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Living with a Spinal Cord Injury: A Workshop for Parenting and Play

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LIVING WITH A SPINAL CORD INJURY:
A WORKSHOP FOR PARENTING AND PLAY

by

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of the

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for the degree of

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This Scholarly Project Paper, submitted by Ana Sobolik and Laura Gunderson 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.

Scinda Janssen
Faculty Advisor

April 28, 2011
Date

PERMISSION

Title: Living with a Spinal Cord Injury: A Workshop for Parenting and Play
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TABLE OF CONTENTS

ACKNOWLEDGEMENTS.....	v
ABSTRACT.....	vi
CHAPTER	
I. INTRODUCTION.....	1
II. LITERATURE REVIEW.....	5
III. METHODOLOGY.....	40
IV. PRODUCT.....	48
V. SUMMARY.....	53
REFERENCES	55
APPENDICES	

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ABSTRACT

Individuals with newly acquired spinal cord injuries (SCI) may experience fears of inadequacy with their ability to be parents. This is a problem due to the fact that the average age of individuals who acquire SCIs is between 16 and 30, the prime child bearing years (Martin, Hamilton, Sutton, Ventura, Mathews, & Osterman, 2010; Mathews & Hamilton, 2009). There is a lack of literature to address these fears by supporting and developing parenting skills for individuals with SCIs. The purpose of this scholarly project is to address the fears of individuals with SCIs and their abilities with parenting occupations, as well as the occupations of their children.

A literature review was conducted to identify parental options and concerns, current barriers, methods used for successful parenting, and resources available. To guide this scholarly project, the occupational adaptation (OA) model was utilized, as well as Bloom's taxonomy, andragogy, and Fink's methods for coursework design. OA was used because of the strong emphasis on building adaptive capacity that an individual with a SCI will need in order to perform meaningful parental occupations with their child (Cole & Tufano, 2008; Schkade & McClung, 2001).

A workshop was created to address concerns/fears, provide ideas and techniques, and supply additional resources for adapting parents' occupations. It also links the occupation of parenting with the child's occupation of play. This workshop was designed to be presented to individuals by occupational therapists (OT) due to

their comprehensive knowledge and skill set regarding adaptation of everyday tasks and life roles within individuals with a SCI as well as their children.

It is recommended that this workshop also be used to train additional OTs who could then administer the workshop for expansion reasons. For continued improvement and tracking, it is recommended that evaluation outcome measures be utilized for research purposes. Overall, this workshop should be implemented at a substantial sized rehabilitation facility or SCI specialized facility at least annually or more if client needs are warranted.

CHAPTER I

INTRODUCTION

Individuals with newly acquired spinal cord injuries (SCI) may experience fears of inadequacy with their ability to be parents. This is a problem due to the fact that the average age of individuals who acquire SCIs is between 16 and 30, which correlates with the prime child bearing years (Martin, Hamilton, Sutton, Ventura, Mathews, & Osterman, 2010; National Spinal Cord Injury Association, 2007). Within this age range, individuals are typically focusing on major life transitions such as marriage, having children, and starting families. At this point in their lives, some individuals may be considering having children in the future, or others may already have them. Many are concerned about their ability to parent due to personal limitations related to their SCI. Parents with a SCI may face more challenges in addition to the normative parental changes including physical, social, psychological, and community barriers (Atkins, 2008; Dudgeon, Tyler, Rhodes, & Jensen, 2006; Linsenmeyer, 2000; Middleton, Tran, and Craig, 2007; National Spinal Cord Injury Statistical Center, 2009; Rutberg, Friden, & Carlsson, 2007). This concern warrants the need to provide resources to assist them with adapting to their role as a parent with a disability, yet availability of these resources is very limited. The purpose of this scholarly project is to develop a workshop for people with a SCI that will provide information and resources to support their occupation as parents.

There is a need for occupational therapists (OT) in particular to address this current issue due to their comprehensive knowledge and skill set regarding adaptation of everyday tasks and occupational roles for individuals with a SCI. OTs focuses on participation in activities of daily living (ADLs), instrumental activities of daily living (IADLs), and adapting activities and environmental factors (American Occupational Therapy Association, 2008). OTs provide the unique perspective of combining the parents' and the children's need for engagement in occupations.

A literature review was conducted to compile and evaluate the current studies and resources. From this review, a need for support and guidance became apparent when planning for parenthood and playing with children to supplement development. Parents with a SCI felt that they may not be mentally or physically fit for parenthood (Alpert & Wisnia, 2008; Duvdevany, Buchbinder, and Yaacov, 2008; Elliot, 2003; Linsenmeyer, 2000).

Using literature to identify focus areas, the student writers of this scholarly project created a workshop. The goal of the workshop is to reduce fears that individuals with SCIs have about their ability to become parents and about their ability to perform play with their children. The occupation adaptation (OA) model, andragogy, and a framework of course design were used to create a workshop specific to adult learning (Anderson & Krathwohl, 2001; Bloom, 1956; Cole & Tufano, 2008; Dreeben, 2010; Schkade & McClung, 2001; Werner DeGrace, 2007). Several terms and concepts specifically pertaining to the OA model were used throughout the scholarly project process. The OA model focuses on the person, environment, and the interaction between the two (Cole & Tufano, 2008; Schkade & McClung, 2001; Werner DeGrace, 2007). Terms unique to the

OA model include *desire for mastery* (innate need to achieve), *demand for mastery* (requirements of the environment), *press for mastery* (combination of the innate need to achieve and requirements of the environment), and *relative mastery*, which is the person's assessment of their efficiency, effectiveness, and satisfaction (Cole & Tufano, 2008; Schkade & McClung, 2001; Werner DeGrace, 2007). In addition, andragogy's five principles of adult learning were incorporated into the planning process and construction of the workshop (Dreeben, 2010).

Throughout this workshop, the participants will have the opportunity to learn new information, interact with other participants, build upon and utilize their own problem solving skills, and hear personal testimonies from those who have experienced a SCI and become successful parents. Within the structure of the workshop, the participants will be guided through a thought process that enhances their comfort and ability with adapting their methods and environment in correlation with the press for mastery. The *adaptation gestalt* is defined as the occupational response each individual has while engaging in a task (Schkade & McClung, 2001). The adaptation gestalt includes the sensorimotor, psychosocial, and cognitive systems, and each individual formulates their own system balance for every task they complete (Schkade & McClung, 2001). This workshop includes the use of all three systems to promote adaptive capacity, and upon completion of the workshop, the participants will be better equipped to complete occupations needed for parenting and will acquire increased relative mastery.

Within this two-part workshop, a significant focus will be on adaptive ideas, techniques, and additional resources. The first session of the workshop focuses on eliminating fears about parenting with a SCI by addressing the primary parental concerns.

The person's desire for mastery is addressed through pictures and involvement in conversation, and demand for mastery is discussed with environmental barriers. This portion of the workshop highlights methods for success and problem solving. The second session of the workshop will include information pertaining to child development, play occupations, and adaptive ideas to increase the parent's ability to interact with their children. The goal of this session is to link the parent's occupation of parenting to the child's occupation of play successfully and productively through activities that enhance adaptive capacity in the workshop participants. The participants are asked to concentrate on pressing for mastery to develop their own methods, thereby evaluating their own relative mastery.

This workshop will positively impact the individuals directly involved and those within the community as a whole. The completion of this workshop will provide enhancement to the parents' occupation of parenting as well as the children's occupation of play. The valuable component of this workshop is that it really focuses on ability rather than disability in the role of parenting among people with SCIs.

Chapter two of this scholarly project contains the findings of the literature review and unmet needs. Chapter three consists of the methodology for the construction of the product and also contains a more comprehensive explanation of the use of the OA model, andragogy, Bloom's taxonomy, and Fink's methods for course design. Chapter four is the product information and recommendations formulated by the needs found within the literature review and the methodology used to guide the process. Finally, chapter five summarizes the scholarly project and details limitations and recommendations.

CHAPTER II

LITERATURE REVIEW

The student writers of this scholarly project conducted a literature review to obtain information about parenting concerns of people who have a spinal cord injury (SCI). The literature serves as a guide for development of this scholarly project to address unmet needs in this population. Aspects to be discussed throughout this literature review include background information, parental concerns, fertility and pregnancy, returning to parenting after a SCI, adaptive equipment and methods for parenting, psychological impact on parents and children, available resources, unmet needs, and the role of occupational therapy (OT).

Background

According to The National Spinal Cord Injury Association (NSCIA), 450,000 individuals live with a SCI in the United States (NSCIA, 2008). Spinal cord injuries are most commonly the result of motor vehicle accidents, violence, or falls (NSCIA, 2008). Injuries are most frequently found to happen at the age of 19 (NSCIA, 2008). Of the 10,000 new SCIs acquired each year, the majority fall between the ages of 16 and 30 and are males (NSCIA, 2008). It is also common within this age range for both male and female young adults within the United States to be thinking of marriage, starting families, and becoming parents (Martin, Hamilton, Sutton, Ventura, Mathews, & Osterman, 2010; Mathews & Hamilton, 2009; Thibodaux, 2005). Parents will also need to understand

their disorder, the classifications and limitations, and how to effectively cope and compensate.

SCI function.

A SCI is a loss of sensation or function as the result of spinal cord damage (NSCIA, 2008). This should not be confused with injuries that result in damage to various bone structures of the vertebrae. In addition, injury can occur anywhere along the entire length of the spinal cord.

The spinal cord is 18 inches in length and encased in vertebrae from the base of the skull down to the coccyx (Atkins, 2008). The spine is a relatively solid structure but articulates for some movement along its normal curvature. The spinal column consists of several segments, including seven cervical vertebrae (C1-C7), twelve thoracic vertebrae (T1-T12), five lumbar vertebrae (L1-L5), five sacral vertebrae (S1-S5), a coccygeal portion, the cauda equina, and the filum terminale. The level of functional ability and sensation directly correlates with the location of the lesion on the spinal cord within these various segments. The segment or area at which the lesion occurs determines if the injury results in the classification of tetraplegia or paraplegia (Atkins, 2008).

Classifications.

To fully understand the basic knowledge regarding SCIs, rudimentary terms and concepts must be defined. Tetraplegia is classified as an injury to the cervical segment of the spinal cord and results in impairment of the arms, trunk, legs, and pelvic organs (Atkins, 2008). Individuals with tetraplegia will probably need to use a wheelchair for mobility, depending upon the severity of their injury. Paraplegia indicates thoracic, lumbar, or sacral segment injury. Unlike tetraplegia, if an individual has paraplegia, they

may have arm, trunk, leg, and pelvic organ function depending on the site of the lesion (Atkins, 2008). Individuals with paraplegia may or may not use a wheelchair. These individuals may have the ability to transfer themselves to and from surfaces and remain almost independent with self care activities.

The severity of the overall SCI can be described as being either complete or incomplete. A complete SCI consists of no sensation or motor activity below the level of the lesion (Atkins, 2008). The spinal cord is often times completely severed. A SCI that is incomplete, however, preserves some sensory and motor function below the level of injury. Functionality and sensitivity can vary between individuals although levels of injury may be similar. Although variability is wide among all SCIs, there are crucial levels of injury that affect primary functions (Atkins, 2008).

Injury to the spinal cord may result in difficulties with respiration, high/low blood pressure, infections due to pressure ulcers, inability to control bowel/bladder function, impaired sexual function, and a possible decrease in quality of life (Atkins, 2008). In individuals with a lesion of C4 or above, ventilatory support is required. Even in lower level lesions, people may experience complications such as compromised breathing and pneumonia. Autonomic dysreflexia is an increase in blood pressure associated with an injury at T6 or above (Atkins, 2008). In contrast, orthostatic hypotension is a decrease in blood pressure upon sitting up or rapidly moving to an upright position. Those with a SCI may also experience pressure ulcers as a result to decreased sensation and skin breakdown from prolonged pressure on bony areas of the body from sitting or lying down. After an injury at the level of S5 or above, one would typically lose the ability to void and defecate on a voluntary basis (Atkins, 2008). Sexual function can be disrupted

for males by experiencing the loss of erection, and women may experience the cessation of menstruation, or amenorrhea (Atkins, 2008; Rutberg, Friden, & Carlsson, 2007).

Middleton, Tran, and Craig (2007) found that quality of life may be jeopardized in individuals with a SCI, secondary to increased amounts of pain, lower self-efficacy, and the severity of limitations. All areas discussed affect an individual's everyday living and would need to be considered when adapting or planning for the role of parenting.

Parental Concerns

There are many concerns that potential parents have when considering parenting with a SCI. These may include their ability to engage in occupations with their children as well as continuing to complete their personal activities of daily living (ADLs). Part of the parent's occupation is to “[provide] care and supervision to support the developmental needs of a child” (American Occupational Therapy Association, 2008). Whether injured in the midst of raising children or before making the decision to have children, parents with a SCI will be required to adapt their lives and roles in order to meet their personal and occupational values. Supporting a child's development is included in the parenting process, and activity adaptations may need to be made.

Parenthood is a life role that entails time and energy-consuming responsibilities, organization of individual and family life tasks and activities, and the overall ability to care for oneself, a spouse or partner, children, and home environment. Following the life-altering changes that accompany a SCI, it is important to establish balance within a healthy lifestyle before taking on the additional responsibilities that parenthood would require. Several areas must be addressed before deciding to become a parent with a SCI such as financial considerations, endurance levels, pain management, and social support.

Finances.

According to the National Spinal Cord Injury Statistical Center (2009), it costs an average of \$244,562 to \$829,843 to cover the initial cost of the SCI and the first year following the injury, with an average of \$17,139 to \$148,645 for each subsequent year. These numbers do not include everyday living costs such as food and housing. These figures, as well as the price of raising a child from birth to the age of 18 or more, must be considered when planning for parenthood. Lino (2009), in conjunction with the U.S. Department of Agriculture (USDA), estimated that annual costs to raise a child are between \$8,330 and \$23,180 per child to care for them until eighteen years of age. Individuals with SCIs that are considering the decision to have children should carefully take into account the financial responsibilities of both their injury and raising children.

In addition to the baseline costs of raising a child, extraneous costs for adaptive equipment, specifically for parenting roles, may need to be purchased. Costs for adaptive equipment may vary depending on whether devices and/or materials are commercial, custom, or home-made. Adaptive equipment can be utilized to assist both the parent and child in reducing fatigue levels and making everyday tasks more manageable.

Pain management and endurance/fatigue levels.

Individuals with a disability such as a SCI may experience usual and unexpected pain after injury (Dudgeon, Tyler, Rhodes, & Jensen, 2006). With usual pain, individuals may implement pain management techniques that they find beneficial. These techniques vary for every individual and are often taught during the rehabilitation process after a SCI. Dudgeon et al. (2006) recommended preventing pain using exercise, diet, sleep, and the avoidance of stress. Different methods or specialized techniques may need to be

added when compensating for physical tasks associated with parenting such as lifting and moving children and various supplies and equipment. Pain may be associated with endurance and fatigue when completing these tasks.

Jensen, Kuehn, Amtmann, and Cardenas (2007) indicated that fatigue is one of the most prevalent secondary complications reported by individuals with a SCI. Individuals become more fatigued when more effort needs to be exerted for daily tasks and activities as they compensate for lower body paralysis. The authors further explored the experience of fatigue throughout the lifetime of a person with a SCI. They concluded that throughout their lifetime, individuals experienced increased fatigue levels. It is important to prepare for the levels of fatigue associated with raising children from infancy to adulthood.

Exercise programs may also need to be implemented to help the individual increase their endurance level for activities (Jensen et al., 2007; Smeltzer & Wetzel-Effinger, 2009). Energy conservation techniques can be utilized throughout the parenting process and integrated into daily tasks to help manage fatigue (Hunter & Coventry, 2003; Jensen et al., 2007; Reid, Angus, McKeever, & Miller, 2003; Smeltzer & Wetzel-Effinger, 2009). Energy conservation techniques are alternative ways of completing tasks such as splitting the task into smaller, more manageable sections to decrease strain (Jensen et al., 2007). Like pain management, exercise programs and energy conservation techniques are usually covered in the rehabilitation process after an injury, and methods are tailored to fit the individual and their specific injury and abilities (Hunter & Coventry, 2003; Jensen et al., 2007; Reid et al., 2003; Smeltzer & Wetzel-Effinger, 2009). Further consultation with appropriate professionals may be needed

when changing activity level. Starting a new routine may assist in enabling an individual to complete tasks. To help with this, support from another source, such as a significant other, spouse, or family member, may be employed.

Social support and assistance.

Humans are naturally social beings and require social contact for healthy living. This means they long for support and comfort from contact with other humans. Horn, Yoels, and Bartolucci (2000) conducted research that explored how social support systems affected the willingness of an individual with a SCI to engage in the rehabilitation process. Horn et al. (2000) found that social support provided by a marriage partner was a positive factor when considering individuals' appropriateness for ongoing therapy. Chan (2000) also found that it was effective for professionals to incorporate the spouse into the patient's treatment to facilitate involvement and relay information. The therapist should stress communication, as it is a key element for problem solving within a relationship and will be needed throughout the therapy process (Chan, 2000). This information may be utilized when deciding if more support is needed to complete the necessary duties of parenting. Able-bodied parents often find that raising and taking care of children can induce stress and that splitting tasks and increasing social support are ideas to consider.

Factors affecting the level of social support needed by individuals include their upbringing and personality type. Physical activities associated with parenting may also induce a need for support from an outside source. Depending on the division of power, another source of help may need to take a forward role in assisting an individual with a SCI to raise a child from both a physical and mental standpoint. Alexander et al. (2001)

reported that mothers with SCIs received more help with household duties from their spouse than did mothers without a SCI. More assistance was issued in the areas of preparing meals, taking out the garbage, buying groceries, and doing laundry (Alexander Hwang, & Sipski, 2001). The authors indicated that the spouses of individuals with SCIs took a more active role in home upkeep and child care activities.

Adaptations may be made to help parents with SCIs be more independent and able to complete parenting tasks without the aid of another person. Depending on individual preferences, some people are satisfied with simply dividing tasks, while others would like to complete all tasks independently. Social or spousal support will also be needed throughout the conception and pregnancy process for individuals with a SCI.

