tasks within the home's limited space? How many tasks will the device perform, and where will task performance occur? Accommodation planning is minimal if a device is devoted to one functional task and one location, such as completing homework in the child's bedroom. The number and type of accommodations that must be planned increase with the variety of activities that involve the assistive device.

## ***Family Needs***

Considering family needs within the task environment is important to ensure the device is assimilated into the home routine. A device generating excessive noise may disrupt other members of the household and their activities unless these extraneous impacts are mitigated. Mitigating impacts of assistive

devices on family members may involve costs that should be considered in the cost benefit evaluation of a device. With proper planning, most devices can be implemented with minimal disruption to the family (Mann & Lane, 1995).

Home modifications include adaptations to the home to permit access or independent mobility and self-care, ensure safety, and increase independence in participation. Examples include widening entranceways and doorways, installing stair-glides, ramps, grab-bars in the bathroom, intercom systems, lowering countertops or cabinets, changing floor coverings, and providing adaptations to fixtures. Home modifications are fundamental if a child with DMD is to live at home.

The typical home has a limited amount of space available for the use of an assistive device. Device selection is influenced by the amount of floor space available compared to the amount required. Floor standing devices need space for the base, and

desktop devices need room on a desk height surface and ceiling clearance.

### *Seating and Positioning*

Seating and positioning aids include modifications or adaptations to wheelchairs or other positioning systems that are used to support the trunk and head in upright posture. Seating and positioning aids may be required for the safe, comfortable and functional performance of activities of daily living, including eating and grooming.

Certain positioning systems such as side-lying frames and floor sitters permit a user to more comfortably and functionally participate in play and recreational activities. They also reduce pressure on weight bearing surfaces to prevent skin breakdown.

Finally, seating and positioning aids are essential to making controls or other equipment accessible for increased independence. Examples include side-lying frames, crawling assists, floor sitters, chair inserts, customized wheelchairs that

tilt in space, standing aids, and simple floor mats. Each particular aid increases function and participation through stable and comfortable positioning. Proper seating and positioning may also reduce secondary disabilities such as hip displacement and scoliosis or health problems such as pressure sores (Olson & DeRuyter, 2002).

### *Goals/Outcomes*

• School-aged children with DMD spend anywhere from one-third to most of their time at home. Therefore these children can use AT at home to increase function, enhance independence and environmental control, improve mobility, increase self-esteem, and enhance play, leisure, and family interaction.

Environmental controls include electronic or computerized systems with switch controls including voice recognition that enable children with DMD without mobility or sufficient manual ability to control household appliances and devices such as the television or lights. They allow children to control the



environment without help from family members or personal assistants whether for performing household chores, playing with toys, or enjoying leisure activities (Olson & DeRuyter, 2002).

## Assistive Technology Interventions for the Home

### *Activities of Daily Living (ADLS)*

Toileting refers to a person's ability to obtain and use supplies, clean oneself, transfer to and from the toilet, and maintain toileting position. Toileting is a highly private and personal act and a person usually desires optimal independence which may be increased by utilizing various forms of adaptive equipment (Olson & DeRuyter, 2002).

#### **Toileting**

- a) Elevated toilet seat
- b) Grab bars on both sides of the toilet for children who require minimum assistance with transfers
- c) Slide-boards for transferring of children who require moderate assistance
- d) Hoyer-lift for dependent transfers
- e) Easily accessible toilet-paper holder



([www.dmeonline.com](http://www.dmeonline.com))

## Grooming

Grooming includes self-care tasks such as oral hygiene, hair care, and hand and face care. Society views proper grooming as a requirement, but a person with decreased arm or hand function may have difficulty grooming. Although brushing teeth and combing hair appear to be simple tasks, they require a person to have adequate upper extremity range of motion, strength, coordination, and endurance (Olson & DeRuyter, 2002). Assistive technology is available to help children with DMD perform grooming tasks more independently.

