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Children with Limb Deficiency: the Impacts of Using a Prosthetic for Functional Independence

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CHILDREN WITH LIMB DEFICIENCY: THE IMPACTS OF USING A PROSTHETIC FOR FUNCTIONAL INDEPENDENCE

by

Kirsten Brandt and Michelle Grimes

Advisor: Dr. Gail Bass, OTR/L

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Submitted to the Occupational Therapy Department
of the
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In partial fulfillment of the requirements
for the degree of
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This Scholarly Project Paper, submitted by Kirsten Brandt and Michelle Grimes 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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Department: Occupational Therapy

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ABSTRACT

Many emotions, questions, and concerns may arise for parents and caregivers upon learning that their child has a limb deficiency. Educational resources for parents of children with limb deficiencies may be lengthy, time consuming to find and read, and full of medical jargon. The purpose of this scholarly project was to develop an educational booklet that is concise and easy to read for parents and caregivers of children with limb deficiencies.

An extensive literature review was conducted addressing the physical and psychological impacts children with limb deficiencies experience during daily activities. Parents with children who have limb deficiencies, individuals with limb deficiencies, and medical professionals who work with this population were consulted to gain a qualitative insight into unaddressed areas of concern. Additional literature which described the use of prosthetic devices and their impacts on functional independence was reviewed.

Based on this review of literature, four areas of concern were identified: (1) there is a lack of immediate resources provided to families, (2) limited resources are available for medical professionals to communicate with this population, (3) multiple client factors and performance skills are affected when a child has a limb deficiency, and (4) prosthetic devices are commonly utilized to increase functional independence in children with limb deficiency.

A user-friendly, educational booklet for parents and caregivers was developed to address identified areas of concern. The booklet was designed for occupational therapist
to give to medical professionals and they, in turn, can give it to parents who have just
learned their child has a limb deficiency. This booklet defines common terminology,
addresses physical and psychological impacts for both the parents and child, and
introduces the rehabilitative process including the use of a prosthetic device. The booklet
is a resource that addresses social and emotional aspects of limb deficiencies for children
and parents, provides a foundation of knowledge and suggestions for additional
resources, and facilitates communication with support groups and medical professionals.
CHAPTER I
INTRODUCTION

Could you imagine seeing your newborn for the first time and not being able to count ten fingers or ten toes? Or having a doctor come out of surgery and tell you that your child’s arm could not be saved? A limb deficiency, whether congenital or traumatic, is an absence or malformation of part of a limb. With the unexpected news of having a child with a limb deficiency, there are many emotions, questions, and concerns that arise. The amount of information combined with the emotional stress of the experience may be overwhelming for parents or caregivers; they may not even know what questions to ask.

Statement of the Problem

Multiple resources have been identified by these authors for parents and caregivers regarding the rehabilitation process, medical concerns, prosthetics, and physical and social impacts on children with limb deficiencies. Although this information is accessible to the public, the materials tend to be lengthy, time consuming to find and read, and full of medical jargon. Based on an extensive literature review four areas of concern were identified: (1) there is a lack of immediate resources provided to families, (2) limited resources are available for medical professionals to communicate with this population, (3) multiple client factors and performance skills are affected when a child has a limb deficiency, and (4) prosthetic devices are commonly utilized to increase functional independence in children with limb deficiency.
The limited amount of resources readily available to parents and medical professionals may be a barrier to communication and family involvement during the rehabilitation process. Reyes-Muralles (2001) is the mother of a child with a congenital limb deficiency who developed a book as a result of her frustration with the lack of information provided to her. She was unable to readily find books and resources addressing her specific questions. Medical professionals who do not specialize in this area tend to have limited exposure to this patient population. According to Watts and Clark (1998), who are orthopedic surgeons, these medical professionals may have limited understanding about how to communicate with and educate the child and family.

Congenital or traumatic limb deficiency in children affects multiple areas of life including: functional performance, physical and psychological well-being, and childhood occupations. For example, after an amputation, a child may experience a shift in his or her center of gravity and a loss of sensorimotor and coordination skills; this can influence a child’s feeling of success and mastery, thus impacting the child’s self-esteem (Morrison & Metzger, 2001; Dolhi, Leibold, & Schreiber, 2003). A prosthetic is a device that can be introduced early in the process to facilitate the occupations of daily living and play, specifically bilateral activities; this can positively influence body image (Svoboda, 1992; Scotland & Galway, 1983).

Purpose of the Product

The results of the literature review and the authors’ area of interest led to the focus of the project on children with upper limb deficiencies, both congenital and traumatic; and the possibility of using prosthetic devices during various areas of occupation. The product was developed to be a user friendly, educational booklet to be
given to parents and caregivers at the beginning of the rehabilitation process. This booklet provides background information, a listing of additional resources, and information about the expected rehabilitation pathway that may be experienced by the child and family. Some areas introduced in the booklet include the grieving process, pain and sensations, the prosthetic process, and commonly used terms. The product is intended to be presented to medical professionals by an occupational therapist as a means to provide general knowledge to parents and caregivers immediately following their learning of their child’s limb deficiency. The occupational therapist’s contact information is provided on the back of the booklet for consultation for parents and medical professionals.

**Theoretical Model Used**

The information in this booklet is designed to incorporate information from the literature review and the Occupational Adaptation model. According to Jackson and Schkade (2001) the Occupational Adaptation (OA) model hallmarks the participation in intrinsically motivating and satisfying occupations leading to functional adaptation. Occupation is defined by the authors as any meaningful activity that an individual participates in. For children, play is the primary occupation to learn and develop skills (Case-Smith, 2001).

The OA model focuses on occupational readiness, such as skill building and understanding pain and sensations; and occupational activity, which includes adapting to the changing needs of the activity. This can include adapting the contexts (physical, social, or temporal), the occupation, and the assistance provided. By adapting and adjusting the activity, the person becomes more competent in the occupation; this is
known as relative mastery. Relative mastery refers to the internal sense of efficiency, effectiveness, and satisfaction received after participation in an activity (Jackson & Schkade, 2001).

The focus of this booklet is to build a foundation of knowledge and prepare the parents for the skills and adaptation necessary to deal with the rehabilitation process. By using this model, it is hoped that the family and child will develop the ability to functionally adapt to new challenges in life as they arise.

Overview

In order to validate the product, a review of literature was completed, the methodology was defined, and recommendations are provided. This document is divided into five chapters with the review of literature following this introduction. The third chapter describes the methodology that was used to develop the product which is presented in chapter four. The final chapter is a summary of the strengths and limitations of the product, recommendations for further research, and a description of the potential for future scholarly collaboration.
CHAPTER II
REVIEW OF LITERATURE

Introduction

According to Watts and Clark (1998) there are over one million people living in the United States with a limb loss or deficiency. Some individuals are born with a limb deficiency and others experience limb loss as a result of an injury or disease. The authors also note that the upper extremities are the most frequent site of limb loss for children. This paper will review the literature on upper limb deficiencies and prosthetics, with emphasis on upper limb deficiencies in children. The types of limb deficiency will be briefly explored, followed by physical and psychological factors experienced by children with limb deficiency and the resulting impact of limb deficiency on childhood occupations. The use of prosthetics for children will be examined, including history, types of prosthetics, and the process of obtaining a prosthetic. Factors affecting prosthetic acceptance or rejection will be reviewed, along with aspects of training, family involvement, client factors, and social issues. The purpose of this literature review is to aid in the development of a handbook for parents or caretakers of children with limb deficiencies.

Congenital versus Traumatic Limb Deficiency

*Congenital Limb Deficiency*

A congenital limb deficiency is an absence or malformation of a limb acquired during an infant’s development in the uterus and “the birth prevalence of congenital limb
deficiency in 1996 was 25.64 per 100,000 live births in the United States” (Amputee Coalition of America [ACA], 2005, Limb Loss FAQs, ¶ 2). Orthopedic surgeons, Watts and Clark (1998) identify that “approximately 60% of children seen in amputee clinics have amputations resulting from congenital anomalies” (p. 8). These authors note that children with congenital limb loss are twice as likely to have the upper extremity involved with the most common site being the below-elbow deletion.