Fertility and Pregnancy

With the prime age range for people with SCIs being 16 to 30 years of age, it is understandable for these individuals to have concerns about marriage, pregnancy, and starting a family. Depending on the level of injury, both males and females may experience dramatic changes within their reproductive systems. Reports have shown that upon their injury, individuals who acquired a SCI have received little to no information during their treatment regarding sexual and fertility functions (Linsenmeyer, 2000).

Although this is a subject that can be uncomfortable for many, it is crucial that individuals with SCIs obtain extensive knowledge and education regarding any and all concerns. Anxieties relating to parenting with a SCI can fall within broad topics such as male fertility, female fertility, pregnancy, and post-pregnancy.

Male fertility.

Because the majority of SCIs occurring within the male population, fertility and sexuality issues for males will be discussed first. Typically following a SCI, males' sexual and/or reproductive systems are compromised. This usually means medical assistance will be needed, as only 10% of males can still father children without medical assistance following their SCI (Elliott, 2003). Complications regarding erection/ejaculation and the quality of semen are the primary barriers that men and their partners face when questioning their ability to become parents following a SCI.

Several methods of assisting the process of ejaculation or retrieving semen are currently being used following a SCI, especially when men and their partners are contemplating their options to have a family (DeForge et al., 2005; Elliott, 2002; Kafetsoulis, Brackett, Ibrahim, Attia, & Lynne, 2006; Linsenmeyer, 2000). The literature emphasizes both efficient semen retrieval and assistive reproductive technologies (ART) as being core concepts to successful fertilization (DeForge et al., 2005; Elliott, 2002; Kafetsoulis et al., 2006; Linsenmeyer, 2000). Two well-known methods that have been widely used for semen retrieval are electroejaculation (EEJ) and penile vibratory stimulation (PVS; DeForge et al., 2005; Kafetsoulis et al., 2006). Both methods have been used over time and have been shown to be able to retrieve semen in the majority of men after SCI (Elliott, 2002). ART include procedures such as intrauterine insemination, intracytoplasmic sperm injection, retrieval of semen from reproductive tissues, and freezing sperm to be used at a later date (Kafetsoulis et al., 2006; Linsenmeyer, 2000).

Of the two semen retrieval methods, PVS has been the preferred initial option due to the increased success rate related to higher amplitudes of vibration, increased semen

quality, less invasiveness, and the convenience of its use in the home environment (Brackett, 1999; Kafetsoulis et al., 2006; Linsenmeyer, 2000). Through PVS, mechanical stimulation is applied directly against the penis through the use of a vibrator in order to induce ejaculation (Brackett, 1999). EEJ consists of inserting a rectal probe that contains electrodes which would deliver electrical stimulation to cause the release of semen (Brackett, 1999). In a study conducted by Kafetsoulis et al. (2006), the authors were found to have success with 55% of the 412 participants that used the PVS method. With the remaining 185 participants that did not experience success with PVS, EEJ was then utilized, which yielded positive results 95% of the time (Kafetsoulis et al., 2006). This finding was also supported by DeForge et al. (2005) who found that when PVS was administered in comparison to EEJ, semen samples demonstrated higher percentages of motile sperm and increased “rapid linear motion” (p. 696). Due to the advantages found within the vibratory stimulation method, and possibly because of its less invasive approach, all participants involved in a study by DeForge et al. (2005) preferred this method over EEJ. Conversely, Kafetsoulis et al. (2006) found that 94% of participants had semen with a high enough total motile sperm level to be considered for successful intrauterine insemination when administering both semen retrieval methods.

Intrauterine insemination is one of the well known and simplest ART methods in addition to in vitro fertilization, intracytoplasmic sperm injection, retrieval of semen from reproductive tissues, and freezing sperm to be used at a later date (Kafetsoulis et al., 2006; Linsenmeyer, 2000). Intrauterine insemination is a procedure in which sperm that is retrieved from the male is implanted into the woman’s uterus (Linsenmeyer, 2000). Similar to this is in vitro fertilization which is not utilized as often due to the need of the

sperm to have valid motility, which is not found in many men following a SCI (Kafetsoulis et al., 2006; Linsenmeyer, 2000). Intracytoplasmic sperm injection, one of the newer ART methods, consists of injecting an individual sperm directly into the ovum (Linsenmeyer, 2000). Kafetsoulis et al. (2006), along with the support of Linsenmeyer (2000), found that retrieval of sperm was conducted directly from the testicles, the epididymis, and the vas deferens when males had little sperm in their ejaculate. Lastly, a further procedure is available for those individuals who experience a SCI and are planning on establishing a family either soon after or sometime in the future. This procedure includes freezing a male's sperm in anticipation of utilizing it at a later date for fertility purposes (DeForge et al., 2005; Linsenmeyer, 2000). The retrieval and freezing process has to be completed quickly after injury, as there is typically only an average of a two week window of opportunity before the quality and viability of the sperm decreases dramatically (DeForge et al., 2005). There have been multiple advancements and ongoing research regarding the large range of complications and barriers regarding fertility among males following a SCI. One of the most common side effects to consider with all ART methods is the increased incidence of multiple births (Kafetsoulis et al., 2006; Linsenmeyer, 2000). Alternatively, Linsenmeyer (2000) reported 40% of men with a SCI who attempted to father children were successful. However, due to the lower percentage of females with a SCI, there is typically less information regarding the fertility difficulties with the female population.

Female fertility and pregnancy.

As the partner in the relationship who would be experiencing the pregnancy process, there are multiple factors for females to consider before pregnancy. As stated earlier, typically a SCI will occur in a woman's life within her prime childbearing years, therefore adding to the importance and concentration of reproductive function and health. The lower rate of occurrence in females than males with SCI results in less quantity and rigorous research about pregnancy issues in women with a SCI. Although adequate amounts of clinical experience and opinion information are currently available, Thierry (2006) reported the amount of population-based studies regarding reproductive experiences for women with SCI are nearly nonexistent. The research that does exist focuses on fertility and preconception care, the pregnancy and delivery process, and post pregnancy issues.

One of the most common hurdles that a female has to overcome immediately following her injury is the expected cessation of menses, which usually will resume to its normal pattern by three to nine months post injury (Smeltzer & Wetzel-Effinger, 2009). There is an abundance of literature on this subject, but only in the form of small study discussions and case reports (Smeltzer & Wetzel-Effinger, 2009). This is an example of the lack of quantitative research available to support common medical issues related to women that have a SCI and their experiences with fertility (Smeltzer & Wetzel-Effinger, 2009). In a study conducted by Rutberg et al. (2007), the authors determined that there was a high risk for women with a SCI to experience hyperprolactinaemia, which is an increased level of prolactin following injury. This condition has been hypothesized to be

caused by the body's reaction to high psychosocial stress and crisis that would accompany the acute stage of acquiring a SCI (Rutberg et al., 2007).

Along with the diagnosis of hyperprolactinaemia, Rutberg et al. (2007) determined there was a positive correlation to amenorrhoea; this is the temporary cessation of menses that women with a new SCI typically experience. As stated earlier, amenorrhoea is generally experienced only for a temporary time period before returning to their regular menstrual cycle. At this point, women can start planning for the pregnancy process.

It is important for women with a SCI to begin the pregnancy planning process with the appropriate team and assistance that will be able to follow them throughout their pregnancy (Smeltzer & Wetzel-Effinger, 2009; Thierry, 2006). This team should include an obstetrical health care provider that will examine and identify any potential barriers or issues early in the pregnancy process to prevent any major complications. This process is difficult for women due to the risks involved with their pregnancies (Smeltzer & Wetzel-Effinger, 2009). Psychosocial health is another vital component that needs to be addressed for comprehensive care when planning for pregnancy. Childbirth educators, as well as counselors, are an essential resource to utilize. They can be specialized to meet unique needs and work specifically with women with disabilities (Smeltzer & Wetzel-Effinger, 2009). Educators can also provide women with existing information concerning outcomes of pregnancy, although the current range of information is small. The lack of literature affects the knowledge base of multiple healthcare professionals and could be partially responsible for negative misconceptions towards women with a SCI preparing for parenthood (Jackson, Lindsey, Klebine, & Poczatek, 2004). An example of

one of these misconceptions comes from Rogers (2006), who indicated that women reported that upon their first doctor visit, healthcare professionals assumed that the reason for their appointment was for termination of their pregnancy.

Along with certain assumptions or misconceptions experienced at doctor visits, women also have physical barriers to address. When starting to attend pre-pregnancy clinical visits, numerous women with SCIs have experienced a lack of accessibility when it comes to comprehensive care (Smeltzer & Wetzel-Effinger, 2009). The most common example of this is inaccessible examination tables for conducting gynecologic exams for thorough preconception and prenatal care, because women could not get on the tables (Smeltzer & Wetzel-Effinger, 2009). The majority of examination rooms did not have the capabilities of properly treating and providing quality care to women with SCIs and their unique situations (Smeltzer & Wetzel-Effinger, 2009).

There are several main topics that women with a SCI should be addressing throughout their prenatal care to ensure preparation is complete. A comprehensive evaluation needs to be completed regarding overall physical health. Along with physical health, a full inventory of medications currently being taken should be gathered to assess for detrimental combinations and/or potential medications that could cause harm to the fetus. Additional concerns or areas to address in advance are the chances of autonomic dysreflexia during pelvic examinations, possible increased respiratory distress, urinary tract infections, pressure ulcers, and thromboembolism (Smeltzer & Wetzel-Effinger, 2009). Additional difficulties related to physical abilities are the inability to self propel their wheelchairs, decreased ability to complete transfers, or the need to change or adapt their bowel/bladder management routines. Quality preconception care has been linked to

improved pregnancy outcomes (Thierry, 2006). Receiving quality preconception care provides the opportunity for an enhanced pregnancy experience.

Pregnancy and labor. Some of the prenatal complications also continue through to pregnancy. Depending on the level of injury, women may have complications due to their sensory deficits and lack of ability to detect physical changes in their body. This can result in problems with detection of the onset of their labor. This results in the need for increased cervical exams after 28 weeks of pregnancy (Smeltzer & Wetzel-Effinger, 2009). Next is the decision women have to make pertaining to the method or choice of their delivery process. Deciding between vaginal delivery and a cesarean section is another step towards pregnancy. Method determination needs to occur based on facts and indications relating to the obstetrics rather than the existing SCI (Smeltzer & Wetzel-Effinger, 2009). Anesthesia decisions also need to be made; however, continuous lumbar epidural anesthesia is recommended as prevention for autonomic dysreflexia (Smeltzer & Wetzel-Effinger, 2009). As with preconception care, autonomic dysreflexia continues to be a risk during pregnancy as well. If it happens to occur during the pregnancy process, the team may indicate a need for an emergency cesarean section (Smeltzer & Wetzel-Effinger, 2009). Another procedure that is avoided is an episiotomy, secondary to the correlation of episiotomies and autonomic dysreflexia (Smeltzer & Wetzel-Effinger, 2009). All of these are the primary considerations and concerns that are involved with the pregnancy process. Although there are risks to address, pregnancy in women with a SCI can be successful for both the mother and child.

Post-pregnancy. Following pregnancy, certain concerns will depend on how the pregnancy process went for both mother and child. If a woman did have an episiotomy

during her delivery, further complications may exist through post pregnancy. Due to the lack of sensation, there is a significant complication of the mother not being able to detect healing abilities. Infection and further problems may result. Once the mother has no remaining complications or health issues to be addressed, she is ready to begin the parenting role. This is another transitional period in which the mother will require either a consultation or a continuation of OT services to collaborate on the engagement in parental tasks.

One of the initial parental tasks that a mother must address and make decisions about is breastfeeding. Women with a SCI are less likely to breastfeed, although it is encouraged and promoted for wellness for both mother and child (Smeltzer & Wetzel-Effinger, 2009). The task of breastfeeding depends on the mother's unique situation and skill level. An area that typically poses as an obstacle is appropriate positioning of the baby, and the level of mobility of the mother, which is where an OT may educate and implement appropriate adaptive strategies (Smeltzer & Wetzel-Effinger, 2009). Some of these adaptive strategies address various ways of positioning the parent, such as out of their wheelchair, or strategies that focus on positioning of the baby with various equipment (Amble & Lannoye-Amble, 2002).

Throughout the literature on healthcare for women with a SCI who plan on becoming a parent, the primary areas of concern elicit, suggest, and warrant a need for specialized care. This specialized care originates from the fact that women with SCIs have such unique situations and risks for complications that are not necessarily being addressed when attempting to mainstream these women into generalized healthcare settings (Smeltzer & Wetzel-Effinger, 2009; Theirry, 2006). Specialized healthcare

should include entire interdisciplinary teams for each mother to assist in managing her care and preparing for the complexity of becoming a parent (Smeltzer & Wetzel-Effinger, 2009). With this approach, mothers with SCIs have experienced successful pregnancies and deliveries, and may continue to do so at an even higher level of quality of life.

Returning to Parenting After a Spinal Cord Injury

Thus far, this literature review has focused on parenting for the first time after an acquired SCI; however, it is important to note that some individuals are already parents when they experience a SCI. They may need to modify their parenting roles, habits, and routines when returning home (Albright, Duggan, & Rahman, 2009). A SCI is an unanticipated and stress-inducing event that requires resources and supports to cope.

Immediately after a SCI, the individual will go through a rehabilitation process (Horn et al., 2000; Hunter & Coventry, 2003). Depending on the severity and extent of the injury, the patient will strive to regain the greatest independence possible (Albright et al., 2009). Some will need to be fitted and trained on wheelchair use and maintenance. At this point in the recovery process, caring for children may prove difficult, if not nearly impossible. Shortly after the injury, the individual will focus on becoming familiar with the new functioning of his or her body, trying new methods of self-care using adaptations and trial and error, participating in training, and taking control of their bodily functions (Albright et al., 2009; Guidetti, Asaba, & Tham, 2007). Until these areas are addressed, parenting may need to be taken over by a significant other, family member, or friend. This event is also concerning and stressful for family and friends, and they may need training to address areas in which they can assist. They may be trained to help the individual with adaptive equipment use, and the equipment may need to be obtained.

The environment a person with a SCI returns to after an injury is familiar, yet many changes need to be made, and some areas of independence are lost. Modifications to the home may need to take place such as widening doors, adding ramps for wheelchair access, using lift chairs, bathroom modifications, and furniture changes (Fänge & Iwarsson, 2005; Reid et al., 2003). Some people even resort to leaving their home to find a more accessible home (Fänge & Iwarsson, 2005; Reid et al., 2003). Many aspects of the home environment will prove to become barriers for the individual and brainstorming will need to take place to restructure the environment to better fit the individual's needs (Fänge & Iwarsson, 2005; Reid et al., 2003).

Adaptive Equipment and Methods for Parenting

Adaptations may be made to help parents with SCIs be more independent and able to complete parenting tasks without the aid of another person. Depending on individual preferences, some people are satisfied with simply dividing tasks, while others would like to complete all tasks independently. The types of adaptive equipment needed for a person with a SCI vary from individual to individual. Equipment may range from adapted vehicles, access ramps, wheelchairs, and lift chairs to built-up handles for grip, adapted bathrooms, or specialized kitchen utensils. For this literature review, the focus of adaptive equipment will be on equipment used specifically for parenting. The types of equipment described may or may not be useful for some individuals depending on the level of their spinal cord lesion. The articles used to review this area researched individuals with hand function. People who do not have use of their hands may not be able to use this equipment, but they can adapt their role by directing others in the care of their children. Adaptive equipment, in its many forms, can greatly assist in childcare but

should be properly tested by the parent before use with an infant to ensure safety and effectiveness.

Cowley (2007) conducted a case report in which a mother with C8 tetraplegia shared her own experiences with adaptive equipment and raising a child. This mother was able to find the resources to assist her in obtaining the adaptive equipment needed for her to independently care for her children. Examples included a high chair, car seat, bouncing chair, stroller, changing table, adapted crib, and a table used to elicit motor development (Cowley, 2007).

The mother interviewed in this case report found that adapted high chairs, car seats, bouncing chairs, and strollers are commercially available for use when raising children with a SCI (Cowley, 2007). Most changing tables are too high and have drawers underneath that hinder the wheelchair, so an adaptation is needed. Changing an infant is possible on a bed or couch, but this may put extra strain on a parent's back or trunk muscles (Alpert & Wisnia, 2008). Changing tables for individuals using a wheelchair are required to be high enough for the wheelchair to comfortably fit underneath. This table might be something as simple as a card table or intricate as a custom made table equipped with side drawers and lowered height. To complete diaper and clothing changes, parents can add Velcro to children's clothing to compensate for weak hand strength (Alpert & Wisnia, 2008).

A wheelchair adapted crib is equipped with two sliding doors that slide open for easy access from the wheelchair level. The crib is equipped with a safety latch that can only be opened from the outside. Cribs for this purpose are commercially available, but in this case study, the crib was specially adapted for the individual (Cowley, 2007).

Transporting infants or young children may also prove difficult if there is limited hand strength or the individual needs his or her hands to maneuver their wheelchair. Alpert and Wisnia (2008) discussed a method for transporting infants using a hands-free sling that is positioned around the parent's shoulders or using a nursing pillow to safely secure the infant in their laps when they propelled their wheelchairs. Cowley (2007) explained a method for lifting the infant from the floor to the lap with limited hand strength. The infant was fitted with extra strength overalls, and the parent was able to lift the infant by the overalls into their lap with one hand. Eventually, the child became too heavy for this method, but by that time, he or she was able to assist their parent with the lifting.

Compensating for weak grasp may include adding Velcro to the infant's bottle or eating utensils or having assistance with small closures such as securing the diaper. A baby carrier attachment on a wheelchair may be used to feed the child (Alpert & Wisnia, 2008). This device attaches to the arm of a wheelchair securely and allows the parent to turn and transport the child as needed.

A parent may encounter difficulties when attempting to play with a child on a ground level. Transfers from the wheelchair to floor and vice versa may take increased strength and energy. Elevated play pens or play centers can assist the parent when engaging with their infant. In the study by Cowley (2007), the mother was concerned about normal milestones in her infant's development, and she had a table developed that enabled her to place the child safely on its stomach or back while the mother's wheelchair was able to roll under the table. She was able to interact with her infant much like an able-bodied mother would while sitting on the floor with their child (Cowley,

2007). Alpert and Wisnia (2008) described a similar piece of adaptive equipment useful for child's play and interaction. This structure was very much like a crib, but it had extra space for using toys and playing with the infant.