- a) Built-up handles on brushes and toothbrushes; a strap to help hold up brushes and toothbrushes.
- b) Long-handled comb for limited upper extremity mobility.
- c) Pump soaps and toothpaste dispensers
- d) Long-handled sponge
- e) Shower chairs or benches
- f) Hand held shower nozzles
- g) Universal cuff to hold a toothbrush



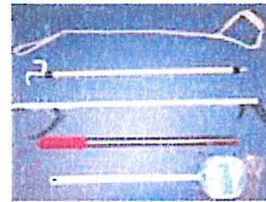
([www.disabilityaids.net](http://www.disabilityaids.net))

## Dressing

Dressing refers to a person's ability to select appropriate clothing, obtain clothing from a storage area, dress and undress sequentially, and fasten and adjust clothing and shoes.

The act of dressing can be a task that requires a person to have physical agility and a considerable amount of endurance

(Olson & DeRuyter, 2002).



- a) Sock aid for lower extremity dressing
- b) Button hooks (www.hopkins-arthritis.org)
- c) Elastic shoelaces, they are stretchy and therefore do not need to be tied
- d) Long-handled shoe horns
- e) Zipper pulls
- f) Elastic waistband pants and shirts that can easily be pulled over the head
- g) Velcro shoes
- h) Dressing stick or reacher

## *Leisure/ Play*

Case-Smith (2001) defines play "as a complex set of behaviors characterized by a dynamic process that involves a particular attitude and action" (p. 529). It involves exploration, experimentation, repetition of experience, and imitation of child's surroundings (Case-Smith, 2001). Play is a very important part of life for all children, including children with a disability (Skar, 2002).

a) Ankle Foot Orthoses (AFO) and Knee Ankle Foot Orthoses (KAFO) can help with walking and slow the development of contractures. Ankle foot orthoses and KAFO's can also be worn at night to prevent the foot from pointing downward (<http://www.mdausa.org/publications/journey/4-4b.html>, 2005).



([www.footssmart.com](http://www.footssmart.com))

b) Switches and controls for battery operated toys

- c) Wheelchairs modified to the DMD child's needs and to decrease the risk of falling
- d) Wheelchair tray tables
- e) Adapted seating to prevent pressure sores and pain for children with DMD who are confined to a wheelchair
- f) Adapted scissors for cutting
- g) Adapted tools for crafts (i.e., paint-brushes)
- h) Basic remote controls to control the T.V. or stereo

### *Social*

#### a) Home modifications

- 1) Lowering countertops
- 2) Widened doorways
- 3) Ramps
- 4) Stair-glide
- 5) Lowered-shelves
- 6) Universal Switch



([www.wheelchairramp.org](http://www.wheelchairramp.org))

- b) Walkers, Wheelchairs for mobility within the home
- c) Intercom
- d) Wall switch extenders or lowered switches and outlets
- e) Cordless phones
- f) Built-up handle cooking utensils

# Assistive Technology in the School



## **Assistive Technology in the School**

Schools are active environments and present a wide range of challenges to all members of the learning community. For students who have learning problems or other conditions that interfere with participating in a traditional school setting, the support provided by AT can be a way to level the learning, living, and playing field. Assistive technology makes significant differences in the quality of life and education for students with disabilities. Assistive technology provides access to general curriculum materials and enables students to show what they know and what they are learning.

### ***Legislation***

The 1997 revision of the Individuals with Disabilities Education Act (IDEA) provides that, if a child with a disability requires AT devices, services, or both in order to receive a free and appropriate public education, the public agency must ensure



that they are made available to the child. These services can include: special education, related services, or as supplementary aids and services. IDEA specifically identified AT as a special factor that must be considered by each individualized education plan (IEP) team. IDEA requires that AT devices, and services and training be provided to children with disabilities by the public agency serving them at no cost to the parents. The results of a traditional assessment may lead to the recommendation of a device geared toward specific school tasks as opposed to a tool to facilitate independent functioning of a child in multiple environments.

### ***Environment***

School-aged children with DMD may spend 6 to 8 hours each day or more school. This is an environment where children learn reading, writing, mathematics and science. It is also an environment where children develop social skills through forming peer and other relationships, eat, and play. In addition, children

learn many life-long skills about independence, productivity, contribution, and participation.

Taking into consideration the child's social environment it is a necessity to consider the child's peers. Peers in the task environment are fellow students. Mitigating any adverse effects of using assistive devices, such as noise or physical disruption, helps increase acceptance by peers. Peer acceptance is a vital source of encouragement and support for device use. Assistive technology can support each of these aspects of development for children with DMD.