According to ACA (2005), there are two theories that have been identified as to the cause of limb deficiency, genetic combination and uterine filaments. Genetic combination refers to a chromosomal abnormality that occurs as the result of a unique genetic pairing from the mother and father. The second theory involves uterine filaments, developing during early pregnancy, detaching from the uterine wall and wrapping around a limb, preventing further limb development. In addition to these theories, it was once believed that limb deficiency was attributed to the use of drugs, such as thalidomide, by the mother during pregnancy; however, there is no evidence to support this. Since the cause of congenital limb deficiency is frequently unknown, Watts and Clark (1998) encourage that further tests be conducted to rule out associated disorders in all children.

Congenital limb deficiency may also result in a surgical amputation (ACA, 2005). According to Watts and Clark (1998):

“Some children with this problem (congenital foot deformity) may be managed without an amputation. The problems are prolonged treatment time and the fact that, in spite of all the effort, the child is often left with a deformed and less well functioning foot and ankle” (p. 5).

A surgical amputation may follow a congenital limb deficiency to reshape the residual limb for ease of prosthetic fitting. From a parent’s perspective, Reyes-Muralles
notes that it is important to consult the medical rehabilitation team to evaluate the best functional needs for each individual child. If the team and family decide to proceed with a shaping amputation for prosthetic fitting, Watts and Clark (1998) recommend performing the surgery at a young age as the child “is less likely to have incorporated the deformed foot into his body image, and an amputation is less likely to be psychologically traumatizing” (p. 6).

Traumatic Limb Deficiency

Trauma is the second leading cause of morbidity in children and the most common cause for amputation (Loder, 2004; Datta, Selvarajah, & Davey, 2004). Seventy-five percent of acquired limb deficiency in children is caused by trauma, occurring more frequently in males (Huang, n.d., pp. 3-4). Traumatic limb deficiency is the result of accidental injury or damage of body tissue (Thomson Gale Inc., 2005). Loder (2004) conducted a study of causes of pediatric limb deficiency in the United States upper Midwest, finds showed that lawnmower injuries were the most common cause of amputation, 69 of the 235 children; followed by farming injuries, 57 of the 235 children; and then by motor vehicle collisions at 38 of the 235 children. The author also found that the average age of the child at the time of injury was 7.9 years old and that 54 of the 69 children who experienced amputation in a lawnmower accident were five years of age or younger (pp. 923-925).

A traumatic limb deficiency can result in complete or partial severation of the body tissue (Freedman, 2004). Replantation, or reattaching the severed part to the limb, may be possible depending on multiple medical factors such as location and type of wound, amount of time passed since incident, along with age and physical condition of
the individual. Children are able to heal and adjust to their acquired disability quicker than adults (Thomson Gale Inc., 2005). Although children are able to adapt more readily to the acquired limb deficiency, rehabilitation concerns focus on skill development, growth and psychosocial issues (Huang, n.d., p. 6).

Physical and Psychological Factors

The level of amputation can vary in both congenital and traumatic limb deficiency. Upper extremity amputation can range from the loss of a finger, to the loss of an entire arm below the shoulder (Dolhi, Leibold, & Schreiber, 2003). Pruitt, Seid, Varni and Setoguchi (1999) found “that the greater the limb loss, the less independently the child performs upper extremity tasks” (p. 823); as the level of limb deficiency varies, so does the loss of function. In comparison to the medically defined normal range of function, a child with a limb deficiency experiences limitations in physical skill and psychological well-being.

Physical Factors

Dolhi et. al (2003) note that the loss of a part of an upper extremity requires adaptation in completing tasks that require bilateral integration, object manipulation, and transportation of objects. The functional capability of the residual limb such as remaining strength, mobility, and healing potential also affect a child’s functional independence. “Loss of neuromusculoskeletal tissue results in limitations in passive and active range of motion (ROM) relative to the site and type of amputation, strength of the extremity, general function, functional endurance, and postural alignment” (p. 801). After an amputation, a child may experience a shift in center of gravity and loss of
sensorimotor and coordination skills. Daily activities and outside expectations also impact a child’s independent functions.

Psychological Factors

Not only are the physical factors affected, but psychological elements are impacted as well. Whether congenital or traumatic, limb deficiency can lead to a person experiencing “grief and decreased self-esteem” resulting in a child feeling “different from their peers” (Adams, 2004, Body Image, ¶ 1). The child also has to “contend with the effects of the amputation on body image, cosmesis, personal care, and functional lifestyle”, which can influence a child’s motivation in participating in daily activities for self and with peers (Dolhi et al., 2003, p. 800). Adams (2004) notes that other psychological factors influencing a person’s ability to cope are a person’s age, level of limb loss, and experience surrounding the amputation.

Sensation and Pain

A child with a limb deficiency may experience a variance in sensation. According to Johnson, Hickey, Scoullar, and Chondros (2002) and ACA (2005), a child’s sensory functions may be limited at the tip or throughout the residual limb. Decreased sensation or hypersensitivity of the residual limb has the potential to impact the child’s ability to function in daily activities. A child may also experience decreased ability to discriminate touch, temperature, and/or pressure. Pain and sensations may be experienced physically throughout the residual limb and/or psychologically throughout the amputated limb. In addition to the loss of function physically, pain and sensory issues can have an impact on the child’s ability to use the limb.
Sensation

Physiological sensation is defined as a person's state of awareness attributed to an internal or external stimulation resulting in change within the body (Merriam-Webster Online, 2005). Sensation of the upper extremity is thought to be a prominent element throughout the rehabilitation process (Thibault, Forget, & Lambert, 1994). “A person who has poor awareness of his or her limb in space (proprioception) or of movement (kinesthesia) is less likely to use his or her arm spontaneously in activity” (Johnson et al., 2002, p. 327). Since children with limb deficiencies have variance in these types of sensations, it is important to notice possible changes in activity participation and functional activities.

Pain

Siddle (2004) describes two different types of pain, “nociceptive” and “neuropathic”, which can occur in individuals with limb deficiency. In nociceptive pain, the nervous system is intact and transmitting signals frequently described as ‘dull’, ‘aching’, or ‘heavy’. Neuropathic pain is the transmission of pain signals through damaged nerve paths; this is often described as ‘hot’, ‘burning’, or ‘shooting’. According to this author, phantom limb pain is an example of neuropathic pain. (p. 664)

Phantom Sensations and Pain

Phantom pain is thought to be defined as “pain that is localized in the region of the removed body part, after the amputation of the limb” (Siddle, 2004, p. 664). Phantom pain and sensations psychologically experienced throughout the amputated limb may be a result of physiological happenings within the child’s nervous system. In a study completed by Wilkins, McGrath, Finley and Katz (2004), phantom pain and sensations
were reported in both children and adolescents with congenital and traumatic limb deficiencies. During the month following an amputation, phantom pain and sensations may be experienced regularly by an individual. Wilkins et al. (2004) reference a study by Simmel in 1962 who found that “while phantom limbs are rare in amputees who have lost a limb before the age of 4, the incidence of phantoms increases with the age at amputation and age at interview” (p. 293).

Siddle (2004) identifies three possible theories that have been developed to explain the occurrence of phantom sensations and pain in the body: The Peripheral Theory, The Spinal Theory, and The Central Theory. In The Peripheral Theory, the remaining peripheral nerves form “neuromas” which produce spontaneous stimuli that can be perceived as pain in the amputated portion of the limb. In contrast, the Spinal Theory identifies that the problem originates with neurochemicals sending mixed signals to the brain resulting in ‘confusion’ as to where the pain impulses are located in the body. In the Central Theory, or neuromatrix, “…the human body is represented in the brain by a matrix of neurons” (p. 665). This neuromatrix is supposedly developed through memories of life experiences which have been known to remain up to 7 years following a limb deficiency.

Disturbances in the nervous system have the ability to create painful and nonpainful sensations. In a study completed by Wilkins et al. (2004) consisting of children with limb deficiency that documented phantom limb sensation through diary entries during a period of time, it was found that the most common descriptions of this nonpainful sensation were “sensory-discriminative in nature and characteristic of the nonpainful paresthesias typically reported by the majority of adult amputees”, such as
'tingling', 'numb', and 'feels like it's asleep' (p. 299). Other common words associated with phantom limb pain are “tingling”, “throbbing”, “piercing”, “aching”, “uncomfortable”, and “sore” (p. 299).