Case studies and personal reports, such as the one cited above, may prove most beneficial when looking at adaptive equipment for parenting. Often, a trial-and-error basis may need to be used when trying and evaluating the usefulness and functionality of equipment (Hunter & Coventry, 2003; Smeltzer & Wetzel-Effinger, 2009). A professional may need to be consulted to ensure appropriateness and attainment of equipment (Ballard, 2009; Smeltzer & Wetzel-Effinger, 2009; Thierry, 2006).

Another area that may need to be adapted for mothers with a SCI in particular is breastfeeding their infant. Due to limited sensation in the breasts, women may have difficulties with the milk let-down reflex. Cowley (2005) reported that mothers used methods such as relaxation, mental imaging, and Oxytocin nasal spray to induce let-down for twelve to 54 weeks. Oxytocin triggers milk let-down, and the neurological triggers may be absent in an individual with an injury at T6 or above; therefore, mothers with an injury higher than T6 will require extra care (Cowley, 2005). When using methods such as relaxation or mental imaging, using a quiet environment with no distractions may be useful. Mental imaging would include the mother picturing the milk releasing or looking at her infant. Cowley (2005) also indicated that confidence in the ability to breast feed positively correlated with the ability to illicit milk let down. Breastfeeding is an area where OTs have the opportunity to work directly with the mothers for promoting and guiding effective care for both mother and child (Conrad & Fox, 2007). Conrad & Fox (2007) developed a breastfeeding program spanning a seven week time period, which

includes benefits, general information, implementation, personal hygiene, stress management, nutrition, time management, and additional resources. This program was designed for mothers who have a disability and highlighted the need for the involvement of OT within this population (Conrad & Fox, 2007). Parents may decide how important they believe breast feeding is for infant growth and development and choose appropriate methods accordingly.

Obtaining adaptive equipment and learning how to use it takes time and patience. This process is crucial for parental development and extra support may be needed. Due to the unique methods and adaptations of parenting with a SCI, psychosocial factors may come into play.

Psychological Impact on Parents and Children

The onset of depression after a SCI may be immediate or an individual may start experiencing symptoms as the years pass. Positive mental health is vital in healthy living for both parents and their children, and some parents with disabilities fear the impact their disability will have on their children's behaviors. The perception of the disability may affect an individual's decision to become a parent, and they may be fearful of rejection or negative impacts on their children (Albright et al., 2009).

Depression and spinal cord injury.

Depression is a mental health disorder that affects all areas of an individual's life. This is a clinical disorder that may have severe effects including suicide. The National Spinal Cord Injury Statistical Center (2009) determined that about one in five individuals with a SCI develop depressive symptoms. The rate of depression among individuals with SCI is from 11% to 37%, and the rate among women tends to be higher than men

(National Spinal Cord Injury Statistical Center, 2009; Krause, Kemp, & Coker, 2000).

These studies indicate that depression is a significant factor after a SCI and may require seeing a counselor or even receiving medication. Managing depressive symptoms is highly encouraged before choosing to have children.

Quality of life is at risk for decreasing after a SCI. Not having information, lack of money and insurance, difficulties with accessibility, fear of intimate relationships, and decreased privacy contribute to decreased quality of life in some individuals with a SCI (Bergmark, Winograd, & Koopman, 2008; Klebine, 2008). It is important to evaluate the specific reasons for having children and confirm that individuals are not having children to counter-effect depressive symptoms or increase quality of life. Although caring for children can create a sense of self worth and the feeling of being needed, lengthy contemplation should be completed before making large decisions.

As the care-giving roles change and adapt, the spouse of the individual with a SCI may also experience stress equal to or more than their injured partners (Chan, 2000; Klebine, 2008). Spouses display high levels of depression, care-giving burden, low life satisfaction, and difficulties with marriage adjustment (Chan, 2000). Spouses are also at risk for depression and may also need to consult a psychiatrist or counselor.

Perception of disability, fear of rejection, and impact on children.

Individuals may wonder how their disability will impact their children. This uncertainty, and perhaps fear, may hold a strong influence over the decision to have children. Duvdevany, Buchbinder, and Yaacov (2008) interviewed twelve males with SCIs about their perspectives on parenting with a disability. This study focused on the perception of the fathers with a SCI and how they believed their disability affected social

attitudes and relationships with their children. From the interviews, it was concluded that the males experienced social stigma, negative attitude toward disabilities, pity from ignorance of others, diminished self-esteem, and feelings of doubt (Duvdevany et al., 2008).

Social attitudes refer to how the general public views the individual with a SCI. There is a stigma surrounding what disabled people are capable of doing, and this, unfortunately, can take a toll on an individual's self esteem and perception of their abilities (Albright et al., 2009; Duvdevany et al., 2008; Klebine, 2008). One individual gave a description of how another person viewed his ability to be a father. He stated:

“He says “Wow! Your kids are so big! How did you manage? How did you raise them? Was it hard? Because, after all, you are . . . or did your wife . . .?” and they automatically think that my wife is raising the kids” (Duvdevany et al., 2008, p. 1024).

This reflection highlights the stigma that can accompany a disability or, specifically, a SCI.

Fathers in particular may experience the assumption that their significant other does the child rearing. This view is supported by cultural norms that exist such as the father being the main money-maker, and the mother taking care of the house and children. Along with this assumption, the general public may also tend to perceive parenthood with a SCI with the same stigma as they perceive disabilities (Albright et al., 2009; American Association of Spinal Cord Injury Psychologists and Social Workers, 2002; Klebine, 2008). Psychologically, this can impact an individual and create guilt and animosity towards themselves.

In a study by Alexander et al. (2001), mothers' SCIs did not adversely affect their children's adjustment, attitudes towards their parents, self-esteem, gender roles, or family functioning. Although in some cases the general public may see individuals with disabilities as unfit parents, this study shows that a parent with a SCI does not negatively impact the children in these areas. Alexander et al. (2001) did find, however, that mothers without a SCI had an easier time adapting to environmental changes. This is because of the limits associated with physical impairments and the use of a wheelchair in some cases.

Parents often have a fear of rejection when parenting with a disability. The fear of rejection is rooted in the psychological belief that their children will find them unfit or too different to bond and learn from them. Duvdevany et al. (2008) concluded from their interviews that children do not reject their parents and are not ashamed of the disability. They also found that:

Fathers with SCI actively shape the way their disability is accepted by their children using three main methods. They discuss the disability with their children, allow the children's friends to understand and become familiar with it, and take steps to ensure that their children's general knowledge of the disability influences their general attitude toward other persons with disability. (Duydevany et al., 2008, p. 1026).

In addition, children of parents with a SCI do not differ in social competency or behavior problems when compared to children with parents without a SCI (Rintala, Herson, & Hudler-Hull, 2000). Parenting skills such as warmth, structure, and strictness produce a

larger impact on children's behavior and social competence than it does to be a parent with a SCI (Albright et al., 2009).

According to current literature, having a SCI does not negatively affect the psychosocial wellbeing of the children, even though there is a negative perception about disabilities. Although parents may have a fear of rejection, these fears may prove unfounded. Methods of parenting correlate more with children's wellbeing than parenting with a disability. Socially, parents with SCI do not have a negative effect on their children, but family roles may be divided differently to compensate for physical inabilities.

Family roles.

Family roles are different among every family group, but common cultural norms exist. When one partner has a SCI, the role of the other partner often is changed. The changing of family roles may be difficult for everyone involved. Spouses in particular may feel additional care-giver burden and may not anticipate the marital adjustments (Albright et al., 2009; Chan, 2000).

First of all, individuals with SCIs may need assistance with their own personal care activities. Many may need help specifically from their partner or spouse (Alexander et al., 2001). Feelings of vulnerability and helplessness may be apparent immediately after a SCI, and family roles will need to be restructured to benefit both the individual with the disability and their family (Albright et al., 2009).

Household tasks may need to be split up into manageable portions for everyone involved. When children are in their infancy, the tasks associated with childcare are more physical and difficult. As the children grow older, they will be able to take on

responsibilities for themselves. The main tasks affected by one partner having a SCI are repairs around the house, house cleaning, taking out the garbage, looking after the car, and caring for plants, the garden, and the yard (Alexander et al., 2001).

Individuals may be apprehensive about how decision making will change after a SCI. Alexander et al. (2001) found that mothers with a SCI did not perceive any difference. They often reported that they shared family decisions more often than families without a partner with a SCI. This may differ with individuals who already have established family roles and then experience a SCI. In this instance, the individual, their spouse, and any children they already have will need to re-divide the decision making roles (Albright et al., 2009).

After a SCI, childcare activities may become difficult. Mothers may need added assistance with feeding, doctor visits, helping with behavior problems, and physical tasks. In a study conducted by Alexander et al. (2001), 42% of mothers with a SCI had an assistant who helped with childcare. This study is generalized to only mothers with SCI, but fathers also need modifications to complete childcare tasks. These tasks need to be delegated and performed on a daily basis to ensure completion and adequacy.

Family roles are necessary for smooth functioning of a home. Personal care, household tasks, family decisions, and childcare are areas to focus on when reforming roles. Resources may need to be sought to complete the division of family roles and adaptations.

Available Resources

Available resources for individuals with a SCI, their families, and people involved in their care include numerous associations and organizations. These resources may

direct individuals to information, research regarding SCIs, support groups, additional resources, and information about financial assistance. The easiest way to access and learn from associations and organizations is through their Internet websites (see Appendix A for a table including organizations and their websites).

These resources can be used at an individual's discretion as indicated by their specific needs. Some of these organizations are strictly sources for research, and others cover user-friendly ideas for adaptations and support groups. In addition to finding information independently, individuals can attend support groups to interact with others who have similar experiences.

Support groups and community resources.

Support groups can be a vital instrument in an individual's recovery. Support groups vary in size and topics, but the common goal is for people with similar experiences to participate, share information and experiences, and offer support to others. Various organizations offer support groups such as associations and hospitals.

The NSCIA (2009) provides an extensive list of support groups and resources, and information is organized by state. Support groups may also be offered by a hospital. It is encouraged that individuals contact their local hospital's human resources department for more information about support groups they offer. Groups exist for people with a SCI and for their families.

Unmet Needs

Several unmet needs are exposed after reviewing the current literature. These needs range from medical needs of the person with a SCI to the needs associated with

parenting. Needs may be met through further qualitative and quantitative studies, education, and support.

Smeltzer and Wetzel-Effinger (2009) highlighted the inaccessibility for women with a SCI in a medical setting. The women had difficulty with equipment and quality of care. Because pregnancies of women with a SCI are riskier and more apt to have complications, some obstetricians may be reluctant to have a patient with a SCI.

Many issues may need to be addressed before a woman with a SCI decides to become pregnant. More counseling is needed pertaining specifically to exploring reasons for becoming pregnant and the physical implications (Smeltzer & Wetzel-Effinger, 2009). There is a need for more counselors who have extensive knowledge about SCIs, the pregnancy process, and psychological aspects of pregnancy for individuals with a SCI.

Parents may fear the psychological impact of their disability on their children. Although they may have these apprehensions, research indicates that there is no negative psychological impact on children with physically disabled parents (Alexander et al., 2001; Duvdevany et al., 2008; Rintala et al., 2000). Parents need more education about this area so they are able to make an educated decision about parenting.

Spouses or significant others also need support to decrease risk of depression and increase life satisfaction (Chan, 2000). It is important not to focus fully on the individual with a SCI, but also supply support and resources for the spouse, significant other, or family. The spouse of a significant other may also have to take on a caregiver role or participate more in daily tasks, which could potentially increase stress levels.

No resources were found with activity ideas for parents with a SCI to complete

with their children. Play is the main occupation of children, and parents with a SCI might meet barriers in their ability to play due to decreased hand strength, difficulty getting onto the floor, and decreased trunk stability. Adapted activities could range from simple fine motor activities to gross motor activities involving large motor groups. This aspect of adapting activities will assist parents when bonding with their children through physical contact and promoting development of their children.

These unmet needs are apparent when researching SCIs. OTs are capable of addressing unmet needs for aspects of SCIs. OTs possess a unique ability to assist individuals with adaptation to activities.

Role of Occupational Therapy

The American Occupational Therapy Association (AOTA) defines occupational therapy as:

...the therapeutic use of everyday life activities (occupations) with individuals or groups for the purpose of participation in roles and situations in home, school, work-place, community, and other settings. Occupational therapy services are provided for the purpose of promoting health and wellness and to those who have or are at risk for developing an illness, injury, disease, disorder, condition, impairment, disability, activity limitation, or participation restriction.

Occupational therapy addresses the physical, cognitive, psychosocial, sensory, and other aspects of performance in a variety of contexts to support engagement in everyday life activities that affect health, well-being, and quality of life (AOTA, 2008, p. 673).

OTs work in several areas of occupation including ADLs, instrumental activities of daily living (IADLs), rest and sleep, education, work, play, leisure, and social participation (AOTA, 2008). When providing therapeutic care for individuals with a SCI, OTs will work closely with them in all of these areas.

ADLs include bathing and showering, bowel and bladder management, dressing, eating, feeding, functional mobility, personal device care, personal hygiene and grooming, sexual activity, and toilet hygiene (AOTA, 2008). Patients who have experienced a SCI may have to change their methods for completing ADLs, and OTs can teach them adaptation methods and how to use specific devices. Sexual activity is also in the realm of OT practice, and OTs are able to supply information and techniques for this area as well. This may pertain specifically to the start of the parenting process for individuals with a SCI or for their own pleasure in personal relationships.

IADLs include care of others (including selecting and supervising caregivers), care of pets, child rearing, communication management, community mobility, financial management, health management and maintenance, home establishment and management, meal preparation and cleanup, religious observance, safety and emergency maintenance, and shopping (AOTA, 2008). Child rearing and caring for others falls under IADLs, and OTs have the unique skill of providing people with a SCI the methods to adjust to their new IADL of parenting.

OTs also work with individuals to increase independence levels in sleep and rest, education, work, leisure, and social participation. Although these areas are key for an individual's wellness and health, they will not be further discussed as they do not pertain specifically to this scholarly project.

Parenting with a spinal cord injury: occupational therapy's role.

OT can play a key role for individuals with a SCI from the pregnancy planning phase all the way through the entire parenting process. OT provides a skill set relating to ADLs, IADLs, and adapting activities. In addition to education, OTs can help individuals acquire equipment and resources. They are qualified and have the experience to work directly with individuals with a SCI in regards to evaluating level of abilities and functioning, determining motivation, facilitating coping skills, and implementing routines into daily life (AOTA, 2002).

When planning for a pregnancy, OTs can supply patients with information and resources regarding fertility, role adaptation, physical adaptations, and psychosocial factors related to parenting with a disability (Ballard, 2009; Hunter & Coventry, 2003; Magill-Evans, Harrison, Rempel, & Slater, 2006; Mulcahey et al., 2010; Reid et al., 2003; Sanders & Morse, 2005; Thierry, 2006). OTs also can educate on adaptations for sexual activity (Amble & Lannoye-Amble, 2002; Smeltzer & Wetzel-Effinger, 2009). When using education to provide facts, an OT will help parents make educated decisions.

Once the individual becomes pregnant, OTs can help prepare the individual or significant other for the tasks associated with caring for an infant. This will include resources for obtaining specific adaptive equipment, home environment modifications, learning to use assistive devices, increasing strength and endurance, and mentally preparing individuals for parenting (Ballard, 2009; Hunter & Coventry, 2003; Magill-Evans et al., 2006; Mulcahey et al., 2010; Reid et al., 2003; Sanders & Morse, 2005;

Thierry, 2006). At this point, OTs are able to evaluate the individuals' abilities and provide interventions specifically for their needs (Hunter & Coventry, 2003; Magill-Evans et al., 2006; Mulcahey et al., 2010; Reid et al., 2003; Thierry, 2005).

After the birth of the child, OTs will continue to work on goals set during pregnancy but will also shift gears towards more comprehensive objectives. The focus of this scholarly project will be providing activity adaptations for a parent with a SCI to use when engaging in play or physical contact with their child. Because of physical limitations, some activities that are crucial for child development may prove extremely difficult or impossible for individuals with a SCI to complete with their children (Cowley, 2007; Hunter & Coventry, 2003; Magill-Evans et al., 2006). OTs can provide the unique perspective of combining the parent and the child's need for engagement in occupations. Because OTs are educated in both adaptations and pediatric development, they can promote engagement in occupations for both the parent and child.

The occupational adaptation (OA) model focuses on occupations, adaptive capacity, relative mastery, and the occupational adaptation process. This model will be used in this scholarly project to assist in meeting the need for adapted activities. Occupations involve the process of meaningful activities that actively involve the person (Cole & Tufano, 2008; Schkade & McClung, 2001). Activities that promote engagement between child and parent are both meaningful and involve the person. The adaptive capacity of an individual is their ability to change, modify, or refine their occupations (Cole & Tufano, 2008). This process is concluded when relative mastery (efficiency, effectiveness, and satisfaction) is reached. The process of adaptation includes these steps and their effect on the person and environment (Cole & Tufano, 2008; Schkade &

McClung, 2001). When adapting activities for someone with a SCI, adaptive capacity will be assessed and the individual will be educated and trained to reach relative mastery.

There is currently a need for OT to assist with promoting active participation in parenting roles within the SCI population and improving the relationship between the primary occupations of parent and child. Individuals with SCIs may experience a multitude of physical and emotional changes to their daily roles, tasks, and routines. When planning for parenthood with individuals with a SCI, it is vital to consider finances, pain management and endurance, social supports and assistance, fertility and pregnancy, adaptive equipment and assistive methods, psychological impacts on both parent and child, and newly defined family roles. Although there are abundant resources within various media available for individuals with a SCI to utilize, there continues to be a need for the emphasis on promoting healthy participation of a child's primary occupation of play and the associated role of the parent with a SCI. This need for a connection between parent and child engagement in occupations should be addressed by OT as they focus on improving the health and well-being of individuals through the engagement in meaningful daily occupations. This scholarly project focuses on promoting the success of engagement in parental roles as an individual with a SCI and providing adaptive strategies and activities to encourage healthy play occupations for the parent-child relationship. In creating this scholarly project, the OA model was utilized as a guide throughout the process. When designing the product, there was also a focus on incorporating andragogy teaching and learning methods, Fink's methods for course design, and Bloom's taxonomy. In chapter three, the authors describe the methodology

used to develop this scholarly project with focus on literature, models, and instructional methods for development of a parenting workshop for people with spinal cord injuries.