Assistive technology devices and services are a necessity to access school life and learning. The selection of a particular AT solution requires unique child and classroom considerations. It is necessary to ensure the AT chosen will meet the goal(s) to be accomplished, and the unique classroom considerations are included.

Classrooms have a limited amount of space for an assistive device so floor space and school desk surfaces are important. Unlike the home, where space may be dedicated solely to the child with DMD and the AT device, space at school must serve multiple uses for all children throughout the course of a day. Assistive devices should not represent an insurmountable obstacle for others. Security is also an important issue for AT devices used in public or shared areas, requiring protocols for using and securing the AT device.

### ***Accessibility & Accommodation***

Accessibility issues described in the home are multiplied in the school setting. Accessibility issues involve school classrooms, offices, cafeterias, restrooms, gymnasiums, and any other locations reached by the student.

Accommodating an assistive device within the school may require modifications to the tasks performed, to the task environment, or to the AT device. A child performs a wide range

of functional tasks at school, each with particular accommodation issues. A thorough plan for accommodating all anticipated tasks will maximize the devices utility. The plan should involve the expected progression of students graduating to the next level. The task environment may change as the child gains proficiency with the AT device. Planning should consider an assistive devices utility in the context of the child's probable future progress.

### *Value of Training*

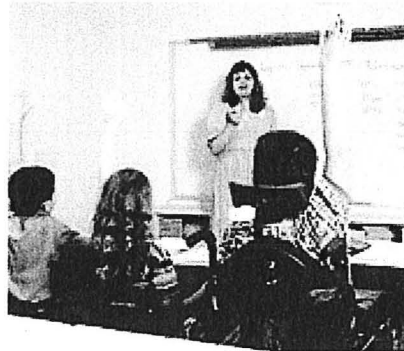
Occupational therapists are instrumental in supporting academic staff by periodically checking, training and retraining as needed so that AT is used and seen as valued tools for academic achievement. This support role would call for each OT, not just a specialty OT, to take an active part in continuing professional development in AT that is based on the needs of the students they see throughout their schools (Schouten, 2003).

# Assistive Technology Interventions for the School

## *Education*

According to the Occupational Therapy Practice Framework: Domain and Process (2002) the definition of education is as follows; "Education includes activities needed for being a student and participating in a learning environment" (p. 620).

- a) Computers
- b) Easels to hold papers while typing
- c) Tape-recorder
- d) Tilt-boards for writing
- e) Electronic page turners
- f) Adapted scissors
- g) Pencil Grips
- h) Classroom Modifications



([www.mdaua.org](http://www.mdaua.org))

- 1) Wheelchair accessible desks
- 2) Widened doorways and aisles for wheelchair access
- 3) Lowered shelves

## *Play/ Leisure*

Play is more than having fun. It is a process through which children develop their physical, mental, and social skills (Olson & DeRuyter, 2002). Playgrounds should be accessible for children with and without disabilities.

- a) Outdoor adaptations
  - 1) Modified swings
  - 2) Ramps onto play equipment
- b) Fat crayons
- c) Paint brushes with adapted handles
- d) Adapted board games
- e) Modified computer games