The occurrence of experiencing phantom limb sensations and pain is variable and contingent to multiple internal and external factors. In a study to determine the prevalence of phantom sensation and pain, Krane and Heller (1995) note that children with limb deficiency reported phantom sensations with 83% experiencing phantom pain. This is supported by Siddle (2004) who states, “phantom limb pain is thought to occur in 60-80% of amputees” (p. 664). Physical and psychological factors connected to phantom limb sensations and pain, such as depression and stress, may trigger an occurrence of phantom sensation and/or pain (Wilkins et al., 2004; Siddle, 2004).

Impact on Childhood Occupations

Occupational therapists define occupations as meaningful and purposeful activities that are influential in all areas of a person’s life (American Occupational Therapy Association [AOTA], 2002). These occupations are unique to each individual, varying by factors such as age, past experiences, abilities, and interests. A limb deficiency may impact a child’s participation in daily occupations.

Client Factors and Performance Skills

There are physical and psychological elements, known as client factors that can affect children with limb deficiencies. Client factors are body structures and functions within a child that influence and affect performance skills. For example, a child with limb deficiency may have decreased sensation therefore may not notice or respond to injurious stimuli. These client factors can interfere with a child’s performance skills,
functional ability, and ultimately childhood occupations. Performance skills “are small units of performance” that include: motor skills, such as object manipulation; process skills, such as adaptation; and communication and interaction skills, such as social engagement (AOTA, 2002, p. 612). According to AOTA, functional ability is a child’s capacity to adapt and perform in his or her environment. Childhood occupations, which are meaningful activities engaged in by the child, are impacted by each individual child’s client factors and performance skills. In other words, a child’s ability to perform meaningful activities within his/her environment is directly affected by client factors and performance skills.

**Play as a Childhood Occupation**

Play is a primary occupation where children are able to develop skills, discover cause and effect, and interact with their environment (Morrison & Metzger, 2001; Henderson & Pehoski, 1995). Exploratory play, interacting with the environment through sight, sounds, taste, and touch, is the first stage of learning for a child (Morrison & Metzger, 2001; Finnie, 1997). A child with a limb deficiency may have limited interaction with the environment; for example, a child may not be able to grasp objects which limit his or her ability to experiment with objects and sequence actions. The occupation of play is an intrinsically motivated behavior and needs to be encouraged when a child experiences limitations in client factors and performance skills as a result of a limb deficiency (Morrison & Metzger, 2001).

As a child grows and develops, occupations change and advance. Postema, van der Donk, van Limbeek, Rijken, and Poelma (1999) state that “as they (children) grow older and attend secondary school, the child’s activities change toward more intellectual
tasks” (p. 248). A child’s level of functional performance correlates with the level of limb deficiency, age, and ability to adapt. Case-Smith (2001), states that “motor, cognitive, sensory or perceptual, communicative, and social-emotional systems contribute to occupational performance” (p. 75). Different types, levels, and demands of play are affected based on the child’s independent level of interaction and participation. Children with limb deficiencies and motor problems may “experience failure or frustrations throughout the day” (Henderson & Pehoski, 1995, p. 225). A young child is already a dependent person; therefore has the advantage of learning a new task or skill instead of re-learning a task in a new way (Watts & Clark, 1998).

Prosthetics

One option to improve functional independence for individuals with a limb deficiency is the utilization of a prosthetic device. A prosthesis is defined in Merriam-Webster Online (2005) as “an artificial device to replace a missing part of the body”. The device is attached to the residual limb, manipulated by the body, and integrated into functional performance. Prosthetics are developed and designed to uniquely fit the occupational demands of each child. The terms prosthetic and orthotic are frequently interchanged; however, each term refers to a different style of assistance for individuals with limb deficiency. Orthotic devices are used as a supplementation to the body; in contrast to prosthetics which serve as “an artificial extension” to replace a missing function (Wikipedia Encyclopedia, 2005). For the purpose of this paper, prosthetics will be the primary assistive device discussed in relation to functional performance of individuals with limb deficiency.
History of Prosthetics

There are indicators of prosthetic-like devices being used in the early Egyptian era. The first successful scientific development of prosthetics was introduced by a French surgeon, Ambroise Pare, in 1529 following his life saving amputation surgeries as a barber-surgeon serving soldiers and generations of French royalty. He invented “Le Petit Lorrain”, an upper extremity prosthetic using springs and catches which was used in battle by a French Captain. Prosthetic devices have since been developed by Dubois L Parmelee who improved the body socket attachment in 1863 by utilizing atmospheric pressure and Dr. Vanghetti, in 1898, who incorporated muscle contraction in the manipulation of the artificial limb (Bellis, 2004).

According to Dougherty, Carter, Seligson, Benson, and Purvis (2004) the development and technology regarding prosthetic limbs was greatly impacted by World War II where approximately 18,000 United States soldiers lost limbs. The United States Army Surgeon General Norman Thomas Kirk recommended the organization of amputee centers in preparation for the volume of patients with limb deficiency requiring skilled care. In 1943, five United States Army hospitals developed amputee centers where veterans had access to “revision surgery, prosthetic fitting, and physical therapy” (p. 177). The need for improved prosthetic devices arose because of the large number of servicemen suffering limb deficiency. “The tragedy of war enabled the growth of the orthopaedic specialty by providing material, personnel, and unfortunately, casualties who required treatment” (p. 180). Since World War II, there have been medical advances in the areas of limb deficiency and prosthetic devices. The opportunities for individuals
with limb deficiency have increased, leading to the development of multidisciplinary teams designed to address the multiple options available.

Types of Prosthetic Devices

There are many styles, designs, and purposes to a prosthetic device. It can range on a continuum from a focus on cosmesis to a focus on function; a majority of individuals utilize both (Martinez, 2004). Prosthetic devices are specifically designed to meet the needs of each individual client.

Cosmetic Prosthetic Device

Cosmetic prosthetics, also known as passive prosthetics, are developed to appear natural, attempting to duplicate the appearance of the body and the coupled extremity. The plastic molded socket is cosmetically enhanced using polyvinyl chloride, (a highly used, rigid plastic known more commonly as PVC), flexible latex, or silicone to please the individual (Martinez, 2004; Advanced Arm Dynamics, 2005). Burger and Marincek (1994) state that 70% of their adult patients wore their prosthesis primarily for cosmetic reasons. These types of prostheses are often lighter in weight and require less maintenance; however, they provide limited functional assistance (Advanced Arm Dynamics, 2005).

Body-Powered Prosthetic Device

According to Advanced Arm Dynamics (2005) a body-powered prosthetic, or conventional prosthetic, is moved and manipulated through gross motor body movements. Cables and springs connect to a shoulder harness to activate the prosthetic. In order for an individual to operate a body-powered prosthetic device, he/she must have sufficient residual limb length, musculature, and range of motion. Body-powered
prostheses are considered more durable and offer more sensory feedback; however, the harness may restrict movement.

*Myoelectric Prosthetic Device*

A myoelectric prosthetic utilizes muscle signals from the residual limb received through electrodes on the socket to activate the prosthetic device. According to Martinez (2004) this provides the most natural function of all the prosthetic options. There are two types of myoelectric units: the two-site/two-function unit, with separate electrodes for flexion and extension, and the one-site/two function unit, with one electrode for both flexion and extension. Variation in the strength of an individual’s muscle contraction is used to differentiate between flexion and extension. Myoelectric prostheses eliminate cables for better comfort, are more cosmetically appealing, and provide good hand function. Despite the benefits, these prosthetics are more expensive, heavier, tend to require more maintenance, and provide less sensory feedback for the individual.

*Hybrid Prosthetic Device*

A hybrid prosthetic utilizes the combination of body-power and electrical power within one prosthetic device. According to Advanced Arm Dynamics (2005) the hybrid prosthetic is usually fabricated with the elbow movement being controlled by cables and the hand movement being controlled myoelectrically. By combining the body-powered and myoelectric control, the individual is able to perform simultaneous movements such as elbow flexion while opening the hand. The disadvantage of this prosthetic is that the challenges of both body-powered and myoelectric need to be considered.
Terminal Devices

A terminal device is a type of device that is attached to the wrist unit of an upper extremity prosthesis. There are different types and styles, with the purpose being to replace the hand, either in appearance, function, or both. Body-powered and myoelectric prostheses are designed to attach to various terminal devices to maximize the functional needs of each individual. According to Martinez (2004) terminal devices are classified as passive or active. Passive terminal devices are usually chosen for cosmetic appearance and tend to be less functional. Active terminal devices are used to serve as a functional replacement for grasping movements of the hand; these are categorized as either prosthetic hands or hooks. There are two types of mechanisms that control the opening and closing of terminal devices: voluntary opening mechanism and voluntary closing mechanism. For the voluntary opening mechanism, relaxation of muscles allows the terminal device to close, while muscle contraction opens the device allowing for a controlled grasp. The voluntary closing mechanism is open when muscles are at rest, then closed during muscle contraction. This type of terminal device allows individuals to have a more powerful grip force, though they are unable to maintain a steady grip upon relaxation (Martinez, 2004; Advanced Arm Dynamics, 2005).