CHAPTER III

METHODOLOGY

The product for this scholarly project is a parenting workshop for people who have a spinal cord injury (SCI) titled “Living with a Spinal Cord Injury: A Workshop for Parenting and Play”. This workshop addresses a serious need as people with SCIs are often concerned about their ability to be a good parent due to their disability (Alexander, Hwang, and Sipski, 2002; American Association of Spinal Cord Injury Psychologists and Social Workers, 2002; Bergmark, Winograd, & Koopman, 2008; Chan, 2000; Duvdevany, Buchbinder, and Yaacov, 2008; Rintala, Herson, & Hudler-Hull, 2000). The original concept for this scholarly project originated from a common interest of both authors, which is SCIs. Upon further research, it was noted that there is ample research involving fertility and pregnancy regarding individuals with SCIs, but information about parenting after the baby is born was sparse. Occupational therapists (OTs) focus on adapting activities so an individual can be as successful as possible in all areas of occupation (American Occupational Therapy Association, 2008). The parents’ occupation is parenting, and the child’s primary occupation is play. Because OTs have training and education in both pediatric and adult development and occupational roles, they have the unique perspective to link the two occupations, thereby supporting “health and participation in life through engagement in occupations” (American Occupational Therapy Association, 2008, p. 626).

Methods for Literature Review

The student authors of this scholarly project conducted a literature review by using search engines such as PubMed, CINAHL, MedlinePlus, Google, and Google Scholar. When using PubMed, CINAHL, and Google Scholar, the authors typed key words into the search boxes such as “spinal cord injuries AND parenting”, “parenting AND disability”, and “spinal cord injuries AND adaptations”. These searches provided articles and information relevant to the scholarly project. The authors made the decision to limit articles to those more recent than the year 2000 unless the information proved to be of significant value. Significant value is defined as a groundbreaking study or an article that was cited in many articles. MedlinePlus was searched for information using key words such as “spinal cord injuries”, “parenting”, “parenting AND disability”, and “spinal cord injury AND occupations”. When using the Google search engine, the authors used key phrases such as “spinal cord injuries”, “spinal cord injuries parenting”, and “spinal cord injuries adaptive equipment”. This search returned items such as the websites for the National Spinal Cord Injury Association and American Spinal Cord Association. These websites had further information regarding parenting with a SCI.

The American Occupational Therapy Association’s website was also used to conduct a literature review. The online archives for the American Journal of Occupational Therapy were searched for information. Phrases and words used to search include “parenting AND spinal cord injury”, “children AND spinal cord injury”, and “children perspectives AND parenting”.

After searching literature using these methods, the authors of this scholarly project chose articles to add to their knowledge bases. The authors read and evaluated

each article and decided how each was related to the scholarly project. Some of the articles were summarized and relevance was noted by the authors. The authors wrote the literature review by combining, contrasting, and paralleling these articles and highlighting the need for the scholarly project and its relation to OT. The authors decided that a workshop would be the most effective method to educate people about parenting with a SCI and adapting activities. The occupational adaptation (OA) model, andragogy, and a framework for course design served as a guide for the workshop development (Cole & Tufano, 2008; Dreeben, 2010; Fink, 2003; Schkade & McClung, 2001; Werner DeGrace, 2007).

Occupational Adaptation Model

The authors of this scholarly project used the occupational adaptation (OA) model to guide the creation of the workshop because of the strong emphasis on building adaptive capacity. A person with a SCI will need adaptive capacity to perform meaningful parental occupations with a child (Werner DeGrace, 2007). The OA model also addresses the influence of the environment on the individual, and this is important to consider as people with SCI will parent in many different environments that could pose challenges related to accessibility (Cole & Tufano, 2008; Schkade & McClung, 2001; Werner DeGrace, 2007).

Cole and Tufano (2008) defined four overarching components unique to this model, which include desire for mastery, demand for mastery, press for mastery, and relative mastery. *Desire for Mastery* describes the innate need to achieve (Cole & Tufano, 2008). When participants attend the workshop described in this scholarly project, they will be seeking and *desiring* mastery of parenting even though they have a

SCI. The authors of this scholarly project supplement their desire for mastery with definitions, statistics, and information regarding parenting. *Demand for Mastery* is defined as the requirements of the environment, and these requirements may warrant changes and adaptations (Cole & Tufano, 2008; Schkade & McClung, 2001; Werner DeGrace, 2007). After a SCI, the environment may pose a great deal of barriers to overcome. Some of these barriers may be the ability to conceive, fertility, the need for adaptive equipment, and decrease in physical abilities.

During the workshop, the participants will be asked to reflect on the barriers they have in regards to the environment. *Press for mastery* is the combination of the desire and demand for mastery (Cole & Tufano, 2008; Schkade & McClung, 2001; Werner DeGrace, 2007). This is reflected throughout the workshop as the participants are asked to problem-solve to create their own adaptations for the environmental demands. *Relative mastery* is achieved when the individual assesses themselves and confirms they are efficient, effective, and satisfied with their adaptation processes (Cole & Tufano, 2008; Schkade & McClung, 2001; Werner DeGrace, 2007). This level of mastery will be confirmed when participants are asked to problem-solve and create their own adaptations for activities.

The OA model also addresses the three fundamentals of person, occupational environment, and the combination of the two (Cole & Tufano, 2008; Schkade & McClung, 2001; Werner DeGrace, 2007). The mastery components of the OA model fit into these fundamentals. Desire for mastery comes from the person, demand for mastery comes from the occupational environment, and press for mastery is the combination of the two. The performance of the person within the environment stimulates adaptation,

and eventually, the person experiences relative mastery (Cole and Tufano, 2008; Schkade & McClung, 2001; Werner DeGrace, 2007).

Finally, the OA model focuses on three aspects of the person that are instrumental when developing their adaptive capacity. These include a combination of psychosocial, cognitive, and sensorimotor systems called the *adaptation gestalt* (Cole & Tufano, 2008; Schkade & McClung, 2001; Werner DeGrace, 2007). The three aspects are “influenced by the genetic, environmental, and experiential/phenomenological aspects of our being or the system’s being” (Werner DeGrace, 2007, p. 99). Each individual has their own *adaptation gestalt* for engagement in every task. This workshop incorporates options for learning using psychosocial, cognitive, and sensorimotor methods to promote the participants adaptive capacity. For example, the peer to peer small group discussions target the psychosocial aspects. These discussions encourage participants to feel comfortable discussing ideas. In addition, the lectures, pictures, and resources in the workshop provide facts and information so that participants can cognitively remember adaptive strategies they can use for parenting. Finally, allowing participants to utilize adaptive equipment during the workshop addresses the sensorimotor aspect of the person and enables them to physically perform adaptive strategies. This form of teaching and learning is a hypothesis used when using the theory of andragogy.

Incorporating Andragogy

Andragogy was used to guide the learning process for the targeted population. Andragogy is defined as “learner-focused education” and was refined by Malcolm Knowles in the United States (Dreeben, 2010, p. 228). Knowles described five principles about adult learning:

(1) informing the learner why the information is important to learn, (2) showing the learner how to self-direct through the information, (3) relating the topic to the learner's experience, (4) taking into consideration the fact that people will not learn until they are ready and motivated to learn, [and (5)] the teacher [helps] the learner overcome behaviors, beliefs, and inhibitions about the learning process (Dreeben, 2010, p. 228).

When constructing the workshop design and teaching and learning methods for this scholarly project, careful consideration was used to gear the information towards individuals with SCI that were either thinking of becoming parents or adapting their current parenting roles due to a newly acquired SCI. The authors of this scholarly project addressed the first principle of andragogy by converting medical language about parental planning and child development into language that is understandable to the general adult population who may not be trained in medical terminology. The second principle of self-directive learning is visible throughout the product when using problem-based learning activities to involve and stimulate conversation among the participants. The third principle was integrated by including opportunities for the participants to take part in discussions and add their own experiences. In accordance with the fourth principle, participants would not attend the workshop unless they are ready and motivated to learn the information presented. Finally, the fifth principle was utilized when participants are also given information about the successes of parents with a SCI to overcome beliefs and inhibitions of their abilities as parents. These principles of andragogy were integrated and combined with Bloom's taxonomy and Fink's methods for course design to synthesize the delivery of the product to the participants.

Bloom's Taxonomy and Fink's Guidelines for Course Design

While andragogy served to guide instructional methods, Bloom's taxonomy was used to guide sequencing of instructional methods. Bloom's taxonomy is a method for teaching that involves a pyramid of six levels: remembering, understanding, applying, analyzing, evaluating, and creating (Anderson & Krathwohl, 2001; Bloom, 1956). Remembering is considered to be the most rudimentary level, and the levels follow a continuum to the highest level: creating.

The instructor of the workshop will guide participants along this learning continuum throughout the workshop. First, they are supplied with the fundamental information about SCIs and parenting. They then build understanding when they connect the information to their own experiences. After they reflect, they also are asked to apply what they have learned during problem-based learning activities that focus on adaptive strategies for parenting. They will then analyze and evaluate the effectiveness of their adaptation, and after the workshop, they are encouraged to create their own adaptations for everyday use.

In addition to using Bloom's taxonomy to sequence instructional methods, Fink (2003) helped organize topics into a cohesive whole. The authors utilized Fink's methods for course design by organizing content into units (Fink, 2003). Grouping contents in this manner helps learners make sense of the information, thereby supporting attainment of knowledge (Fink, 2003).

In summary, OA served as the overarching model to help people with a SCI build adaptive capacity for the role of parenting (Cole & Tufano, 2008; Schkade & McClung,

2001). Andragogy guided the teaching and learning methods unique to adult learners (Dreeben, 2010). Bloom (2001) helped to sequence instructional methods along a continuum. Finally, Fink (2003) provided a method by which to organize contents in a way that helps learners make sense of the knowledge they gain during the workshop. See figure 3.1 in Appendix B for the model of the workshop design. In chapter four, the authors describe the product of this scholarly project, which is the parenting workshop for people with a SCI.

CHAPTER IV

PRODUCT

The literature review findings indicated a need to address both the primary concerns about parenting with a spinal cord injury (SCI) and the promotion of adaptive techniques to assist with the child's play activities. The authors of this scholarly project used the literature findings to create a workshop to remedy this need. The full workshop design is presented in Appendix C. The goals of the workshop include reducing concerns/fears and linking the occupations of parenting with the child's occupation of play. An occupational therapist (OT) would instruct the workshop because of the emphasis on occupations related to the role of parenting.

The workshop was divided into two half-day portions instead of a day-long arrangement in consideration of the population. This will ensure the ability to attend and the comfort of the participants. The length of each session will only be three to four hours, depending on attendance and involvement/participation of attendants. The workshop could be scheduled in the morning or afternoon based on the participants and presenters preferences; however, it is recommended that the two parts of the workshop are within two to three weeks of each other to ensure that the participants can recall information from the first workshop and then expand more through application activities

during the second workshop. Weekends would in all likelihood fit best into both the presenters' and participants' schedules.

Within this two-part workshop, a significant focus will be on parental concerns, adaptive ideas, techniques, and additional resources. The first session of the workshop includes pain management, endurance and fatigue levels, social support and assistance, male fertility and female fertility and pregnancy, returning to parenting, adaptive equipment, psychological impact (depression, perception of disability, fear of rejection, and impact on children), adjusting family roles, and further information on associations/organizations, support groups, and community resources. The goal of this session is to counteract the fears experienced by individuals with SCIs through providing options and specialized knowledge to support successful parenting.

The second session of the workshop includes information pertaining to child development, play occupations, and adaptive ideas to increase the parent's ability to interact with their children. The goal of this session is to link the parents' occupation of parenting to the child's occupation of play. Both parts of the workshop include problem solving activities to enhance understanding and participation, handouts to promote self-directed learning, and evaluations to examine participant growth and satisfaction (see Appendix D).

The method chosen to present the information was Powerpoint slides using a computer and projector. The slides were created specifically for the format of the workshop. Information was compiled from the literature review and other resources including books and national websites for SCIs. Pictures of adaptations and parenting were used with permission (see Appendix E).

The location of the workshop needs to be carefully evaluated to be appropriate for the population in attendance. The location needs to be accessible both inside and outside. The room needs to have adequate space and handicap accessible tables to accommodate the participants. Care should be taken to choose a centralized venue in relation to participants' location, public transit, accessible streets/sidewalks, level of traffic, and parking capabilities. The venue should also have adequate technological capabilities and options for presenting the workshop slides.

Participants should be encouraged to bring other individuals who support them and want more information. This would include significant others, partners, friends, medical personnel, and/or family. These individuals may also assist them with transfers in and out of the building, restroom breaks, asking questions, voicing concerns, and/or writing/taking notes.

Asking a parent with a SCI to speak at the workshop would be valuable to both the presenters and the participants. This would create an opportunity for the participants to learn more about application of the information and could be encouraged by a successful story. After several completions of this workshop, it is anticipated that past participants will be willing and able to share how they have applied information to their lives as parents.

In order to market this workshop to potential participants, the presenters will disperse brochures among therapists, physicians, social workers, and additional medical professionals throughout medical facilities in the area (see Appendix F). Word of mouth will also be a crucial element when marketing this workshop to individuals with a SCI. OTs and physical therapists will give brochures for the workshop to each client with a

SCI who attends therapy services. The therapists will also verbally invite the clients to the workshop. This type of contact tends to be more welcoming and offers an opportunity to inquire more about the workshop.

In order to make the participants as comfortable as possible, frequent breaks are incorporated into the workshop schedule. The breaks also have a duration of at least twenty minutes. Participants should receive encouragement to leave and/or reposition/provide pressure relief as needed. A complete list of recommendations and considerations for delivery of the workshop is located in Appendix G.

The OTs who conduct the workshop will determine success of the workshop by distributing a pre- and post-evaluation to be completed by the participants with SCIs. These evaluations include questions about their knowledge, perceived ability to parent, and their confidence with parenting before and after attending the workshop. An increase in score will indicate success of the workshops. There will be the opportunity to follow-up with participants and discuss successful outcomes. These outcomes in turn can be shared with other individuals with a SCI contemplating parenting and used to evaluate long term successes and challenges associated with parenting. The authors and designers hope that this workshop will be implemented and/or used as a guide to reach out to those individuals with a SCI who are contemplating parenthood.

The occupation adaptation (OA) model guided both the literature review and the actual construction of the product. In the product, the participants are guided through the components of desire, demand, press, and relative mastery. These components are addressed by using photographs to create desire, assessing the barriers the environment creates, highlighting the need and method for adapting activities, and instilling a feeling

of efficiency, effectiveness, and satisfaction in the participants after they successfully adapt the activities themselves. The goal for the end of the workshop is for the participants to have an increased adaptive capacity.

Andragogy was used in the product to guide the teaching strategies implemented. Components such as problem-solving activities, discussion, and hands-on learning were incorporated into the workshop to enhance the way adults learn. Bloom's taxonomy also guided the creation of the product by defining the continuum of the adult learning process and sequencing the information presented. Lastly, Fink's methods for course design served to divide the content of the product into units to more effectively structure the workshop.

The product can be changed and modified to fit the presenter and the specific participants attending. Additional information about each slide is included in a note format to enhance both the presenter's flow of ideas and information and the participants learning. This workshop is not meant to be an exhaustive view of parenting with a SCI; therefore, more up to date information should be added as more research is available.

CHAPTER V

SUMMARY

After reviewing literature, finding a specific need, and compiling the information, the authors of this scholarly project created a workshop for individuals with spinal cord injuries (SCI). The workshop included information about the primary concerns about parenting with a SCI and adaptive strategies to pair the parents' occupation of parenting with the child's occupation of play. Occupational therapists (OT) are uniquely qualified to create and implement this workshop because of their ability to promote participation in meaningful occupations through education, adaptation, and clinical reasoning. As stated by AOTA (2008),

...the defining contribution of occupational therapy is the application of core values, knowledge, and skills to assist clients (people, organizations, and populations) to engage in everyday activities or occupations that they want and need to do in a manner that supports health and participation (p. 626).

The workshop process is guided through the use of the occupational adaptation (OA) model, andragogy, Bloom's taxonomy, and a model for coursework design.

Limitations of this scholarly project include the focus on individuals who are thinking of becoming parents. The ability to generalize the information from this workshop to other populations is limited since the workshop addresses adaptations that

may be specific to those people who have had a SCI. Although some information is provided for individuals who have children during the onset of their SCI, most information is specific to potential parents. Another limitation is that all application is hypothetical, and some learners may find hands on adaptation with children present to be more beneficial.

Recommendations include using this workshop to train other OTs to present this workshop. This way, expansion can be created and a larger population can be reached. Another recommendation is to include speakers who have successfully parented with an SCI to share their testimony during the workshop as well as other medical professionals who specialize in diverse areas of interest. This workshop should be offered annually in order to provide the information to as many people with SCIs as possible. For future continuation and improvement of this workshop, it is recommended that more effective and specific outcome measures, along with tracking forms be designed and utilized to serve as research tools.

This workshop will potentially change healthcare in two years by increasing awareness and confidence of parents with a SCI. Stemming from this awareness, this workshop has the potential to change healthcare in ten years by expanding to larger parenting programs such as mentorship programs or in-hospital programs specifically for parenting with a SCI. Parenting with a SCI is possible and can be a rewarding experience. There is a need, however, for information and support for the parents throughout the development of their children. The OT profession provides the holistic care that individuals with a SCI will need to succeed in their occupations and roles as parents.