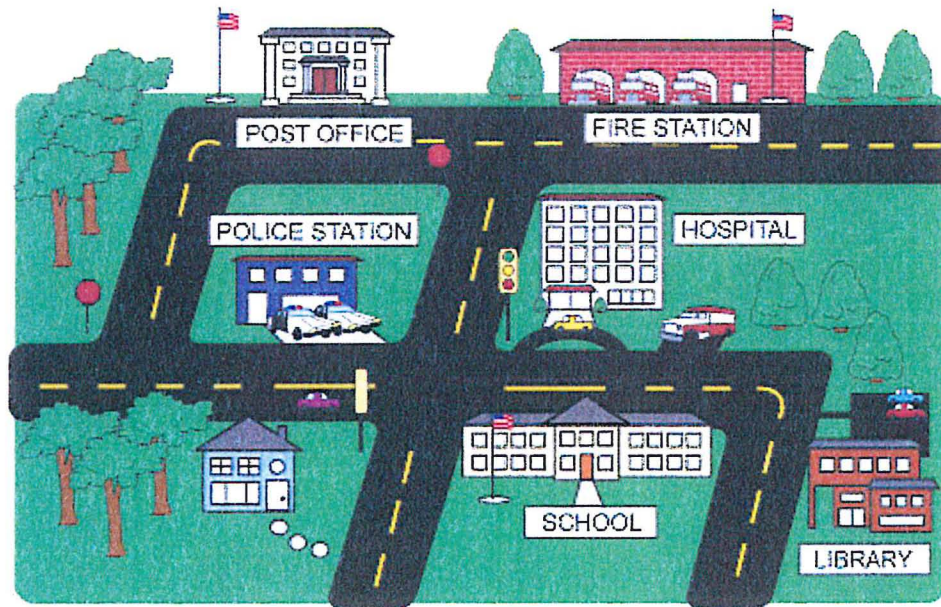
## *Social*

- a) Adapted board games and computer games
- b) Wheelchairs or walkers for mobility
- c) Cafeteria Modifications
  - 1) Widened doorways
  - 2) Widened aisles between tables
  - 3) Handicap accessible tables



([www.mdausa.org](http://www.mdausa.org))

# Assistive Technology in the Community



## **Assistive Technology in the Community**

Advances in assistive technologies have occurred that help in children with DMD to enjoy recreation, sports, and leisure. Recreation, leisure, and play modifications can include specialized equipment or adaptations to accommodate a variety of leisure and recreational pursuits in the community, access to materials and activities allowing peer interaction, hobby development and enjoyment, and good use of free time. Some examples include playground adaptations to slides and swings, hand-powered bikes, and adapted or specialized wheelchairs which allow children to participate in sports such as basketball (Olson & DeRuyter, 2002).

Access to parks, theaters, shopping centers, and other community facilities is essential to quality of life for persons who are disabled. The OT works with children with DMD and their families in determining which community facilities they will be



using and assess the facilities for accessibility. If there are problems with accessibility, the OT will work with the facilities to make modifications or recommend AT that can overcome the obstacles to accessibility.

# Assistive Technology Interventions for the Community

## *Leisure*

([www.playgrounds.com](http://www.playgrounds.com))

### a) Modified Playgrounds

- 1) Ramps to equipment
- 2) Modified swings
- 3) Transfer platform to



allow for front or side transfer onto playground equipment

- 4) Firm, slip-resistant surface
- 5) Wheelchair accessible sand play areas
- 6) Wheelchair accessible water play areas
- 7) Accessible routes to picnic tables
- 8) Accessible routes to all playground equipment
- 9) Handicap accessible water fountains
- 10) Handicap accessible restrooms

### b) Modified Shopping Centers

- 1) Ramps
- 2) Appropriate spacing between displays
- 3) Wheelchair accessible restrooms
- 4) Wheelchair accessible dressing rooms
- 5) Handicap accessible water fountains
- 6) Handicap accessible doors

7) Elevators

c) Modified Pools

1) Pool chairs

2) Ramps into pool

3) Hydraulic chair into pool



([www.mdauusa.org](http://www.mdauusa.org))

4) Handicap accessible restrooms

5) Handicap accessible dressing rooms

6) Handicap accessible showers, lowered water control knobs and hand-held shower nozzles.

7) Widened hallways and doorways into pool

8) Modified swimwear

9) Modified water fountains

***Social***

a) Modified Restaurants

1) Handicap accessible restrooms

2) Widened hallways and doorways

3) Adequate spacing between tables

4) Handicap accessible tables

5) Lowered buffet counters

6) Ramps into restaurant

b) Modified sports/recreation

1) Recreational wheelchairs/sports wheelchairs

2) Wheelchair access to medical facilities

3) Modified indoor and outdoor  
games

4) Adapted rules for handicap

5) Modified sport equipment

6) Handicap accessible restrooms

7) Widened doorways and hallways

8) Handicap accessible water fountain



(www.mdausa.org)

### ***Community Mobility (IADL)***

a) Family Vehicle Modifications based on various degrees of  
DMD severity

1) Collapsible Wheelchair

2) Sliding board

3) Wheelchair tie down and Occupant Restraint  
Systems (ORS)

4) Wheelchair loading device

b) Public Transportation

1) Wheelchair loading device

2) Wheelchair tie down and ORS

3) Appropriate storage for a collapsible wheelchair

4) Appropriate seating area



(www.mdausa.org)

\* There are many areas of the community, but for the purpose of this project we chose to focus on the above areas.