Fabrication

The general process of prosthetic fabrication consists of making a cast of the arm, creating a plaster mold, and then pouring hot plastic over the plaster cast to create the socket. The socket is the hollow concave portion on the top of the prosthesis that serves as the connection between the residual limb and the prosthesis (Hanger Orthopedic Group, Inc., 2005). Once the mold for the socket is made, fabrication of the prosthesis
varies depending on the type of device chosen. A prosthesis may be chosen for cosmetic purposes only, or for functional use. If a functional prosthesis is chosen, it may be either body-powered, myoelectric, or a combination of both, known as a hybrid combination.

Cost

Cost will vary depending on the individual's choice of prosthetic system; the system includes the prosthesis and terminal device. Cost can range from approximately $3,500 for a prosthetic with a hook terminal to $13,000 for one with a myoelectric hand (Pruitt et al., 1999).

Prosthetic Process

Martinez (2004) found that for prosthesis use to be successful, the prosthesis must be comfortable to wear, easy to put on and take off, lightweight, durable, cosmetically pleasing, and function well mechanically. To achieve this success, various people, agencies, and organizations are involved including: medical professionals, family, caregivers, and support organizations. There are also several stages to the rehabilitation process to improve the likelihood of successful long-term use of the prosthetic: pre-operative, operative, and post-operative.

Medical Professionals Involved

The medical professionals involved in the surgical and rehabilitation process may vary based on the individual needs of each child. According to Reyes-Muralles (2001) medical professionals that may be included as part of the rehabilitation team include: orthopedic surgeon, prosthetist, physical therapist, and occupational therapist. These individuals bring to the rehabilitation team professional expertise and skills to assist in the decision making for the family and treatment for the child.
Orthopedic surgeons address medical issues including: addressing a child’s medical needs following a trauma, reshaping of a limb in preparation for the prosthetic, remodeling the limb throughout the childhood years, and providing medical information to the caregivers and/or family involved. A prosthetist is involved in the production, fabrication and repair of the prosthetic device. This professional works in collaboration with the family and other medical professionals in determining the appropriate prosthetic and terminal device for a child (Reyes-Muralles, 2001). Rozelle (2005) writes about the importance of close communication and comfort with a prosthetist. “A prosthetist must know how you walk, jump, run, dance, ski, and fall” (p. 184). The child and family will also work with therapists to determine the functional and psychological needs of the child. Physical therapists address a child’s physical balance, strength, coordination, endurance, and range of motion. Occupational therapists are involved in educating and training the child and family to be independent in functional activities while creating a supportive environment for the child to develop and learn. Along with physical skills, occupational therapist’s address social, cognitive, and emotional concerns of the child and family (Reyes-Muralles, 2001).

Stages of the Prosthetic Process

According to Martinez (2004) the prosthetic process entails a general timeline that is followed by the majority of patients with a limb deficiency: pre-operative stage, operative stage, and post-operative stage. The post-operative stage includes a continuum of prosthetic devices used in the rehabilitation process: temporary, preparatory, and definitive.
**Pre-operative stage.** In the pre-operative stage, a child is seen by a rehabilitation team to evaluate and assess his or her current level of function, surgical considerations, child and family goals, and expected level of function. During this meeting, a collaborative effort is made to determine the rehabilitation needs of the child (Martinez, 2004). In the situation of a limb deficiency as a result of trauma, this pre-planning stage is not always possible.

**Operative stage.** The operative stage entails the process of shaping and protecting the residual limb. The length of the residual limb is determined by the level of injury, expected level of function, cosmetic appearance, and chosen prosthetic device (Martinez, 2004). Watts and Clark (1998) state, “in general, in an amputation in a child, it is preferable to save as much length as you can” (p. 2).

**Post-operative stage.** In the acute post-operative stage, attention is directed toward wound healing, pain management, mobility, range of motion, strength, child and family education, and performance skills for daily activities. This phase also includes preparing the residual limb for prosthetic wear incorporating a skin desensitization program, edema control, scar reduction, and shaping (Martinez, 2004).

At times, a temporary prosthesis is applied to the child’s limb immediately after surgery; this is used as the first step in the rehabilitation process. Robinson, Andrews, and Vitali (1975) conclude that “the use of an immediate prosthesis appears to carry very little risk to the primary healing of the patient’s stump” (p. 636). The residual limb is measured throughout to ensure proper fitting of the socket (Hanger Orthopedic Group, Inc., 2005). A temporary prosthetic, which may be heavy and bulky, is used while the residual limb is still maturing; this can help mold the shape of the residual limb.
Psychological and/or physical reasons may be involved in the decision to utilize a temporary prosthesis. This allows the child to physically feel the weight and psychologically accept an artificial limb. By using a temporary prosthetic, the child is able to work with the prosthetic early in the process (Martinez, 2004).

A preparatory prosthesis, following the removal of sutures, may be used for a short period of time after the temporary prosthesis to promote the rehabilitation process (ACA, 2005). The sooner the prosthesis is applied and training is initiated, the quicker the child is able to learn using the prosthesis while performing functional activities (Robinson et al., 1975). After the residual limb has reached a stable size and shape, the child will be re-evaluated to receive a definitive or long-term prosthesis.

A definitive prosthesis is “a replacement for a missing limb or part of a limb which meets accepted check-out standards for comfort, fit, alignment, function, appearance, and durability” (ACA, 2005, Limb Loss FAQs, ¶ 10). The socket fitting for this prosthesis cannot take place until three to four months after surgery (Martinez, 2004). The definitive prosthesis can be finished in a more cosmetically pleasing appearance than the temporary prosthesis and/or preparatory prosthesis; however, it requires more time and collaboration with the prosthetist for proper fabrication and fit. The final prosthesis will usually last between 2-5 years depending on the individual’s activity level and daily use. This time frame may be shorter for children, however, due to continuous physical growth (Hanger Orthopedic Group, Inc., 2005).
Person – Prosthetic Fit

Age of Fitting

The average age of fitting an infant or toddler with a prosthetic device is controversial with the optimal age yet to be defined (Pruitt et al., 1999). The literature supporting early prosthetic fitting states that there are increased psychological and physical benefits. Physical benefits cited include such things as promoting balance, reducing scoliosis, and encouraging bilateral integration. In studies focusing on the effects of prosthetic training, researchers found that fittings within 30 days of an amputation result in a greater acceptance of the prosthesis because the child is able to incorporate the prosthesis into his/her body image and becomes less dependent on the tactile input of the residual limb (Lake, 1997; Case-Smith, 2001). Robinson et al. (1975) found that immediate fitting allows the individual to maintain a sense of complete body image with a representation of the missing upper extremity.

Another reason for early fitting is to prevent compensation learning. An individual may learn to adapt by using the residual limb when performing daily activities; this has been found to result in abandonment or rejection of a later fitted prosthetic (Robinson et al., 1975). Researchers state that early prosthetic fitting is responsible for reducing the drop-out rate of prosthetic wear in children; Scotland and Galway (1983) found that only 22 percent of patients fitted before the age of two abandoned their prosthesis. Berke and Nielson (1991) found that if a child is fit with a passive prosthesis before the age of one, he or she will continue to wear the myoelectric prosthesis full-time. A time gap between prosthetic fittings when no prosthetic is worn, such as transitioning between a body-powered to a myoelectric, can also result in rejection. Berke and Nielsen
(1991) write that individuals who have experienced a time gap between fittings rejected both prostheses despite avid wearing of a prior prosthesis.

According to some of the literature, disadvantages to early fitting have also been noted. Early fitting of a prosthetic can interfere with sensory input to the residual limb which may result in rejection of a prosthetic (Watts & Clark, 1998). Pushing prosthetic fitting too early can also result in abandonment of the prosthetic if the parents are not psychologically and financially ready for their child to wear an artificial limb (Watts & Clark, 1998; Sener, Yigiter, Bayar & Erbahceci, 1999). If the family expresses negative attitudes towards the prosthesis early in the process, there is a greater chance that the child will reject the prosthetic device even if family attitudes change (Case-Smith, 2001).