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APPENDICES

APPENDIX A

Table 2.1

Spinal Cord Injury Organizations and Websites

Organization	Website.
American Spinal Cord Injury Association	http://www.asia-spinalinjury.org/
Center for Paralysis Research	http://www.vet.purdue.edu/cpr/
Center for Spinal Cord Injury - Rehabilitation Institute of Michigan	http://www.centerforscirecovery.org/
Christopher and Dana Reeve Foundation and Paralysis Resources Center	http://www.christopherreeve.org/
Darrell Gwynn Foundation	http://darrellgwynnfoundation.org/
Foundation for Spinal Cord Injury Prevention, Care & Cure	http://www.fscip.org/
International Campaign for Cure of Spinal Injury	http://www.campaignforcure.org/iccp/
Miami Project to Cure Paralysis	http://www.miamiproject.miami.edu/
Mike Utley Foundation	http://www.mikeutley.org/
The Morton Cure Paralysis Fund	http://www.mcpf.org/
National Spinal Cord Injury Association (NSCIA)	http://www.spinalcord.org/
The Paralysis Project of America	http://www.paralysisproject.org/
Paralyzed Veterans of American	http://www.pva.org/
Point of Care, Team-based Information System	http://calder.med.miami.edu/pointis/handbook.html
Sam Schmidt Paralysis Organization	http://www.samschmidt.org/

Spinal Cord and Brain Injury Research Center	http://www.mc.uky.edu/scobirc/
Spinal Cord Injury – For Your Information	http://www.tbi-sci.org/scifyi/
Spinal Cord Injury Information Network	http://www.spinalcord.uab.edu/
Spinal Cord Injury Network International (SCINI)	http://www.spinalcordinjury.org/
Spinal Cord Society	http://www.scsus.org/
United Spinal Association	http://www.unitedspinal.org/
W. M. Keck Center for Collaborative Neuroscience	http://keck.rutgers.edu/

APPENDIX B

Workshop Layout



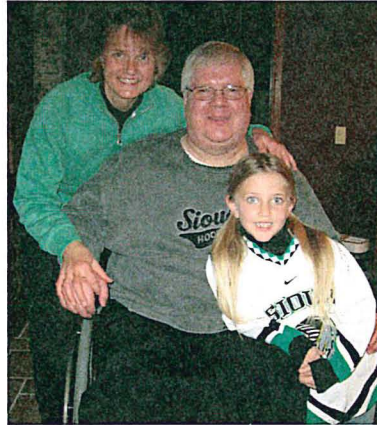
Bloom's Taxonomy



Occupational Adaptation



APPENDIX C



(Photo Used with
Permission)




LIVING WITH A SPINAL CORD INJURY: A WORKSHOP FOR PARENTING AND PLAY - PART I

Ana Sobolik, MOTS

Laura Gunderson, MOTS

* Pass out Pre-Workshop Questionnaire (see Appendix E) to participants, allow time to complete, and collect before beginning.

AGENDA

- 8:30-9:40 – Planning, Fertility and Pregnancy, Returning to Parenting
 - 9:40-10:00 – Break
 - 10:00-11:10 – Adaptive Equipment, Psychological Impact, Family Roles
 - 11:10-11:30 – Break
 - 11:30-12:00 – Resources, Wrap-up
- 

*Note: These times and the layout may be changed to be the most advantageous to the learners and presenters.

*Note: Encourage participants to leave if needed.

OVERVIEW

Session 1 Goals

- **TODAY**
- Will understand concerns such as:
 - Planning
 - Fertility
 - Adaptive equipment
 - Psychological impact
 - Family roles
 - Resources

Session 2 Goals

- **NEXT TIME**
- Will understand:
 - Basic child development stages
 - Basic occupational play stages
 - Interactive play activity options, adaptations, & ideas

*Note: Add in dates to ensure that the participants know when the next session will be. Also, tell them the location and time.

○ By the end of this session, learner will:

- Have an overview of how to regulate endurance, fatigue, and pain throughout parenthood
- Understand possibilities and options for fertility and pregnancy
- Appreciate the impact of social support during parenthood
- Identify options for adaptive equipment for parenting
- Realize the possible psychological impact related to the entire family
- Recognize psychological dynamics within the family unit



WARM-UP

Lets get thinking...

You gain strength, courage, and confidence by every experience in which you really stop to look fear in the face. Do the thing you think you cannot do.

-Eleanor Roosevelt



- *"How did you hear about us?" i.e. Support group, personal OT, physician, acquaintance, friend?
- *Who here is already a parent and who is considering parenthood?
 - *Ask those who are already parents to add input throughout presentation
- *What do you expect to learn today? Specific areas? Who is just here to learn?
- *To get a feel of who is here today, at what levels are your spinal cord injuries?
- *Think of the top 3 areas of concern that you have regarding parenting with spinal cord injury.
- *Who is willing to share?
 - *Note: as each area is verbalized, ask who else in the audience also feel this is of concern. Establish links between individuals, and highlight the fact that they have similar concerns.

PARENTAL CONCERNS

- Planning for parenthood
 - Pain management
 - Endurance/fatigue levels
 - Social support and assistance
- Fertility and pregnancy
 - Male
 - Female
- Returning to parenting
- Adaptive equipment
- Psychological impact on parents and children
 - Depression
 - Perception of disability
 - Fear of rejection
 - Impact on children
- Family roles
- Resources
 - Associations, organizations
 - Support groups
 - Community resources



*You will need instructor notes that describe delivery of each slide.

PLANNING FOR PARENTHOOD

Finances: Spinal Cord Injury

- First year after injury:
 - \$244,562 to \$829,843
 - Some or most might be covered by insurance
- Following years:
 - \$17,139 to \$148,645



(Microsoft Corporation, 2011)

(National Spinal Cord Injury Statistical Center, 2009)

*Reflective questions: “Who has started to address finances for parenting?”, “What have you found?”, “For those of you who are already parents, what are/were the main struggles regarding finances?”

*Note: most participants probably have already absorbed the expenses from the first year.

*Encourage participants to budget yearly income with expenses pertaining to both their SCI and child rearing.

*Numbers do not include everyday living costs (ex: food and housing)

PLANNING FOR PARENTHOOD CONT.



(Microsoft Corporation, 2011)

Finances: Raising Children

- Per year for each child:
 - \$8,330 to \$23,180

- Until 18 years of age

(Lino, 2009 in conjunction with the U.S. Department of Agriculture)

*These costs may vary greatly depending on the individual situation (cost of living, insurance coverage, etc.).

*It is VERY important to budget. Budgeting assists with making costs manageable for families.

PLANNING FOR PARENTHOOD CONT.

Budgeting

- Budget all expenses
 - SCI
 - Raising a child
 - Housing
 - Food
 - Adaptive equipment

- Is there the means to raise a child?



(Microsoft Corporation, 2011)

*Hand out budgeting spreadsheet (see Appendix E)

*Give an example of total cost: minimum total cost is 25,469, maximum cost is 171,825

*Careful budgeting – with spouse or significant other. Perhaps the help of a professional? (financial advisor, financial assistant, etc.)

PLANNING FOR PARENTHOOD CONT.

Pain Management

- Exercise
- Diet
- Sleep
- Avoidance of stress
 - Dudgeon, Tyler, Rhodes, & Jensen (2006)
- Medication
- Stretching
- Splitting or scheduling tasks
- Use of adaptive equipment
- Analyze
- Prioritize
- Distractions

*Participants may already know pain management techniques. Ask for them to add examples or input.

*“What are some examples of pain management techniques that you use and find to be affective?”

*Article: Authors found that not getting exercise, poor diet, lack of sleep, and high stress contributed to usual stress.

*Usual or expected pain: predictable, everyday pain; Unexpected pain: no warning (ex: after a specific movement)

*Medication: prescription meds, over the counter meds

*Stretching: home program

*Analyze: Do I have to do this activity? Is there an easier way to do this activity?

*Prioritize: What NEEDS to get done today?

*Distractions: get mind on something else other than pain (ex: talk to someone, read, watch TV, etc.)

PLANNING FOR PARENTHOOD CONT.

Pain Management

- May need to be altered for child rearing
- Specialized pain management teams
 - Physician
 - Psychologist
 - Occupational Therapist
 - Physical Therapist
 - Nurse
 - Vocational Specialist
 - Dietician
- Occupational Therapy's role
 - To increase:
 - Physical capacity
 - Performance in life tasks, roles, within personal environments
 - Mastery of environment through occupations/activities and education

(American Occupational Therapy Association, 2008)

*OTs could implement the following: Examples:

*Establishing healthy schedules/routines

*Task analysis and break-down of occupations involving or causing pain

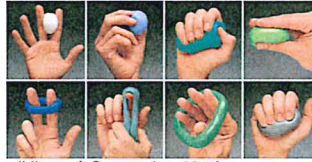
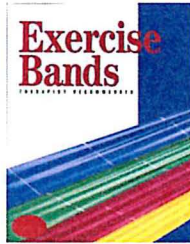
*Providing options or adaptations to specific tasks that promote pain alleviating postures

*Education on improving physical health

PLANNING FOR PARENTHOOD CONT.

Endurance and Fatigue

- Fatigue: most prevalent secondary complication reported
 - Jensen, Kuehn, Amtmann, & Cardenas (2007)
- Exercise programs
- Energy conservation
 - Splitting tasks
- Adapted routine
- Support from another individual



(Microsoft Corporation, 2011)

*"What have you done to decrease fatigue? What about to increase endurance?"

*These types of exercise (exercise bands, theraputty) are for SCIs with upper extremity movement

PLANNING FOR PARENTHOOD CONT.

Exercises After Pregnancy For Women

- Promote weight loss
- Improve cardiovascular fitness
- Restore muscle strength
- Condition abdominal muscles
- Boost energy level
- Improve mood
- Relieve stress
- Help prevent postpartum depression

(Mayo Clinic Staff, 2009)

*"What exercises have you tried?" "Is anyone using an exercise program at this time?"
"What has worked for you? What has not?" "Feel free to jot down any exercises
that you feel would be beneficial for you."

PLANNING FOR PARENTHOOD CONT.

Exercises After Pregnancy For Women

- Start exercising as soon as possible after a birth
- Start gradually and increase exertion
- Stay hydrated and stop if there is pain!



(Microsoft Corporation, 2011)

(Mayo Clinic Staff, 2009)

FERTILITY AND PREGNANCY

Male Fertility Options

○ Semen Retrieval Methods

- Penile vibratory stimulation (PVS)
- Electroejaculation (EEJ)

(Microsoft Corporation, 2011)



○ Assistive Reproductive Technologies

- Intrauterine insemination (IUI)
- Intracytoplasmic sperm injection
- Retrieval from tissues
- Sperm freezing

***Positive Note: 40% of men with a SCI who attempted to father children were successful!**

*PVS:

- *Less invasive approach
- *55% success rate in study by Kafetsoulis, Brackett, Ibrahim, Attia, and Lynne (2006)
- *Higher percentages of motile sperm & increased motion
- *Most preferred by users

*EEJ:

- *95% success rate after PVS had failed in study by Kafetsoulis et al. (2006)

*When both used together: 94% found sperm count to be successful for IUI

*Sperm Freezing:

- *More common today than ever!
- *Act fast – the window to complete procedure is around two weeks post-injury before sperm viability decreases

*Resources: (Brackett, 2009; Elliot, 2003; Elliot, 2002; DeForge et al, 2005; Kafetsoulis et al., 2006; and Linsenmeyer, 2000)

FEMALE FERTILITY AND PREGNANCY

*Less overall research regarding females with SCI due to smaller population vs. males.

○ Fertility & Pre-pregnancy

- Obstacles/barriers
- Pre-pregnancy health team planning
- Pre-natal care
- Decreased physical abilities



(Microsoft Corporation, 2011)

*Quality pre-conception care has been linked to improved pregnancy outcomes.

*Obstacles/barriers:

- *Amenorrhea – experienced for certain time periods (3-9 mos. post-injury) before returning to normal
- *Hyperprolactinaemia – correlation to amenorrhea along with hypothesized cause of body's reaction to high psychosocial stress & crisis
- *Misconceptions – 1st dr. visit professionals' assumption was termination of pregnancy
- *Physical obstacles – inaccessible examination tables

*Health-care Team:

- *Obstetrical health care provider – challenging process due to risks
- *Childbirth educator/counselor – psychological aspects & specialized readiness care

*Pre-natal Care:

- *Comprehensive evaluation including overall physical health and inventory of meds
- *Additional concerns: autonomic dysreflexia with pelvic exams, increased respiratory distress, UTIs, pressure ulcers, thromboembolism

*Resources: (Jackson, Lindsey, Klebine, & Poczatek, 2004; Rogers, 2005; Rutberg, Friden, & Karlsson, 2007; Smeltzer & Wetzel-Effinger, 2009; Theirry, 2006)

FEMALE FERTILITY AND PREGNANCY

○ Pregnancy & Labor

- Difficulties
 - Decreased physical abilities
 - Lack of sensation/detection of physical changes & onset of labor
- Decisions
 - Method of delivery
 - Anesthesia
- Risks
 - Autonomic dysreflexia



(Microsoft Corporation, 2011)

*Physical abilities:

- *Inability to self-propel wheelchairs
- *Decreased ability to complete transfers
- *Change/adapt bowel/bladder management routines

*Lack of ability to detect physical changes:

- *Increased number of cervical exams after 28 weeks of pregnancy

*Methods of delivery:

- *Vaginal vs. Cesarean section
- *Anesthesia: lumbar epidural recommended as prevention for autonomic dysreflexia
- *Autonomic dysreflexia: huge risk & also correlation with episiotomies (so avoided)

*Resources: (Amble & Lannoye-Amble, 2002; Thierry, 2006)

FEMALE FERTILITY AND PREGNANCY

- Post-pregnancy:
 - Dependent on delivery
 - Extended complications if episiotomy was administered
 - Lack of sensation for healing purposes – infection risks
 - After healing – another transition warrants OT consult
 - Parental tasks:
 - Decisions on breastfeeding



(Microsoft Corporation, 2011)

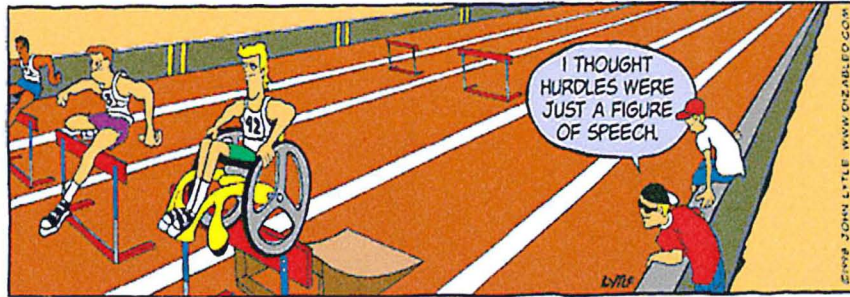
*Breastfeeding:

- *Promoted for wellness for both mother & child
- *Barriers can decrease with appropriate positioning from mother & mobility abilities

*OT's role with adaptive strategies:

- *Positioning with mother & child (both in & out of wheelchair)
- *Positioning with adaptive equipment for child

BREAK



(Used with Permission from John Lytle)

*Hand out "Problem-Solving Exercise" & will discuss when participants return (See Appendix E)

ADAPTIVE EQUIPMENT

General Adaptive Equipment

- Adapted vehicles
- Access ramps
- Wheelchairs
- Lift chairs
- Built up handles
- Adapted bathrooms
- Specialized kitchen utensils



(Microsoft Corporation, 2011)

*Most modifications will have been made if the participant has completed the rehabilitation phase

ADAPTIVE EQUIPMENT CONT.

Cribs



(Photo Used with Permission from
<http://www.howtoadapt.com>)

- *Note: This piece of adaptive equipment may not be appropriate for all levels or classifications of injury.
- *Note: This is only an idea for a crib. This crib may or may not be tested for safety.
- *Crib is high enough for the wheelchair to fit comfortably underneath
- *Doors swing open for access from the wheelchair level
- *Parent in wheelchair will be able to reach the child no matter where he/she is in the crib.
- *Cribs may be commercially available or custom made. The easiest way to obtain these pieces of adaptive equipment is to contact a local disability resource center or do online searches.
- *Picture: Commercially available crib with custom adaptation of the front doors. May consider hiring a family member or carpenter to custom construct equipment.
- *"Does anyone already have an adapted crib? What are the characteristics of your crib? Was it commercially made or custom made?"

ADAPTIVE EQUIPMENT CONT.

Cribs cont.

(Photo Courtesy of the University of Rochester - Used with Permission)



*Picture: Adapted crib made for a class project for a Medical Engineering Program at the University of Rochester

ADAPTIVE EQUIPMENT CONT.

Changing Tables



(Photo Used with Permission from tetrasociety.org)

- May use a card table
- Use commercial table and add custom buffers along sides
- Allows wheelchair to slide underneath

*Picture: over-the-bed hospital table

*Tetrasociety.org: good resource. Non-profit organization that make custom equipment for individuals who are disabled

ADAPTIVE EQUIPMENT CONT.

Bathtub

- Use a sink if it is wheelchair accessible
- Commercially available portable baby tub on a card table or counter



(Microsoft Corporation, 2011)

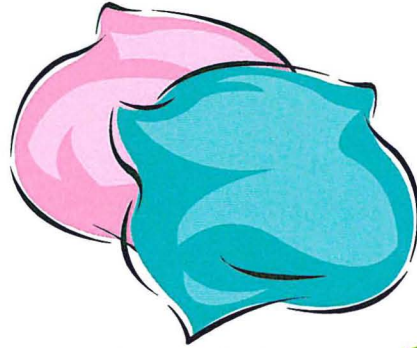
*Ensure sturdiness of equipment before use

*As child ages, may need to modify size of tub

ADAPTIVE EQUIPMENT CONT.

Pillows

- Commercially available pillow
- Breast feeding wedge
- Use regular pillow
- Lap tray on wheelchair



(Microsoft Corporation, 2011)



- *Pillows sit on mother's lap. Baby is able to feed without being held by mother.
Example: "My Breast Friend" – available at retail stores such as Walmart, Target, Babies R Us, Amazon.com
- *Regular pillows could be used on the lap to decrease need for arm strength for breast feeding.

ADAPTIVE EQUIPMENT CONT.