# Resources



[mrtech.com](http://mrtech.com)

## Resources

### *Assistive Technology Resources at School*

Council for Exceptional Children  
1920 Association Dr.  
Reston, VA 20901  
Telephone: (703) 820-4940

### *Assistive Technology at Home*

Home Automation: Home Controls for All Abilities, Home Tech,  
Seaside Education Associates, Inc.  
PO Box 6341  
Lincoln Center, MA 01773  
Telephone: (800) 886-3050 (V), (617) 899-3804 (TT)  
E-mail: info@seaside.org  
Website: <http://www.seaside.org>

### *General Resources*

National Rehabilitation Information Center (NARIC)  
1010 Wayne Avenue  
Suite 800  
Silver Spring, MD 20910-5633  
Telephone: (800) 346-2742

### **RESNA**

1700 N Moore St.  
Suite 1540  
Arlington, VA 22209-1903  
Telephone: (703) 524-6686

## Internet Resources

Ability Hub

<http://www.abilityhub.com>

ABLEDATA Database

[http://www.abledata.com/Site\\_2/prod\\_type.htm](http://www.abledata.com/Site_2/prod_type.htm)

Assistive Technologies for Kids Web Directory

<http://www.disabilityresources.org/AT-KIDS.html>

Assistivetech.net

<http://www.assistivetech.net>

[www.atnet.org](http://www.atnet.org)

## CHAPTER V

### SUMMARY

The purpose of this Scholarly Project was to develop a tool to guide OT's in using AT in the treatment of elementary school-aged children with DMD. The AT guide is intended to be a valuable tool for the OT to more effectively integrate AT into the daily treatment plan for children with DMD. An extensive literature review was completed utilizing various textbooks, journals and pertinent websites. Currently there is limited research-based information on the subject of DMD and AT. Much of the information that was found was outdated therefore was not applicable for the purpose of this project. Time constraints were also a factor in the completion of this project.

Information from the review of literature was compiled into a guide designed for the occupational therapist to maximize treatment intervention using assistive technology for elementary school-aged children with Duchenne Muscular Dystrophy. The guide is organized based on the three main areas in which an elementary school-aged child with Duchenne Muscular Dystrophy is involved in which include the home, the school, and the community. The product was organized using the Ecology of Human Performance Model as well as the Occupational Therapy Practice Framework: Domain and Process.

This project could be implemented as a resource to OT students during their course of schooling. It could also be utilized as a resource for entry-level therapists or



practicing occupational therapists that may not be aware of the area of assistive technology with children diagnosed with DMD.

The use of AT may give children with DMD opportunities that they otherwise would not have. When children with disabilities use properly selected AT devices, proper positioning, and electronic aids to daily living (EADLs), they have increased access to the world around them. They are able to communicate with others, play, move, and explore like their normally developing peers. Their ability to be active participants in these activities of daily living is crucial to their cognitive, physical, social, and psychological development. This development, facilitated by AT devices, gives children with disabilities a strong foundation to participate successfully in their natural environments (Isabelle, Bessey, Draga, Blease, Shepherd, & Lane, 2002). Occupational therapy practitioners understanding of their clients daily occupational needs, abilities, and contexts make them ideal collaborators in the design, development, and clinical application of new or customized technological devices (Webb, 2005).

Before an occupational therapist (OT) can consider using assistive technology (AT) with a child who has Duchenne Muscular Dystrophy (DMD), adequate research needs to be completed in order to gather the most relevant and up-to-date information that can assist in the treatment. The more resources, awareness and knowledge an OT has about the numerous forms of AT, the more the child with DMD will benefit. It is recommended that further research be completed on this topic in order to gain a better understanding of the benefits assistive technology will have on the lives of elementary school-aged children with DMD.

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