Although there are varying views on the optimal age for prosthetic fitting, most clinicians initiate the prosthetic process using the development marker of independent sitting balance, known as “Fit with Sit” (Pruitt et al., 1999 & Watts & Clark, 1998, p. 9). This is the developmental stage where the child is beginning to develop the capacity to sit without assistance, about the age of five to six months of age. The prescription of a prosthetic is in preparation for future motor development such as crawling, pulling up to a standing position, and clasping large toys (Pruitt et al., 1999).

Factors Affecting Prosthetic Acceptance

The person-prosthetic fit consists of identifying factors for compliance, motivation, acceptance, and activity involvement coordinated with child and family goals. The motivation of the child and family impacts the willingness to further investigate the person-prosthetic fit for each individual child. Comfort, functionality, and cosmesis are also considerations for prosthetic acceptance, as the child and family must
believe that there are benefits to wearing the prosthetic device (Davidson, 2002; Postema et. al, 1999). Scotland and Galway (1983) found that adolescents, around the age of 13 years, abandoned their prosthetic as they became more mindful of the cosmetic appearance. If a prosthetic is uncomfortable, it may not be worn by the child. Loss of comfort may be due to physical or phantom pain and sensations, weight of the prosthesis, or contralateral body compensation, along with the fact that wearing a prosthesis may be hot (Watts & Clark, 1998; Datta et al., 2004).

Developmental stage. The prosthetic device and components are adjusted appropriately to facilitate the current developmental stage of the child (Watts & Clark, 1998). If the prosthetic device is not adapted to meet the skill level of the child, it may no longer be perceived as being beneficial (Postema et al., 1999). As an example, toddlers or young children are usually fitted with fixed elbows and a terminal device that can be manipulated by a parent or therapist, allowing the child to hold objects placed in the hand for developing eye-hand skills (Watts & Clark, 1998; Case-Smith, 2001). An active terminal device is usually introduced between the ages of 15 and 24 months to facilitate more complex movements and tasks (Case-Smith, 2001).

Activity participation. A child’s activity involvement is another factor in choosing the proper prosthetic. A myoelectric prosthetic may be more beneficial for a child requiring more open shoulder movement, as myoelectric prosthesis allow for more functional range of motion. However, the utilization of this prosthesis may require more time to complete an activity, as task performance can take up to twice as long using a myoelectric prosthesis compared to a conventional prosthesis (Stein & Walley, 1983).
Family involvement. Child and family involvement in prosthetic care is also a factor in finding the right prosthetic for a child. In a study utilizing chart reviews of pediatric patients with limb deficiency conducted by Berke and Nielson (1991), only 50 percent of children fit with myoelectric prosthesis returned for continued care such as socket changes and general maintenance of the device. This study did not include why the other 50% of children did not return for care. Continued care is essential to ensure proper function and fit on a growing child.

Phantom limb pain. Comfort of a prosthetic device not only pertains to the physical contact of the device to the residual limb, but phantom limb pain and sensations also need to be considered when choosing a prosthetic. For a child, phantom limb pain can vary throughout the day and may interfere with his/her ability to wear a prosthesis (Davidson, 2002; Datta et al., 2004).

Rejection of a Prosthetic Device

Some children and families may choose not to utilize a prosthetic device to assist with functional performance. Factors for rejection of a prosthesis may include: “lack of functional gain, unattractive appearance, functional possibilities with prosthesis was less than expected, parents were not involved in the decision about the type of prosthesis, inadequate socioemotional guidance by the team, and that the prosthesis was too heavy” (Postema et al., 1999, p. 246; Datta et al., 2004). Other factors that may contribute to the rejection of a prosthesis are related to issues with the residual limb such as level of limb loss, pain, decreased shoulder motion, and functional adaptations utilizing the residual limb (Davidson, 2002). People with a unilateral limb deficiency may be able to adjust to
one-handed activities, therefore are more likely to reject a prosthesis than those with bilateral limb deficiency (Lake, 1997).

Training

Key factors in prosthetic training for a child and family include physical abilities, psychological factors, family and child education, and prosthetic fitting which focuses on the fact that “a child is not a small adult” (Watts & Clark 1998, p. 7; Robinson et al., 1975). The main goal of prosthetic training is to allow the child to experience a sense of mastery during functional tasks involving the prosthetic and residual limb. Not only does prosthetic integration training promote efficiency and skill, it may also decrease discouragement and prosthetic abandonment (Lake, 1997).

Training Objectives

Training for a child after a limb deficiency focuses on bimanual activities for play, school, and self-care which are developmentally structured and sequenced (Case-Smith, 2001). These activities should be taught with and without using a prosthesis so the child has the opportunity to choose which method works more effectively in order to achieve maximal independence (Datta et al., 2004; Johnson et al., 2002). Along with family training, it is important for the child to gain mastery in independent donning, doffing, and care of the prosthesis. In his book, Back in action: An American soldier’s story of courage, faith, and fortitude, Captain Rozelle (2005) describes his first training session using a prosthesis stating, “It was like any other sport; it just took a few passes to figure out the muscle motion, and I was off to the races” (p. 184). Along with physical training, psychological factors such as self-concept and social play can also affect a child’s sense of mastery (Case-Smith, 2001).
Family Involvement

For a child, client-centered treatment focuses on the entire family becoming an integral part of services. Each family context is different and unique; therefore, parents and/or caregivers may have different ideas regarding what is best for their own child. A supportive family and environment is necessary when determining the child’s own needs and to facilitate the development of independent functional activities (Case-Smith, 2001).

Training for prosthetic use not only entails helping a child use the prosthetic device, but also includes educating the parents on the use of the device, the care of the device, and the psychological impacts the limb deficiency and device use may have on the child and family. To achieve optimal results, it is essential to involve parents in planning, education, treatment, as well as the training process (Postema et al., 1999; Berke & Nielsen, 1991). During the learning process, a child may become frustrated; it is at this time that the parents and/or therapist must allow time for the child to persist with the task in order to enhance skill development and a child’s sense of mastery (Case-Smith, 2001). With a well-fitted prosthesis, training, and family involvement, a child is able to master skills and find an opportunity of living equally with peers (Sener et al., 1999).

Childhood Occupations and the Use of Prosthetics

Performance Skills and Client Factors

Aspects Affecting the Child

The overall goal for the use of a prosthetic is to replace lost function instead of replacing a missing anatomical part (Watts & Clark, 1998). Wearing a prosthetic, however, does not correlate directly with the concept of function (Sener et al., 1999).
There are dynamic variables such as self esteem, level of amputation, social support, and adapted learning that significantly impact a child’s functional ability when using a prosthetic (Svoboda, 1992).

**Performance skills: motor skills.** Not only does a child have to adjust to wearing a prosthetic physically and psychologically, but he/she also has to learn how to complete functional tasks utilizing the prosthetic. Some tasks can be achieved with or without use of a prosthetic. Others, however, are best accomplished with the use of a prosthetic. For example, children can be independent in self-care, feeding, and hand skills with and without a prosthesis. They will generally using a prosthesis for bilateral activities, such as bicycle riding and cutting paper (Sener et al., 1999; Berke & Nielson, 1991; Pruitt et al., 1999). Individuals with limb deficiency are often more satisfied with their functional performance in completing bilateral hand activities when using a prosthesis or adaptive device (Davidson, 2002).

**Client factors: neuromusculoskeletal.** The unique physical aspects of a limb deficiency may impact potential use of a prosthesis. Scotland and Galway (1983) state that the longer the residual limb is in length, the more likely the child abandons the prosthesis. Conversely, Datta et al. (2004) conclude that the higher the level of upper limb loss, the less dependent an individual is on his/her prosthesis for functional activities. Children with congenital bilateral limb deficiency often decline wearing a prosthesis; they adapt by using other anatomical parts such as teeth, legs, and feet, to assist in function tasks (Watts & Clark, 1998).