Baby Carriers



(Photo Used with Permission from tetrasociety.org)



(Photo Used with Permission from <http://www.dppi.org.uk/journal/5354/resources.html>)

*Picture, left: carrier secured to a bar on the bottom of the table

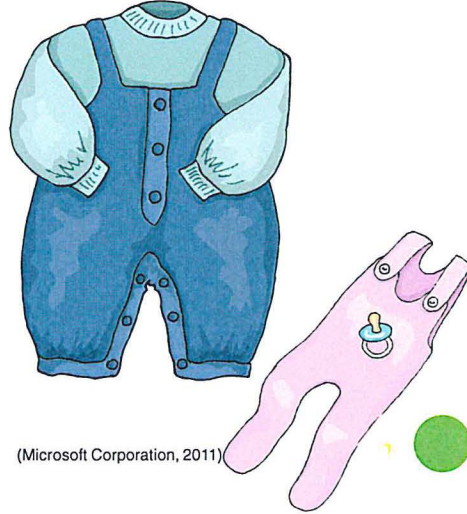
*Picture, right: stroller that attaches to front of wheelchair

*Note: adaptive device on right is only commercially available in the UK

ADAPTIVE EQUIPMENT CONT.

Transferring and Transporting

- Lift child from floor to lab by holding onto the child's extra strength overalls
 - Cowley, 2007
- Hands free sling
 - Alpert & Wisnia, 2008



(Microsoft Corporation, 2011)

ADAPTIVE EQUIPMENT CONT.

Feeding, dressing, play

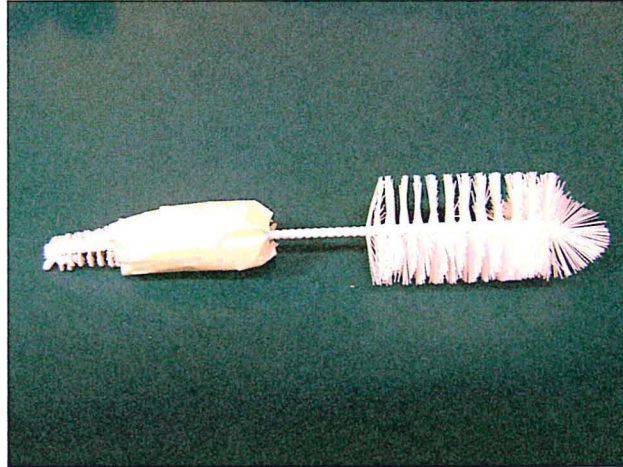


Built-up Bottle

- Weak grasp
 - Velcro on diapers, clothing
 - Built up handles on feeding utensils, bottle
 - Alpert & Wisnia, 2008
 - Built up handles on rattles, toys, games, etc.



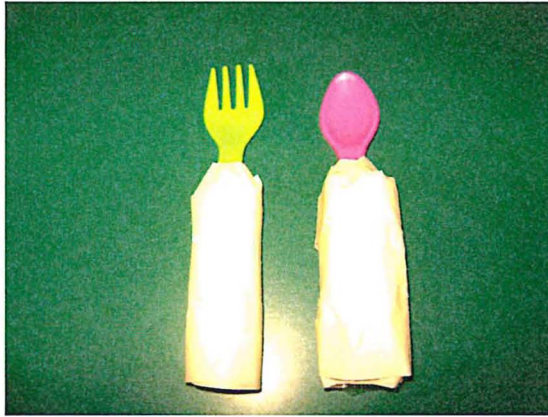
ADAPTIVE EQUIPMENT CONT.



Built-up Handle on a Bottle Brush



ADAPTIVE EQUIPMENT CONT.



7 Built-up Handles on A Baby Fork and Spoon



ADAPTIVE EQUIPMENT CONT.



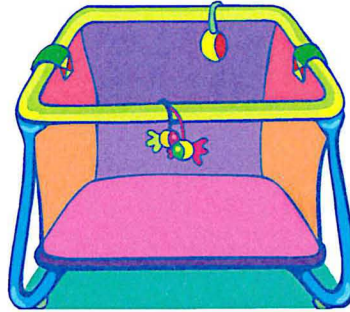
Sippy Cup

- *A sippy cup of this style may be beneficial. If an individual has a weak grasp, they can hold the entire bottom of the cup while feeding the child.
- *Promote the child feeding themselves as soon as possible

ADAPTIVE EQUIPMENT CONT.

Elevated Playpen

- Similar to elevated crib, but with room for child to play with parent
- Custom made
- Table with guards or bars
- Commercial playpen secured onto a table top
- One side opens so parent is able to roll wheelchair



(Microsoft Corporation, 2011)

*Cowley, 2007: Mother was concerned about normal milestones in her infant's development. Table enabled her to interact with her child while lying on stomach or back.

ADAPTIVE EQUIPMENT CONT.

Summary



(Microsoft Corporation, 2011)

- Trial and error basis
- Use state and online resources for equipment ideas
- Consult a professional

*Trial and error to find the best equipment for each person and child

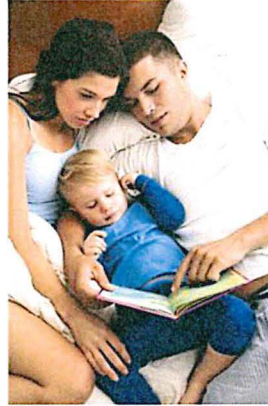
*Example: North Dakota Association for the Disabled (NDAD)

*Professionals: OTs, PTs

PLANNING FOR PARENTHOOD

Social Support and Assistance

- Humans are social beings
- Physical assistance for tasks?
- Support affects willingness to participate
 - (Horn, Yoels, & Bartolucci, 2000)
- Some need more support than others



(Microsoft Corporation, 2011)

*Might not be a spouse, but significant other, family member, etc.

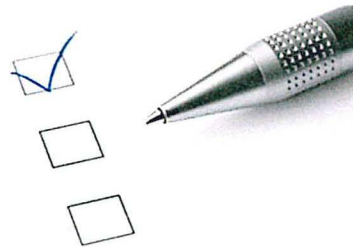
*Help for the physical tasks of parenting (ex: preparing meals, taking out garbage, buying groceries, doing laundry, etc.)

*Different personality types may need more or less support

PLANNING FOR PARENTHOOD CONT.

Social support and assistance

- Emotionally: Is there enough support?
- Physically: Is there enough support?
- How can more support be gained if needed?



(Microsoft Corporation, 2011)



*Support activity

*"Talk with someone next to you about emotional and physical support in your life."

*Give them 3-5 minutes to discuss.

*"What emotional supports do you have?", "What physical supports do you have?", "How will you obtain more"

*These are questions to ask yourself before deciding to become a parent

FAMILY ROLES

Cultural Norms

- Man makes the money
- Woman takes care of the children and housework
- Roles may change after a SCI



(Microsoft Corporation, 2011)



*Start discussion

*"How do you feel about these cultural norms?", "Are these roles similar or different to your household?", "How might these roles change?"

FAMILY ROLES CONT.



(Microsoft Corporation, 2011)

Caregiver Assistance

- Help from caregiver of spouse
- May feel vulnerable or helpless
 - (Alexander, Hwang, & Sipski, 2001)
- Spouses may feel caregiver burden or not anticipate marital adjustments
 - (Chan, 2000)



*Caregiver assistance may completely change to the new roles of each family member

FAMILY ROLES CONT.

Modifications

- Splitting household tasks
- How will decision making be changed?
- Splitting up childcare tasks
- Children taking on tasks when age appropriate
- Hiring an assistant?



(Microsoft Corporation, 2011)

*42% of mothers with a SCI had an assistant who helped with childcare (Alexander, Hwang, & Sipski, 2001).

RETURNING TO PARENTING AFTER A SCI CONT.



(Microsoft Corporation, 2011)

- Rehabilitation
- Immediately after injury the focus is on:
 - Becoming familiar with functioning
 - Learning new methods
 - Trial and error
 - Training
 - Taking control
 - (Guidetti, Asaba, & Tham, 2007)



*This slide may be omitted if all participants are done with the rehabilitation process.

*Individual will focus on becoming familiar with the new functioning of his or her body, trying new methods of self-care using adaptations and trial and error, participate in training, take control of their bodily functions.

*"Would anyone like to share their experiences throughout the rehabilitation process?"

RETURNING TO PARENTING AFTER A SCI

- Already parents at time of SCI
 - Immediate support from others
 - May need to learn wheelchair use
 - Changes to be made in roles, routines, and environment
 - Increased stress



(Microsoft Corporation, 2011)

*This slide may be omitted if all participants are done with the rehabilitation process.

*"How many of you were already parents when you experienced your SCI?"

*Immediate support from others: take care of children while in the hospital or during the rehabilitation process

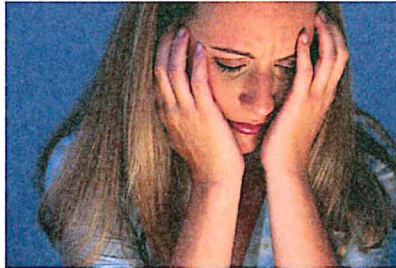
*"How did your roles and routines change?"

*Resources: (Horn, Yoels, & Bartolucci, 2000; Hunter & Coventry, 2003; Fänge & Iwarsson, 2005; Guidetti, Asaba, & Tham, 2007; Reid, Angus, McKeever, & Miller, 2003)

PSYCHOLOGICAL IMPACT

Depression

- Immediate after injury or throughout years after
- 1/5 individuals with SCI develop depressive symptoms
 - (National Spinal Cord Injury Statistical Center, 2009)
- Decreased quality of life



(Microsoft Corporation, 2011)

*Contributions to decrease quality of life: not having information, lack of money and insurance, difficulties with accessibility, fear of intimate relationships, decreased privacy (Bergmark, Winograd, & Koopman, 2008)

*Important to evaluate if the reason to have children is not to increase quality of life or counter-effect depressive symptoms

PSYCHOLOGICAL IMPACT CONT.

Symptoms of Depression

- Depressed mood, nearly every day during most of the day
- Marked diminished interest or pleasure in almost all activities
- Significant weight loss (when not dieting), weight gain, or a change in appetite
- Insomnia or hypersomnia (excess sleep)
- Feelings of worthlessness or inappropriate guilt
- Impaired psychomotor agitation or psychomotor retardation
- Fatigue or loss of energy
- Feelings of inability to concentrate or indecisiveness
- Recurrent thoughts of death, recurrent suicidal ideation

(Blesedell Crepeau, Cohn, & Boyt Schell, 2009)

*If you experience these symptoms, get help! It is better to receive treatment as soon as possible after the onset of these symptoms.

*"Take a moment and read over these symptoms. Are you experiencing any? If you are, you may want to consult a professional."

PSYCHOLOGICAL IMPACT CONT.



(Microsoft Corporation, 2011)

Depression Cont.

- Women tend to be at higher risk than men
 - (Krause, Kemp, & Coker, 2000)
- May need to seek psychiatric treatment or counseling
- Symptom management



*Symptom management should be attained before becoming a parent

PSYCHOLOGICAL IMPACT CONT.

Impact on spouse

- Spouse many feel:
 - High levels of depression
 - Care-giving burden
 - Low life satisfaction
 - Difficulties with marriage adjustment
 - (Chan, 2000)
- Spouses may also need to seek psychiatric treatment or counseling



PSYCHOLOGICAL IMPACT CONT.

Perception of a Disability

- Stigma surrounding what individuals with disabilities are capable of doing
- Impact self esteem and perception of abilities
- Individuals may experience discrimination
 - (Duydevany, Buchbinder, & Yaacov, 2008)



(Photo Used with Permission)

*Social attitudes – how the general public views an individual with a disability

PSYCHOLOGICAL IMPACT CONT.

Fear of Rejection

- Will my child accept my disability?
- Will my spouse find me to be a fit mother/father?
- Will I negatively impact my child?

Impact on Children



(Microsoft Corporation, 2011)

PSYCHOLOGICAL IMPACT CONT.

Fear of Rejection

- Children did not reject their parents
- Not ashamed of their parents disability
 - (Duydevany, Buchbinder, & Yaacov, 2008)

Impact on Children

- Children do not differ in social competency and behavior problems
- Parenting skills such as warmth, structure, and strictness make more of an impact
 - (Rintala, Herson, & Hudler-Hull, 2000)



RESOURCES

Associations and Organizations

- Research
- Support groups
- More resources
- Adaptation ideas
- Financial assistance
- Resources handout



(Microsoft Corporation, 2011)

*The websites may contain more research, info on support groups, more resources, or financial assistance information

*Resources handout (see Appendix E)

*Go through handout and provide information about different associations and organizations

RESOURCES CONT.



(Microsoft Corporation, 2011)

Support Groups and Community Resources

- Support groups
 - Individuals can:
 - Participate
 - Share experiences
 - Share information
 - Offer support to others
- National Spinal Cord Injury Association website
 - List of support groups by state
- May also be offered by a hospital



SUMMARY

- Overviewed how to regulate endurance, fatigue, and pain throughout parenthood
- Addressed possibilities and options for fertility and pregnancy
- Discussed the impact of social support during parenthood
- Identified options for adaptive equipment for parenting
- Explored the possible psychological impact related to the entire family
- Recognized psychological dynamics within the family unit



QUESTIONS?



Thank you!

Knowledge is of no value unless you put it into practice.
-Anton Chekhov



***Pass out Post-Workshop Questionnaire (see Appendix E) to participants, allow time to complete, and collect before departing.**

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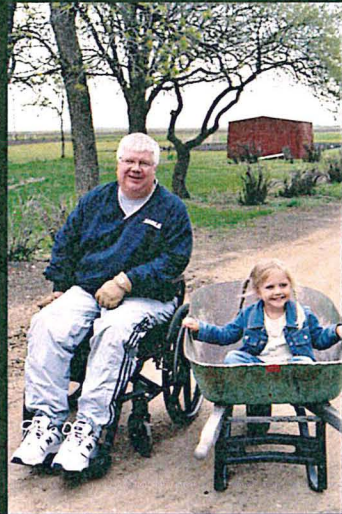


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Living with a Spinal Cord Injury: A Workshop for Parenting and Play – Part II



(Photo Used with Permission)

Ana Sobolik, MOTS
Laura Gunderson, MOTS


- *Pass out Pre-Workshop Questionnaire (see Appendix E) to participants, allow time to complete, and collect before beginning.
- *Note: throughout the presentation, promote audience participation with statements such as “Is this adaptation applicable to your life?”
- *“Can anyone think of any other ways to adapt this activity?” “What are your experiences?”
- *Note: If available, bring in a parent with a spinal cord injury to speak about how they adapt activities
- *Note: Bring adapted activity equipment to demonstrate throughout the presentation

Agenda

- 8:30-9:30 – Introduction, Theory
- 9:30-10:00 – Break
- 10:00-11:10 – Adapted Activities: Birth → 3 years old
- 11:10-11:30 – Break
- 11:30-12:00 – Adapted Activities: 3 Years old → 18 years old – Wrap up

*Note: These times and the layout may be changed to be the most advantageous to the learners and presenters.

*Note: Encourage participants to leave if needed.

- 
- By the end of this session, learner will:
 - Exhibit a basic understanding of child development and play occupations
 - Identify stages of development and types of play in relation to each
 - Explore adaptive ideas for interaction with children

What have you seen?

- What have you used?
- What needs to be adapted?
- Any other ideas?

*Promote participation and ideas

Neuromaturation



(Microsoft Corporation, 2011)

- Primitive reflex patterns → voluntary, controlled movement
- Milestones – achieving major motor movements

(Case-Smith, 2005)

Neuromaturation Cont.



(Case-Smith, 2005)



(Microsoft Corporation, 2011)

*Cephalocaudal direction (head to tail)

Piaget 's Theory – Cognitive Development

- Piaget 's Theory of Cognitive Development
 - Environment + innate abilities = cognitive development
 - Learning from interaction
- Vygotsky
 - Children learn through *scaffolding*
 - Support from caregivers



(Microsoft Corporation, 2011)

(Case-Smith, 2005)

- *Need to be able to provide a challenging environment for the child to promote development
- *Children need a “just right” challenge to stimulate development (according to Vygotsky)
- *Scaffolding – support from caregivers initially, but eventually tapering off until the child is able to complete themselves

Neuromaturation Cont.



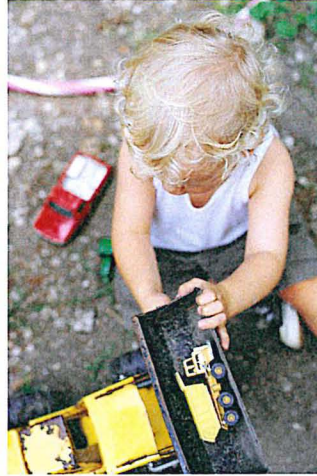
(Microsoft Corporation, 2011)

- Parents promote development by:
 - Modeling actions
 - Assisting first attempts at an activity
 - Reinforcement with praise

(Case-Smith, 2005)

Neuromaturation Cont.

- Developing performance skills
 - Exploring
 - Perceptual learning
 - Skill achievement



(Microsoft Corporation, 2011)

(Case-Smith, 2005)

*Exploring – interaction and experimentation

*Perceptual learning – feedback and reinforcement

*Skill achievement – selecting best action for achievement



**What are some
duties/activities or
“occupations” that
are included in
parenting?**

*Ask the participants to verbalize a list of the occupations they consider to be part of a parenting role.

The Occupation of Parenting

Bathing

CHANGING DIAPERS

Doctor visits

Dressing

Feeding/
nutrition

Educating

Playing

Role model

Comforting

- *"How is this the same as the list you constructed? What is different?"
"Do you think that all of these occupations are essential for child development?"