**Client factors: mental functions.** Another fundamental factor of prosthetic acceptance is the psychological considerations, focusing mainly on body image and self
esteem. A child’s constantly changing self-concept incorporates physical, psychological, and social aspects. The physical context, social context, task demands, motivation, and training relate to child’s sense of competency in play thus encouraging a positive self-concept (Johnson et al., 2002; Case-Smith, 2001). There is a positive correlation between self-acceptance and success in areas such as appearance, behavior, social support, and athletic ability. Therefore, it is important for a child with a limb deficiency to have a positive body image and self-esteem (Svoboda, 1992). In a study focusing on skill mastery for adolescents with limb deficiency conducted by Pasek and Schkade (1996), adolescents who gained a “sense of mastery over their fears, their limb deficiencies, and the challenging physical environment” demonstrated an increase in self esteem (p. 30).

Aspects Affecting the Family

*Client factors: mental function.* As children with limb deficiency adjust to the changing physical and psychological demands, family members and care givers are forced to adapt to these changing needs. The child and family members have the responsibility to grow and accept these changes throughout the child’s development. Following a limb loss, whether congenital or traumatic, there are a variety of emotions experienced by a child and family members. According to Svoboda (1992) after the initial shock of this experience, fear, anger, depression, and denial are common emotions. For emotional recovery, time and effective communication with the child, peers, family members, and medical professionals is necessary before adaptation, reorganization, and acceptance is experienced (Svoboda, 1992; Brooks & Shaperman, 1965).
Social Perceptions

It is important to understand the impact a limb loss, whether acquired or congenital, has on a child and his or her parents, family and friends (Svoboda, 1992). It is not uncommon for parents (and an older child) to go through a grief process, making it difficult to understand and accept the situation at first. Parents, along with the child, are challenged to cope with and adapt to the loss. Along with loss of the limb, there is loss of the “ideal” childhood experience. Parents need to take the responsibility of educating themselves, their child, and others about limb deficiency. Chad Crittenden, an individual with lower limb deficiency who was interviewed by LaGrossa (2005) stated “as an amputee… his biggest challenge in life now is getting over people’s preconceived notions of who disabled people are and what they are capable of” (p. 23). Despite the level of acceptance expressed by a child and family, negative social perceptions may remain and influence a child’s physical and psychological development. Parents and caregivers are responsible for teaching a child to manage and cope with social challenges such as uncomfortable stares, questions, and confrontational situations in regard to curious and/or uneducated peers, friends, family, and community members (Svoboda, 1992).

Current Resources Available

The birth of a baby with a congenital limb deficiency or limb loss for a child caused by an accident is likely to be unexpected and shocking. For the parents and the child, there are many emotions, questions, and concerns that arise. As evidenced by this literature review and the following reference list, which is not exhaustive, there are numerous resources available on limb deficiency and use of prosthetics. Despite this, there are limited resources that focus specifically on the immediate need of general
information for parents and children with limb deficiency. At the point of first 
experiencing a child’s limb deficiency or limb loss, parents and caregivers may be 
overwhelmed with emotions, and have increased demands on their resources (time, 
energy, or money). Although information can be accessed through books, academic 
journals, and through the internet; the information parents may find is lengthy and 
difficult to understand because of technical and medical jargon. Parents and caregivers 
may also have difficulty sorting through what information is relevant for their child’s 
situation.

Reyes-Muralles (2001), the mother of a child with a congenital limb deficiency, 
and the author of For the Love of Jody, wrote her book in response to her frustration in 
finding available information for parents. Medical professionals, who do not specialized 
in this area, are not always aware of the resources that would be most useful to parents, 
and some have limited understanding as to how to educate the child and family (Watts & 
Clark, 1998). Better training and resource development for medical professionals would 
be a useful direction in assisting families and children with limb deficiencies. For this, a 
handbook developed for parents could be made available to medical professionals. These 
professionals would be directed to offer the handbook to families at the point of entry 
into the medical system, at birth when there is congenital limb deficiency or at the time of 
a traumatic limb loss for an older child. This handbook would facilitate medical 
professionals and parents to initiate conversation about resources and individual concerns 
from the child and family to better meet each child’s unique needs.
Conclusion

Congenital and/or traumatic limb deficiency in children affects multiple areas of life including functional performance, physical and psychological well-being, and childhood occupations. There will be a number of major decisions that need to be made, including decisions about surgery, use of prosthetics, or ongoing rehabilitation. Parents are an integral part of treatment planning and have the right to know the pros and cons in regard to the overall process that occurs for children with limb deficiencies. After learning of a child’s limb deficiency, the amount of information available combined with emotional stress of the experience may be overwhelming and this may create barriers to making an informed decision for the child. By providing a user friendly handbook for parents to consult, initial questions can be answered and additional resources can be provided. This is a simple and non-intrusive method to begin the educational process for parents and caregivers, while empowering them to make an informed decision for their own child.
CHAPTER III

METHODOLOGY

Following an introductory review of literature, and after gathering information from various professionals, organizations, and agencies, it was identified that there are a variety of concerns presented by parents who are raising a child with a limb deficiency. For further investigation, an extensive literature review was conducted focusing on children with limb deficiency in regard to the physical and psychological impacts on function and occupation. As the authors’ background is in occupational therapy and occupational therapy practices focus mainly on upper extremity limb deficiency, the review of literature was narrowed to primarily concentrate on upper extremity function for children with limb deficiencies and the impact on childhood occupations. The review of literature also focused on the use of prosthetics and the overall treatment care provided to children and their families. In order to expand on the perspective in the literature, various individuals who work with or have been impacted by this particular population were consulted.

The review of literature served as a guide and foundation for the development of the booklet: *Empowering Your Child: A Parent’s Guide*. Chapter IV of this Scholarly Project contains a representation of this booklet.
CHAPTER IV

PRODUCT

This product is a user-friendly booklet, with a focus on upper extremity involvement, for parents and/or caregivers of children with limb deficiencies. The information in the booklet was based on a literature review and information gathered from individuals who work with or have been impacted by this population. The information is presented in an introductory form, with limited medical jargon, and addresses the physical and psychological impacts of limb deficiency on the child and family. The booklet includes definitions of common terminology that the family will be exposed to, and it also outlines various decisions the child and family may encounter throughout the rehabilitative process including the use of a prosthetic device. Since this booklet is introductory, additional resources are provided to the family members for later use.

The booklet is designed for occupational therapist to give to medical professionals and they, in turn, can give it to parents who have just learned that their child has a limb deficiency. It is the authors' intent that therapists put their contact information on the booklet for both medical professionals and parents. Medical professionals may consult the occupational therapist on patient needs, additional resources, and potential referrals. Parents may contact the occupational therapist with questions, concerns, and requests for additional resources. This booklet designed to facilitate communication and interaction between the medical team, child, and family.
Empowering Your Child

Enabling your child with a limb deficiency to live a life without limitations.
Your Rehabilitation Team

Surgeon ____________________________
Contact ____________________________

Prosthetist __________________________
Contact ____________________________

Occupational Therapist ______________
Contact ____________________________

Physical Therapist __________________
Contact ____________________________

Additional Team _____________________
Contact ____________________________

Additional Team _____________________
Contact ____________________________

Additional Team _____________________
Contact ____________________________

Additional Team _____________________
Contact ____________________________
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Introduction

Whether your child was born without a limb or lost a limb due to a traumatic incident, it is an emotional time for everyone involved. There are several terms used to describe the loss of a limb including: limb loss, amputation, limb difference, and limb deficiency. The term limb deficiency is used in this booklet. These are just a few of the terms you will encounter in your journey with your child.

The purpose of this resource guide is to help you as a parent during this difficult and emotional time. The booklet has been developed to help you understand what may happen from this point and to provide you with resources when you are ready for them. We hope it will help in answering some of the many questions that you may have at this time.
As the caregiver of your child, there are many responsibilities and expectations placed upon your shoulders; at the same time, you will be dealing with your emotions now and in the future. We want to empower you by helping you start gathering information and become educated about the possibilities for your child. This book contains:

- An introduction to some of the terms that you will encounter
- A brief description of the medical professionals you may be working with
- An introduction to prosthetic process and devices used
- Information on play, your child’s approach to growth and learning
- Additional pages for your personal notes

Please remember that this guide is not all inclusive; use it as a starting place, take what you need from it, and explore elsewhere as the need arises. It is a long journey, but it can be very exciting and rewarding for you and your child.
Limb deficiency is categorized as congenital or traumatic. Congenital limb deficiency is a difference in or loss of the limb that occurs while the child is still developing in the uterus. Some parents know of this difference ahead of time and others find out once their child is born. There have been multiple theories about the cause of congenital limb deficiency; however, it is usually unknown. Your child being born with a limb deficiency is not the result of anything you did wrong. You may have a wide range of feelings at this time, and all of your feelings are valid. However, it is important not to blame yourself.

Traumatic limb deficiencies occur sometime after the child is born. The term traumatic limb deficiency is used when a child looses a limb as the result of accidental injury or as the result of a disease. Regardless of the cause of a limb deficiency, there does not have to be a change in your or your child’s dreams. Dreams can be achieved, although the path may be extraordinary.

Adapted from Amputee Coalition of America (2005); Watts & Clark (1998)
You, as the parent, are the main decision-maker for your child. At this time, you may be facing decisions in several different areas:

- You may wonder about surgery as an option to repair or replace your child's limb. Surgery may be used to form a residual limb, reshape a limb in preparation for a prosthetic device, improve appearance, or to increase function.

- Another avenue to explore is the use of assistive technology. It is important to choose assistive devices that will aid in meeting your child's needs without taking away skills that are already present or can be developed.

- One device that is used to increase independence is a prosthesis. If a prosthesis is chosen, another series of decisions will need to be made.

- You will also be making decisions about the type of treatment your child will receive. For example, your child may be involved in rehabilitation services through occupational or physical therapy.
As a parent, you should be an integral part of the rehabilitation team. It is your role to make the final treatment decisions based on input from other team members. Team members will welcome your questions, thoughts, and concerns. The medical team members can provide you with professional knowledge as well as assist you in utilizing appropriate resources. This team might include a surgeon, prosthetist, physical therapist, occupational therapist, and additional family members; all of whom might aid you in choosing the right steps and direction for your child.
• The surgeons bring to the team knowledge regarding medical issues such as surgical reshaping options and various health concerns for your child.

• The prosthetist can provide information about artificial limbs as an option.

• Physical therapists will look at your child's balance, strength, coordination, and endurance.

• Occupational therapists are involved in teaching and training your child to be as independent as possible, while educating you on how to assist and empower your child during daily activities.

Adapted from Reyes-Muralles (2001)
Simply put, prosthetic devices are artificial limbs. One of the decisions that you and your rehabilitation team will be making is whether or not your child would benefit from using a prosthetic device. There are many issues to consider, and even among professionals, there are different opinions as to the appropriate time and age for a child to be fitted with a prosthetic device. It is important to gather as much information as you can and work with your rehabilitation team to determine if, when, and what type of prosthetic device is appropriate for your child.

If you decide to introduce your child to using a prosthetic device, there are additional considerations. Martinez (2004) and Watts and Clark (1998) have identified the following steps in the prosthetic process:

- **Surgery** may be recommended to shape, protect, and / or increase function for the residual limb. Surgery options will vary, depending on the type of limb deficiency.
• Rehabilitation involves wound healing, pain management, movement and strength of the limb, limb shaping and desensitization. After the prosthetic device is introduced, therapy is started to incorporate the prosthetic device into daily activities.

• The type of prosthetic device used varies depending on several factors. See the chart (on the next page) for more information about types of prosthetic devices.

• Fitting involves consideration of comfort, fit, body alignment, function, appearance, and durability. Your child may have “trials” with different prosthetic devices to ensure a good fit.

• Training will be a part of the process for both you and your child. Training will include use and care of the prosthetic device. It will also include time for practice in using the prosthetic device for daily activities.
**Categories of Prosthetic Devices**

**Temporary**
- Used immediately after surgery
- For limb shaping and psychological preparation

**Preparatory**
- Used following removal of stitches
- For limb shaping and practice with prosthetic device

**Definitive or Long-term**
- Lasts for 2-5 years depending on child’s growth and amount of daily use
- *Types:*
  - Cosmetic
    - Appears natural
    - Has limited function
  - Body-Powered
    - Uses a shoulder harness and cables to move the prosthetic device for functional use.
  - Myoelectric
    - Uses electrodes placed on the skin to receive muscle signals and transmit these signals to move the prosthetic device and terminal device

**Terminal Device**
- Serves as a “hand” for functional activities or cosmetic purposes
- Can be attached to a body-powered and/or myoelectric prosthetic device
- Multiple devices are available to choose from that help the child complete different tasks
  - Hook
  - Prosthetic hand
  - Specialized attachments for leisure activities

Your child may have changes in how he or she experiences pain or sensation. The affected limb may have areas of increased or decreased sensation making it difficult for your child to identify touch, temperature, and/or pressure. As a parent, it is important to be aware of this in determining safety needs for your child.

Phantom pain and sensations may also be experienced by your child. The word “phantom” means to experience something that has no physical reality. Phantom pain and sensations are feelings that your child experiences as occurring in the part of the limb that is missing, even though that is physically not possible. For example, phantom sensations might include a child ‘feeling’ that his or her missing limb is moving. It is also possible for your child to ‘feel’ tingling, aching, and/or shooting pain in the section of limb that is absent. These sensations are common and vary during the day. Be open to talk to your child about these experiences and offer information and reassurance. It will be helpful for the medical team to know if your child is experiencing this so that they can also offer ideas for helping your child to cope with this.

Adapted From Siddle (2004); Wilkins, McGrath, Finley & Katz (2004)
Additional Notes & Reminders


Moving On

The Grieving Process

You will probably experience a wide range of emotions after learning that your child has a limb deficiency. You may feel confused and overwhelmed at times. You may have positive feelings at the same time you are experiencing negative feelings. It is important to recognize all of your feelings and work through them in a way that fits you best.

A sense of grieving is a normal reaction after learning that your child has a limb deficiency because you are in the process of re-visioning your hopes and dreams for your child. Know that grieving is a normal part of healing.

5 stages of the grief process have been identified:
- Denial and isolation
- Anger
- Bargaining
- Depression
- Acceptance and hope
Grief has no "rules". The process and the amount of time spent in each stage varies for each individual, and you may move back and forth in the stages. Research has shown that men and women may grieve in different ways, so be patient with your partner who may be going through the process in a different way. For example, sometimes men may not talk about their feelings as often as women do – men may "work it out" physically or through tasks.

Adapted from Svoboda (1992)
Here are some ideas to help you reach the stage of acceptance and hope:

- Talk about it - express your feelings
- Seek help from your personal support systems - family, friends, and co-workers
- Seek help from formal support systems - join a support group to connect with other parents who have children with limb deficiencies or seek out a professional counselor as a resource
- Ask questions and speak to your team of medical professionals
- Release your emotions in healthy ways – for example: exercise, relax, cry, listen to music, or write in a journal
- Acknowledge anger as part of the process and find healthy ways to release that anger
- Get back to your routine - doing normal, everyday things
- Use humor as a release
- Remember that this experience is part of your life – not the totality of your life or your child’s life
Self esteem is not about body image or physical capabilities. Self esteem is much broader than that, and encompasses all of the strengths and talents of an individual. More importantly, self esteem is built upon our perception of our own competency. There is no reason why your child will not be a competent and capable individual, with confidence and a positive sense of self.

Here are some ways to encourage your child and help him or her build self confidence:

- Encourage your child to be active
- Let your child accomplish as much he or she can independently
- Help your child learn to adapt and problem solve through exploration and practice
- Empower your child by giving him or her information
- Provide social opportunities
- Be encouraging and use positive language – help your child be comfortable with his or her own uniqueness

Adapted from Svoboda (1992); Case-Smith (2001)
Social situations can present some challenges – especially if your child looks noticeably different physically. You and your family will need to consider how you choose to respond to comments or reactions from others. Advance preparation can prevent uncomfortable moments for you, your child, and others.

The manner in which you and your child approach social situations will influence how others respond. People may stare or ask questions because your child appears to be different physically. As a parent, your immediate reaction is to protect your child from hurtful or embarrassing experiences.
Here are some tips for handling social situations:

- When possible, prepare your responses in advance – rehearse them so that you can respond positively and without defensiveness.

- Know that others may be curious or uneducated about a condition that your child has experienced. Simple explanations can go a long way in changing attitudes of others.

- Add a positive comment about a skill or strength of your child.

- Initiate a conversation about your child’s differences if someone appears hesitant or uncomfortable with interaction.

- Help your child build coping skills by rehearsing and preparing for social situations as he or she gets older. Your child will learn a great deal by watching – you will be a great role model.