■ Parents' occupation = PARENTING



(Microsoft Corporation, 2011)

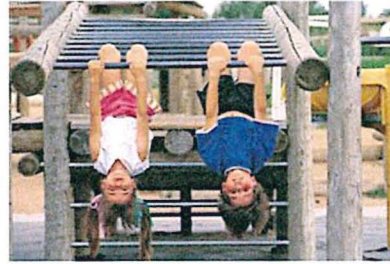


(Microsoft Corporation, 2011)

■ Childs' occupation = PLAY

The Occupation of Play

- “Any spontaneous or organized activity that provides enjoyment, entertainment, amusement, or diversion”

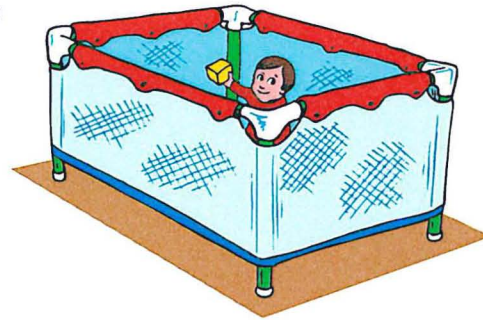


(Microsoft Corporation, 2011)

(Parham & Fazio, 1997 as cited by the American Occupational Therapy Association, 2008)

Play Equipment for Parents with a SCI

- Elevated playpen
 - Similar to elevated crib, but with room for child to play with parent
 - Custom made
 - Table with guards or bars
 - Commercial playpen secured onto a table top
 - One side opens so parent is able to roll wheelchair underneath



(Microsoft Corporation, 2011)

*May be one of the easiest and most effective tools for interacting with infant

PLAY

- Birth to 6 months
 - Exploratory play
 - Social play
- Skills
 - Gross grasp
 - Gross motor
 - Cognitive
 - Social



(Case-Smith, 2005)

(Microsoft Corporation, 2011)

*Gross grasp: Reaches for objects, palmar grasp patterns, brings objects to mouth, hand to hand transfers, looks at objects

*Gross motor: Lifts head, sits propped up, bounces when supported by parents, rolls

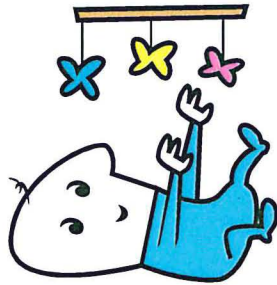
*Cognitive: Repeats pleasurable actions, multiple sensory systems are used

*Social: Coos, smiles, laughs, cries, simple facial expressions

*Note: Important for parents to support these skills and play to promote normal infant development.

Occupational Activity – Introducing Objects

- Promotes reaching, grasp, motor, lifting head, sensory, and social interaction

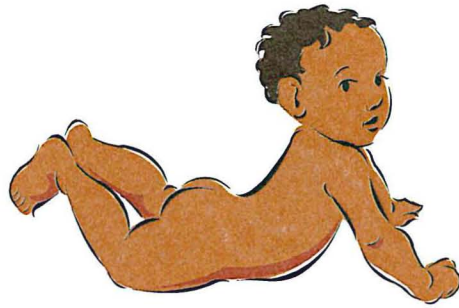


(Microsoft Corporation, 2011)

- Introducing appropriate toys in infant's environment
- Adaptations
 - Parent with decreased grasp:
 - Built up handles on objects
 - Ex: rattles
 - Adapting switches
 - Putting floor gyms on table
- Can be done in crib, on floor, and/or in playpen

*May want to use bright colored objects to illicit interest. i.e. mobiles over crib.

Occupational Activity – Rolling



(Microsoft Corporation, 2011)

- Promotes mobility
- Adaptation
 - Place infant in an elevated playpen or on floor
- Encourage infant to move around when interacting

Occupational Activity – Reaching

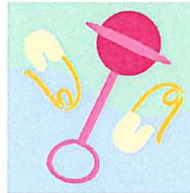
- Addresses reaching, grasp, lifting head, sensory, and social interaction
- Hold objects above infant and promote reaching for the object
- Adaptation
 - Using built up handles
 - Using elevated playpen or in crib
- Examples: interactive books, colorful stuffed animals, rattles



(Microsoft Corporation, 2011)

PLAY Cont.

- 6 to 12 months
 - Exploratory play
 - Functional play
 - Social play
- Skills
 - Fine motor and manipulation
 - Gross motor
 - Cognitive
 - Social



(Microsoft Corporation, 2011)

(Case-Smith, 2005)

- *Fine motor and manipulation: mouths toys, reaching for toys, plays with toys, releases objects, grasps small object in fingertips, pointing, crude tool use
- *Gross motor: sitting, rolling, lay to sit, pivots, stands with support, plays in supported standing, crawls, walks when held
- *Cognitive: responds to name, recognizes words and names, gestures, listens, imitates, acts on toys with intention
- *Social: dependence on parents, content with parents, some interaction with other infants

Occupational Activity – Shape Sorters

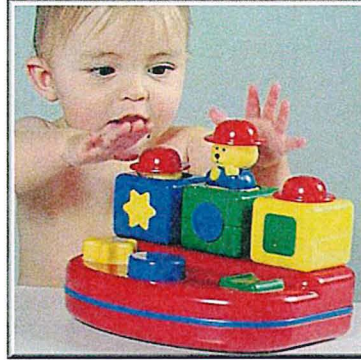
- Promotes in-hand manipulation, grasp and release, naming objects, imitation, social interaction
- Adaptation
 - Use on a bed or in a high chair so parent can be on child's level
 - Use larger objects if parent has decreased grasp



(Microsoft Corporation, 2011)

Occupational Activity – Action/Reaction toys

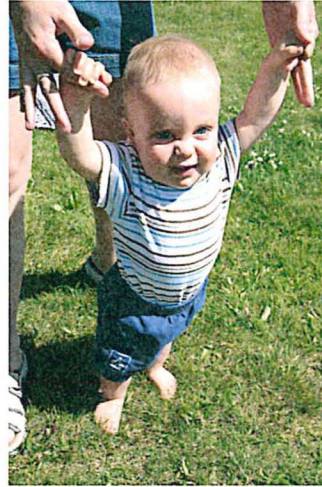
- Promotes manipulation, grasp and release, imitation, social interaction, cause/effect
- Adaptations
 - Decreased grasp: switch modification (ex: a pulley rather than an on/off switch, large buttons)
- Examples
 - Jack in the box
 - Toys that need to be wound
 - Toys with push buttons



(Microsoft Corporation, 2011)

Occupational Activity – Standing

- Promotes strengthening, muscle memory, motor learning, movement initiations, and eventually walking
- While sitting in wheelchair or in a chair, put child on floor and help them pull themselves up into a standing position

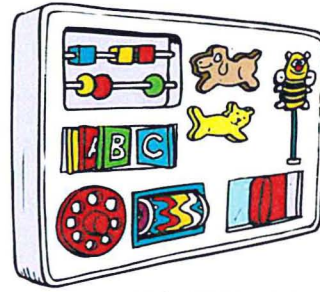


(Microsoft Corporation, 2011)

*Note: make sure child is not going to pinch fingers or fall into wheelchair.

Occupational Activity – Standing Cont.

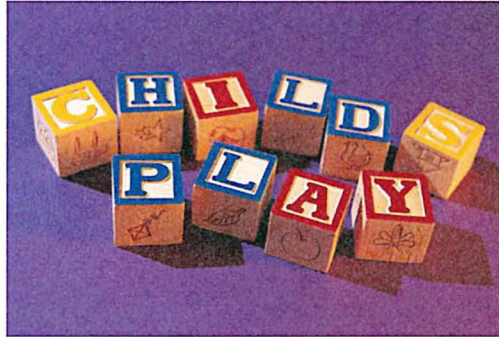
- While standing next to chair or couch, provide toys to manipulate and help increase balance



(Microsoft Corporation, 2011)

PLAY Cont.

- 12 to 18 months
 - Relational and functional play
 - Gross motor play
 - Social Play
- Skills
 - Fine motor
 - Gross motor
 - Cognition
 - Social



(Microsoft Corporation, 2011)

(Case-Smith, 2005)

- *Fine motor: scribbles with crayons, holds and releases toys, stacks blocks, attempts puzzles, opens and shuts containers, points with index finger, uses both hands to play
- *Gross motor: sits in chairs, plays in standing, walks, picks up toys on floor, throws objects, begins to run, pushes and pulls toys
- *Cognition: imitation, understands function and how things work, trial and error problem solving, recognizes names of various body parts
- *Social: moves away from parents, shares toys with parents, facial expressions

Occupational Activity – Musical Instruments

- Promotes grasp, in-hand manipulation, unilateral/bilateral movements, arms to midline, gross motor movements
- Adaptation
 - 1 vs. 2 part instruments
 - Using various tools as substitutes (larger objects instead of small diameter drumsticks)
 - Homemade large "plate" maracas vs. smaller-handled versions



(Microsoft Corporation, 2011)

Occupational Activity – Themed Play-sets

- Promotes attention span, concentration, grasp, goal-oriented actions, cause/effect, sequenced actions, decision making
 - Adaptations
 - Encourage various play activities by asking child to demonstrate tasks/skills, point out objects, etc.
- Examples:
 - Kitchen sets
 - Dollhouse sets
 - Shopping
 - Cars/garage sets
 - Farm sets
 - Transportation sets (airplanes, trains, etc.)



(Microsoft Corporation, 2011)

Occupational Activity – Categorized Puzzles



- Promotes spatial relations, visual perceptual skills, visual motor skills, problem solving, in-hand manipulation skills, trial-and-error, learning acquisition for related objects.
- Adaptations
 - Include child within wheelchair position with utilizing lap tray
 - Utilizing elevated play-pen
- Examples of puzzles:
 - Animal
 - Vehicles
 - Seasons
 - Inset laid puzzles



(Microsoft Corporation, 2011)

PLAY Cont.



(Microsoft Corporation, 2011)

- 18 to 24 months
 - Functional play
 - Pretend or symbolic play
 - Social Play
 - Gross motor play
- Skills
 - Fine motor/manipulation
 - Gross motor
 - Cognitive
 - Social

(Case-Smith, 2005)

*Fine motor/manipulation: simple puzzles, stacks blocks, simple crayon drawing, strings beads, simple tools, multipart tasks, turns book pages

*Gross motor: runs, squats, climbs, uses playground equipment, kiddy car, throws ball, jumps, up and down stairs

*Cognitive: multiple steps, nonrealistic objects to pretend play, object permanence

*Social: expresses affection, emotions, frustration, solitary play laughs at silly things

Occupational Activity – Sandbox



(Microsoft Corporation, 2011)

- Promotes gross motor play, pretend play, use of simple tools, solitary play
- Adaptation
 - Elevated sandbox that a wheelchair can fit underneath
 - Sides high enough so child is safe
 - Can use other sensory objects such as water, rocks, twigs, etc. to pretend play

Occupational Activity – Reading a Book



(Microsoft Corporation, 2011)

- Promotes fine motor, social interaction, and functional play
- Adaptation
 - At this age, child is able to help turn pages
 - Parent may use page turners for decreased grasp or a book stand
 - Child may sit in parents lap to read the book or parent may transfer on chair or child's bed

Occupational Activity – Kiddy Car

- Promotes gross motor play, social play, and leg strengthening
- Adaptation
 - Parent may want to take child to a flat, paved surface (ex: basketball court, driveway)
 - Parent can move around in wheelchair while child uses legs to move car



(Photo Used with Permission)

PLAY Cont.



(Microsoft Corporation, 2011)

- 24 to 36 months
 - Symbolic play
 - Constructive play
 - Gross motor play
 - Social play
- Skills
 - Fine motor/manipulation
 - Gross motor
 - Cognitive
 - Social

(Case-Smith, 2005)

*Fine motor/manipulation: using scissors, tracing, coloring in large forms, draws circles, builds towers, puzzles (4-5 pieces), toys with moving parts

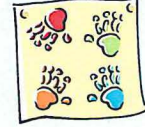
*Gross motor/mobility: rides tricycle, catching large ball, jumps from step to step of small height, hops on one foot

*Cognitive: play scenerios, costumes and imaginative play

*Social/interaction: cooperative play, enjoys friends, shy with strangers, dialog with a few words

Occupational Activity – Tactile Art

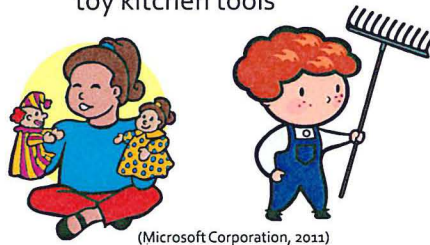
- Promotes tactile sensory development, gross motor movements, motor learning, planning, decision making, imaginary play, spontaneous/unstructured play
- Adaptations
 - Specialized/heightened seating for child to perform at counter-top surfaces, kitchen table, mirrors, etc.
- Examples:
 - Finger painting
 - Clay/play-dough
 - Drawing
 - Shaving cream drawings



(Microsoft Corporation, 2011)

Occupational Activity – Role Play Toys

- Promotes spontaneous play, planning/initiation, thought processing/completion, imaginative play, problem-solving/critical thinking
- Adaptations
 - Use various rooms in the house as well as furniture pieces
 - Encourage child to offer alternative play areas
- Examples:
 - Playing “mom” or “dad” with dolls or tools
 - Using pretend lawn maintenance toys such as mowers, clippers, sprinklers, etc.
 - Playing “restaurant” with toy kitchen tools



(Microsoft Corporation, 2011)

Occupational Activity – Small/Simple Sports

- Promotes fine/gross motor development, hand-eye coordination, balance, bilateral integration, visual motor skills.
- Not concentrating on rules, guidelines
- Examples:
 - Small-version golf sets
 - Basketball ball/hoop
 - T-ball set
 - Soccer
 - Tennis

- Adaptations

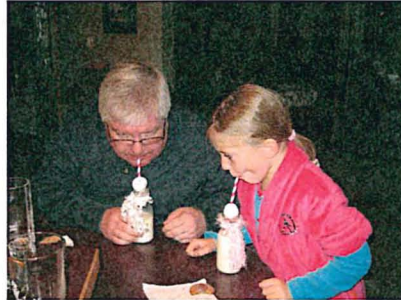
- Use a flat surface to be wheelchair friendly
- Each take turns performing various duties
 - Golfing from wheelchair level
 - Shooting baskets



(Microsoft Corporation, 2011)

Break

Imagination is more important than knowledge.
Knowledge is limited. Imagination encircles the
world.
-Albert Einstein



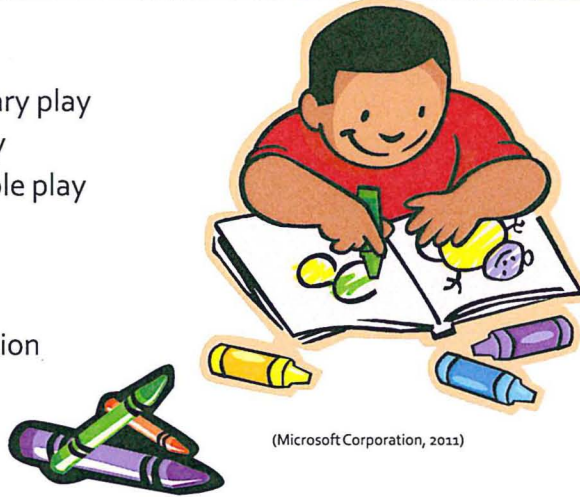
(Photos Used with Permission)



*Hand out "Problem-Solving Exercise" (see Appendix E) & will discuss when participants return.

PLAY Cont.

- 3 to 4 years
 - Complex imaginary play
 - Construction play
 - Rough-and-tumble play
 - Social play
- Skills
 - Fine motor/manipulation
 - Gross motor
 - Cognitive
 - Social



(Microsoft Corporation, 2011)

(Case-Smith, 2005)

- *Fine motor/manipulation: precision grasp, colors in the lines, copies shapes and letters, scissors
- *Gross motor: jumps, climbs, runs, skip, hop, tricycle, stands on 1 foot, jumps down with two feet
- *Cognitive: imaginary objects, dolls and little men play interaction, sorts objects
- *Social: play with others, social conversations, interest in being a friend, same sex playmates

Occupational Activity - Coloring

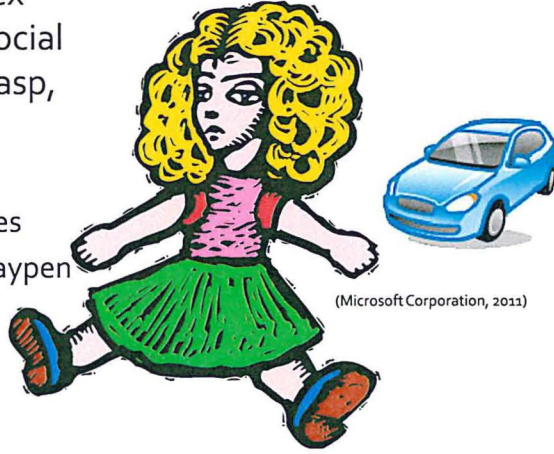


(Microsoft Corporation, 2011)

- Promotes tripod grasp, copying, imagination, and social interaction
- Adaptation
 - Cuffs for holding crayons
 - Use a card table so parent can roll wheelchair close to child
 - Child sits in booster seat

Occupational Activity – Dolls and/or Cars

- Promotes complex imaginary play, social play, precision grasp, and cognition
- Adaptation
 - Built up accessories
 - Using elevated playpen for play area



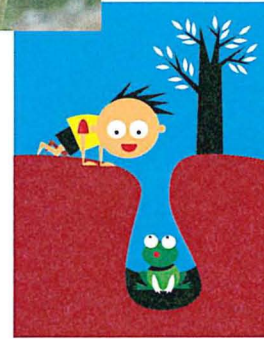
Occupational Activity – “I Spy” Game



- Promotes visual scanning, figure-ground, visual perceptual skills, direction following
- Interactive learning & verbal game that would be appropriate for high-level SCI



(Microsoft Corporation, 2011)



PLAY Cont.