Adapted from Pasek & Schkade (1996); Case-Smith (2001); Sener, Yigiter, Bayar, Erbahceci (1999)
Additional Notes & Reminders
Play is the most important way for a child to learn new behaviors and develop future skills. It motivates your child to participate in physical activities, thus enhancing physical capabilities.

Play allows all children to become independent and interact with the world. Children learn about the world by exploring the environment.

Play will help your child:

- Learn cause and effect
- Learn problem solving skills
- Adapt to his or her environment
- Gain functional independence
- Learn social skills

By encouraging play, your child will grow and gain physically, mentally, and emotionally.
Some tips for play:

- Adapt an activity to your child’s unique abilities

- Be creative by adapting toys or changing the way your child can play with the toys

- Relax! He or she will fall and get bumps and bruises – just like every other child. If you are worried about an activity being harmful to your child, ask someone on the medical team.

- Your child can do everything — missing a limb does not mean your child has to miss a part of life!

Adapted from Morrison & Metzger (2001); Finnie (1997); Henderson & Pehoski (1995)
• Stay positive and motivated for yourself, your family, and your child

• Be an advocate for your child by educating yourself and staying involved during this entire journey

• Encourage your child to be as independent as possible while he or she is learning new skills; however, offer support as needed

• Be patient - with your child, and with yourself

• Understand and prepare yourself and your child for uncomfortable social situations

And most importantly:

• Love and accept your son or daughter with all your heart
The thoughts we want to leave you with are that you are not alone - there are multiple resources to help you throughout your journey. Growing up requires all children to move from weak to strong, from dependent to independent, from incapable to capable. Your journey may be somewhat different, but your task is no different than that of other parents. Ask questions to gather information and find opportunities for your child. We want to remind you to be a proactive advocate for your child. With your guidance, and your help in accessing resources and opportunities, your child will grow to be strong, independent, and capable. Your child is amazing and be amazed by your child. Love, understand, and praise your child.
Resources

Resources for additional information

Internet Sites

Amputee Coalition of America, ACA
http://www.amputee-coalition.org/index.html
☆ National, non-profit organization that provides information, resources, and support groups to individuals and their families

Disability Links
http://www.inspirationministries.org/links.html
☆ Offers links for on-line supports, orthotics & prosthetics, and an amputee shopping mall

Helping Hands Foundation
http://www.helpinghandsgroup.org/index.html
☆ Providing support and information to families with children with limb deficiency
☆ Online discussion board

Limbdifferences.org
http://www.limbdifferences.org
☆ Online resources for families and friends of children with limb differences

Ontheotherhand.org
http://www.ontheotherhand.org
☆ Provides information, support, and suggestions for parents, friends, and caregivers of children with hand differences
Pediatric Prosthetics, Incorporated
http://www.kidscanplay.com/index.htm
  ✫ Provides information regarding the prosthetic fitting process, insurance reimbursement, medical technology, definitions, contact information, and more
  ✫ Addresses social and personal questions complete with parent perspectives and frequently asked questions for parents who have children with limb deficiency

Superhands Network
http://www.superhands.us
  ✫ Provides child and adult inspirational stories, numerous helpful resources, contacts, and links

Variety Myoelectric Center at the Rehabilitation Institute of Michigan
http://www.variety-detroit.com/program.htm#myoelectric
  ✫ Children’s charity that provides programs, services, and prosthetic devices to kids and their families around the world

Books

Captain Hook, That's Me
By Ada Bass Litchfield
  ✫ Written for children ages 4-8 years
  ✫ About an active 3rd grader who is afraid of being accepted at her new school

Harry and Willy and Carrothead
By Judith Caseley
  ✫ Written for children
  ✫ The story focuses on building self-acceptance
Fanny (Serendipity Series)
By Stephen Cosgrove
☆ Written for young children
☆ About a cat with 3 legs, dealing with social aspects of disabilities

For the Love of Jody
By Tamara Reyes-Muralles
☆ Written for parents of children with limb deficiencies
☆ The book is written from the view of a parent, telling of her frustrations, emotions, and education

Oliver’s High Five
By Beverly Swerdlow Brown
☆ Written for children
☆ The story focuses on dealing with rejection and finding acceptance in society

Playing from the Heart
By Crawford and Bowker
☆ Written for parents and teenagers
☆ An autobiography of growing up, playing sports, and gaining social acceptance with a limb deficiency

The Making of My Special Hand: Madison’s Story
By Jamee Riggio Heelan,
☆ Written for parents and young children
☆ Written by an occupational therapist from the child’s point of view, this book describes the process of developing a prosthetic arm

Who is Amelia? Caring for Children with Limb Deficiencies
By Watts and Clark
☆ Written for medical professionals
☆ Orthopedic surgeons wrote the book to provide decision making information for colleagues
Additional Resources
Abrasions: Rubbing away skin through friction

Adherent Scar Tissue: Healing skin that sticks to underlying tissue

Body Image: Perception of person’s physical appearance and function

Contracture: Inability to move a joint due to a permanent stiffness of a muscle

Cosmesis: Used to describe the outer, natural appearance of a prosthetic device

Desensitization: Reduce or stop the sensitivity to touch or contact

Distal: A part of the body that is farther away from the center of the body than another part

Donning and doffing: Putting on and taking off something, for example a prosthetic device

Edema: Swelling

Elastic Wrap: Elasticized bandage used to help with swelling and encourage shrinking
**Extremity or limb**: Relating to an arm or leg

**Functional**: Relating to the functions of the body, such as movement and sensation

**Lateral**: To the side of the body

**Lower extremity (LE)**: Limbs of the lower body

**Medial**: Toward the middle of the body

**Neuroma**: The end of a nerve left after amputation

**Proximal**: Part of the body that is closer to the center of the body than another part

**Posterior**: The back side of the body or body part

**Range of motion**: The amount of movement a limb has at a joint

**Residual limb**: Portion of limb remaining after amputation. Some people refer to it as a "stump"

**Upper extremity (UE)**: Limbs of the upper body

Adapted from Amputee Coalition of America (2005)
Additional Terms
References


CONTACT INFORMATION

Name of Occupational Therapy Department
Name of Occupational Therapist
Telephone
Email

Please contact us with any questions, concerns, or any other needs regarding your child.
CHAPTER V
SUMMARY

Clinical Practice Strengths

This booklet can be used by occupational therapists as an introductory tool to facilitate communication with other medical professionals and parents of children with limb deficiencies. Since this booklet is introductory, the information is intentionally brief and designed to assist parents in beginning to build a foundation of knowledge. It includes a brief overview of the types of services occupational therapists can provide for the child and family. It is the authors’ intent that occupational therapists put their contact information on the booklet as a reference guide for both medical professionals and parents. This booklet is a non-intrusive method for all medical professionals to build rapport, involve the family, and begin the educational process.

Limitations

This scholarly project was limited to information about upper extremity limb deficiencies in young children, highlighting prosthetics as an assistive device. Therefore, generalization of the information will be limited. During the development of the product, the authors had limited access to multiple facilities when gathering resources and determining needs from medical professionals and parents of children with limb deficiencies. There has not been trial usage at a facility to evaluate the potential benefits of this booklet.
Recommendations

It is recommended that outcome measures be utilized to evaluate the benefits of using the booklet with families of a child with a limb deficiency. This may be completed by surveying occupational therapists who work with this population to determine the relevancy of information, additional areas to address, and the plausibility of collaborating with other medical professionals. Parents of children with limb deficiencies should also be surveyed to identify advantages and limitations of the booklet.

Presentations are recommended in order to educate occupational therapists and allied medical personnel about the availability of the booklet and its possible benefits to the family. Inservices may be presented locally or nationally at various Occupational Therapy conferences, such as the North Dakota Occupational Therapy Association conference and American Occupational Therapy Association annual conference. In addition, trial implementation is recommended. Opportunities for implementation on a trial basis should be explored through facilities that routinely provide care to this population. Success will be measured through research questionnaires designed for occupational therapists and other medical professionals, and parents of children with limb deficiencies who are involved in the trial implementation.

It is also recommended that further research be completed on the impact of congenital or traumatic limb deficiency on the family and child. Research areas should address developmental milestones, occupational transitions, and assistive devices to increase functional independence. It is recommended that this booklet be continually evaluated and modified as new information is obtained, resources change, and services advance.
REFERENCES


http://www.hanger.com