(Microsoft Corporation, 2011)

- 4 to 5 years
 - Games with rules
 - Construction play
 - Social play: dramatic play
- Skills
 - Fine motor/manipulation
 - Gross motor
 - Cognitive
 - Social

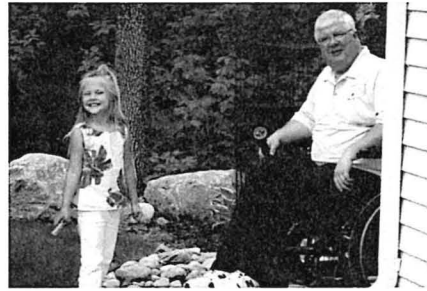


(Case-Smith, 2005)

- *Fine motor/manipulation: tripod grasp, copies simple shapes, puzzles up to 10 pieces, scissors to cut simple shapes, colors within the lines, two handed tasks, drawing, copies own name, strings ¼ inch beads
- *Gross motor/mobility: jumps forward and down, throws ball, hops for long sequences, climbs on playground equipment, throws ball, skips, walks up and down stairs reciprocally
- *Cognitive: understands rules in a game, remembers rules with a few reminders, makes up stories, goal-oriented, cooperative play, plans a play activity, begins abstract problem solving
- *Social/interaction: enjoys clowning, sings whole songs, role plays based on parents' roles

Occupational Activity – Helping in the Garden

- Promotes social interaction/ appropriate turn-taking & following directions, fine motor skills, problem solving
- Adaptation
 - Child can help the parent get to hard to reach areas to water plants
 - Parent would direct and teach child about gardening



(Photo Used with Permission)

Occupational Activity – Helping in the Garden Cont.



(Photo Used with Permission)

Occupational Activity – Dress-up/Pretend Play

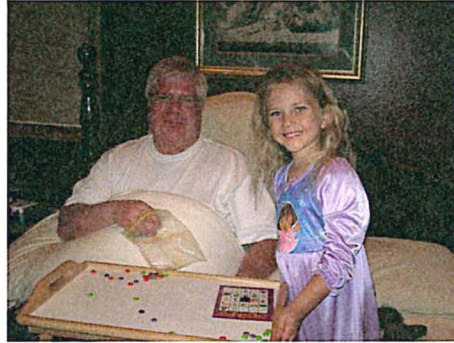
- Promotes coordination, planning, creative thinking, planning, social interaction, fine motor skills
- Adaptation
 - Encourage child to choose various items for parent to wear
 - Decorations for wheelchair
 - Allow child to conduct hair/make-up management or design for parent



(Microsoft Corporation, 2011)

Occupational Activity – Simple Board Games

- Promotes social interaction/
appropriate turn-taking & following directions, fine motor skills, problem solving
- Adaptations
 - Use various settings
 - Enlarged tools/boards, cards, etc.



(Photo Used with Permission)

Occupational Activity – Simple Board Games Cont.

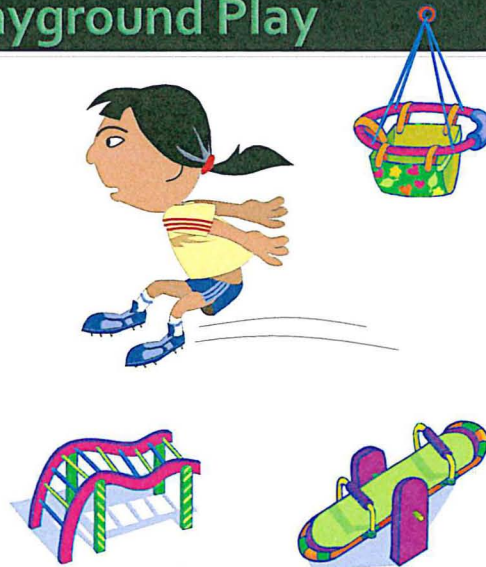


(Photo Used with Permission)

- Examples:
 - Shoots & Ladders
 - Don't Spill the Beans
 - Candyland
 - Start using educational-geared games about spelling, matching, sequencing

Occupational Activity – Obstacle Course/Playground Play

- Promotes social play, gross motor, sequencing, and imaginary play
- Adaptation
 - Use various household objects that are already accessible
 - Relate to imaginary concepts for increased pretend-play
 - Utilize community Universal Playgrounds



(Microsoft Corporation, 2011)

PLAY Cont.



(Microsoft Corporation, 2011)

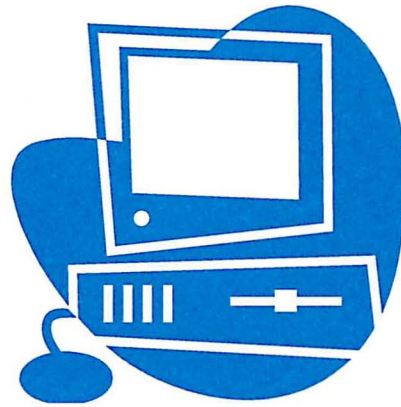
- 5 to 6 years
 - Games with rules
 - Dramatic play
 - Sports
 - Social play
- Skills
 - Fine motor/manipulation
 - Gross motor
 - Cognitive
 - Social

(Case-Smith, 2005)

- *Fine motor/manipulation: cuts with scissors, prints name from copy, copies more detailed shapes, puzzles up to 20 pieces, traces and copies letters, manipulates tiny objects in fingertips without dropping, two handed complimentary movements
- *Gross motor/mobility: hops for long distances, skips, catches ball with two hands, kicks with accuracy, stands on one foot for 8-10 sec
- *Cognitive: figures out simple problems, bases play more on real life, participates in organized games, complex scripts in play, demonstrates deferred imitation
- *Social/interaction: organized, complex games, same sex friends, enjoys singing and dancing, understanding of others' feelings

Occupational Activity – Computer Games

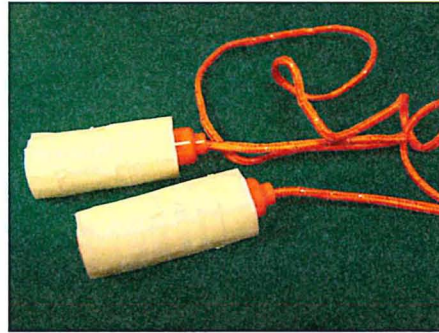
- Promotes games with rules, social play, manipulation, problem solving, organized games, and understanding
- Adaptations
 - Specialized keyboards
 - Joystick or rollerball use
 - Head stick



(Microsoft Corporation, 2011)

Occupational Activity – Jump Rope

- Promotes social play, hopping, balance, participation, social participation
- Adaptation
 - Built up handles for decreased grasp
 - Tie one end of rope to a door or piece of furniture – swing rope while sitting in wheelchair



Occupational Activity – Verbal Storytelling

- Promotes dramatic play, reconstruction of the real world, social participation, problem solving, complex scripts, understanding of feelings
- Adaption
 - Parent can sit in chair or however comfortable
 - Can help child act out story to the best of their ability



(Microsoft Corporation, 2011)

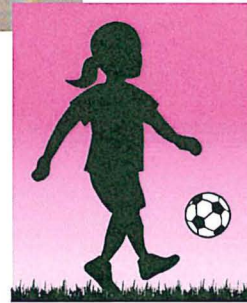
PLAY Cont.

- 6 to 10 years
 - Games with rules
 - Crafts and hobbies
 - Organized sports
 - Social play
- Skills
 - Fine motor/manipulation
 - Gross motor
 - Cognitive
 - Social

(Case-Smith, 2005)



(Microsoft Corporation, 2011)



- *Fine motor/manipulation: good dexterity for crafts and construction, bilateral coordination, precision and motor planning evident in drawing, completes complex puzzles
- *Gross motor/mobility: runs with speed and endurance, jumps, hops, skips, throws ball at long distances, catches ball with accuracy
- *Cognitive: abstract reasoning, mental operations, flexible problem solving, solves complex problems
- *Social/interaction: cooperative, less egocentric, tries to please others, has a best friend, part of cliques, less impulsive and able to regulate behavior, competitive relationships

Occupational Activity – Card and/or Dice Games

- Promotes social interaction/ appropriate turn-taking & following directions, fine motor skills, problem solving

- Adaptations

- Utilize fun/unusual settings in which to play
- Use of adaptive card holder tools/devices
- Use of larger grasp containers to shake dice



(Microsoft Corporation, 2011)



Occupational Activity – Scavenger Hunts

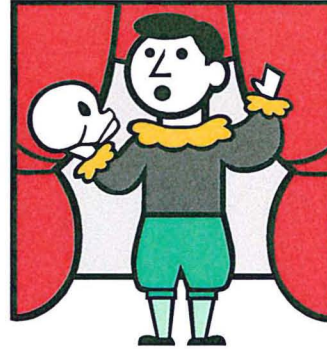
- Promotes social interaction, critical thinking, sequencing, categorization, memory skills, following multiple steps
- Adaptations:
 - Written/verbal directions & clues
 - Task performance steps
 - Utilize various areas throughout the house, garage, yard
 - Go to additional community areas such as public parks, playgrounds, etc.



(Microsoft Corporation, 2011)

Occupational Activity – Play Writing & Acting

- Promotes spontaneous but goal-directed play, planning/sequencing skills, active/gross motor interaction, social skills
- Adaptations
 - Do co-writing to incorporate wheelchair into props used
 - Parent acts as director/producer



(Microsoft Corporation, 2011)

Occupational Activity – Helping in the Kitchen

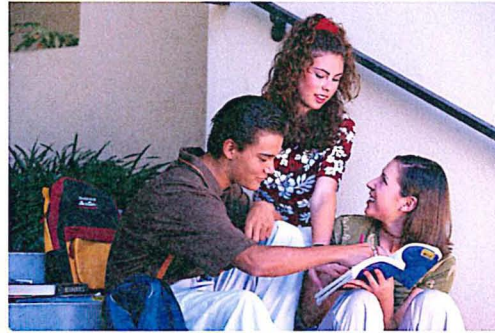


(Photo Used with Permission)

- Promotes social interaction/ appropriate turn-taking & following directions, fine motor skills, problem solving
- Adaptation
 - Place items on a surface that are accessible by a wheelchair

AND BEYOND!

- 10 years and up
 - Focus on developing and using knowledge
 - Child will be more independent in choosing/deciding on personal interests and activities
 - Parents role:
 - Guidance
 - Encourage
 - Support

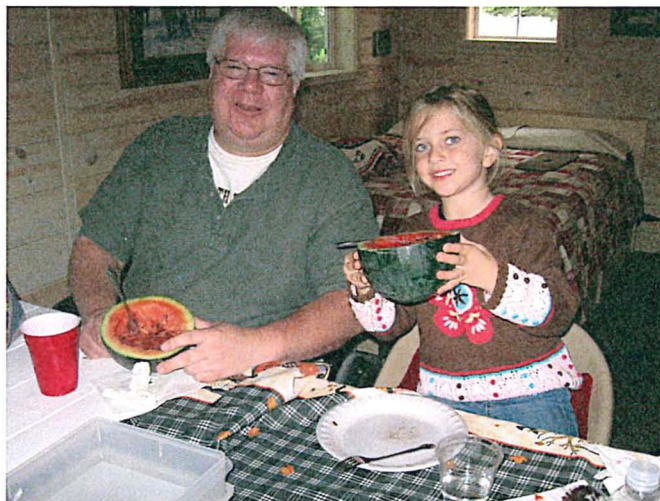


(Microsoft Corporation, 2011)

Summary

- Created a basic understanding of child development and play occupations
- Identified stages of development and types of play in relation to each
- Explored adaptive ideas for interaction with children

QUESTIONS??



(Photo Used with Permission)

Thank you!



(Photo Used with Permission)

"Knowing is not enough; we must apply. Willing is not enough; we must do."

-Johann Wolfgang von Goethe

***Pass out Post-Workshop Questionnaire (see Appendix E) to participants, allow time to complete, and collect before departing.**

References

- American Occupational Therapy Association (2008). Occupational therapy practice framework: Domain and process (2nd ed.). *American Journal of Occupational Therapy*, 62, 625-683.
- Case-Smith, J. (2005). *Occupational therapy for children*. St. Louis, Missouri: Elsevier Mosby.
- Microsoft Corporation (2011). *Images and more*. Retrieved on April 2, 2011 from <http://office.microsoft.com/en-us/images/??Origin=EC790014051033&CTT=6&ver=12&app=powerpnt.exe>

APPENDIX D

Budgeting Spreadsheet Page 2

DEPOSITS								
Date	Deposit #	Description	Amount	Work	Personal Check	Transfer	Returns	Misc
3/5/2010		From Savings	\$ -					
			\$ -					
			\$ -					
			\$ -					
			\$ -					
			\$ -					
			\$ -					
			\$ -					
			\$ -					
			\$ -					
			\$ -					
			\$ -					
			\$ -					
			\$ -					
Total Deposits			\$ -	\$ -	\$ -	\$ -	\$ -	\$ -
OUTSTANDING DEPOSITS								
			\$ -					
			\$ -					
			\$ -					
			\$ -					
			\$ -					
			\$ -					
			\$ -					
Total Outstanding Deposits			\$ -	\$ -	\$ -	\$ -	\$ -	\$ -
Checking Balance								
Banks Balance			Personal Balance					
Beginning Balance				Beginning Balance				
Total Withdrawals	\$ -			Total Withdrawals				
Outstanding Withdrawals	\$ -			Total Deposits				
Total Deposits				Ending Balance	\$ -			
Outstanding Deposits	\$ -							
Ending Balance	\$ -							

RESOURCES

American Spinal Cord Injury Association	http://www.asia-spinalinjury.org/
Center for Paralysis Research	http://www.vet.purdue.edu/cpr/
Center for Spinal Cord Injury - Rehabilitation Institute of Michigan	http://www.centerforscirecovery.org/
Christopher and Dana Reeve Foundation and Paralysis Resources Center	http://www.christopherreeve.org/
Darrell Gwynn Foundation	http://darrellgwynnfoundation.org/
Foundation for Spinal Cord Injury Prevention, Care & Cure	http://www.fscip.org/
International Campaign for Cure of Spinal Injury	http://www.campaignforcure.org/iccp/
Miami Project to Cure Paralysis	http://www.miamiproject.miami.edu/
Mike Utley Foundation	http://www.mikeutley.org/
The Morton Cure Paralysis Fund	http://www.mcpf.org/
National Spinal Cord Injury Association (NSCIA)	http://www.spinalcord.org/
The Paralysis Project of America	http://www.paralysisproject.org/
Paralyzed Veterans of American	http://www.pva.org/

Point of Care, Team-based Information System	http://calder.med.miami.edu/pointis/handbook.html
Sam Schmidt Paralysis Organization	http://www.samschmidt.org/
Spinal Cord and Brain Injury Research Center	http://www.mc.uky.edu/scobirc/
Spinal Cord Injury – For Your Information	http://www.tbi-sci.org/scifyi/
Spinal Cord Injury Information Network	http://www.spinalcord.uab.edu/
Spinal Cord Injury Network International (SCINI)	http://www.spinalcordinjury.org/
Spinal Cord Society	http://www.scsus.org/
United Spinal Association	http://www.unitedspinal.org/
W. M. Keck Center for Collaborative Neuroscience	http://keck.rutgers.edu/

Problem-Solving Exercise

Brain Teaser??

What types of adaptive equipment do you currently own, have you used in the past, or have been introduced to?

AND

What other uses can you think of for these pieces of equipment or what additional daily activities would these help you with?

Additional Notes from Discussion:

Problem-Solving Exercise

Now that we have covered some adaptive activities for birth through 3 years, let's see how YOUR adaptive skills are coming along...

Brain Teaser??

Your 2 year old asks you to play/draw with chalk outside on the driveway. What are some adaptations you can make to this activity to encourage participation for both of you??

Additional Notes from Discussion:

Pre-Workshop Questionnaire

1. Were you a parent prior to your spinal cord injury?

Yes.

No.

2. How much do you currently know about fertility and/or pregnancy options for people with spinal cord injuries?

Very Much

Very Little

3. How comfortable are you with using adaptive equipment for parenting purposes?

Very Comfortable

Not at All

4. How often have you used medical information, books, and/or websites to help you with concerns?

Very Often

Not at All

5. How confident are you today with your ability to be/become a parent?

Very Confident

Not at All

Post-Workshop Questionnaire

1. After today's session, how much do you know about fertility and/or pregnancy options for people with spinal cord injuries?

Very Much

Very Little

2. After today's session, how comfortable are you with using adaptive equipment for parenting purposes?

Very Comfortable

Not at All

3. After today's session, how often do you think you will use medical information, books, and/or websites to help you with parental concerns?

Very Often

Not at All

4. After today's session, how confident are you with your ability to be/become a parent?

Very Confident

Not at All

5. Any additional comments on the presenters' methods of teaching, workshop information, or suggestions for improvement:

Pre-Workshop Questionnaire

1. Were you a parent prior to your injury?

Yes.

No.

2. How much do you know about the importance of play in a child's development?

Very Much

Very Little

3. How much do you know about a child's typical milestones?

Very Much

Very Little

4. How comfortable are you with engaging in play activities with children of all ages?

Very Comfortable

Not at All

5. How comfortable are you with adapting play activities to fit your individual capabilities?

Very Comfortable

Not at All

Post-Workshop Questionnaire

1. After today's session, how much do you know about the importance of play in a child's development?

Very Much Very Little
○ ○ ○ ○ ○

2. After today's session, how much do you know about a child's typical milestones?

Very Much Very Little
○ ○ ○ ○ ○

3. After today's session, how comfortable are you with engaging in play activities with children of all ages?

Very Comfortable Not at All
○ ○ ○ ○ ○

4. After today's session, how comfortable are you with adapting play activities to fit your individual capabilities?

Very Comfortable Not at All
○ ○ ○ ○ ○

5. Any additional comments on the presenters' methods of teaching, workshop information, or suggestions for improvement:

APPENDIX E

I, Martha Schuster, am verifying my legal guardianship of Elizabeth, and give permission for any photos of my child to be used in Laura Gunderson and Ana Sobolik's scholarly project, handouts, presentation, posters, and other related uses.

Martha Schuster
Name

3/25/11
Date

I, Mark Weber, give permission for my photos to be used in Laura Gunderson and Ana Sobolik's scholarly project, handouts, presentation, posters, and other related uses.

Mark Weber
Name

3-25-11
Date

I, Kim Weber, give permission for my photos to be used in Laura Gunderson and Ana Sobolik's scholarly project, handouts, presentation, posters, and other related uses.

Kim Weber
Name

3/25/11
Date

Consent #1

Date: Tue, 01 Mar 2011 09:19:28 +0000 [03/01/2011 03:19AM CDT]
From: Nina Evans <mpsnme@bath.ac.uk>
To: Laura Gunderson <ldgunderson@medicine.nodak.edu>
Subject: Re: Permission to Use Pictures

Dear Laura

Yes it is fine to use them in a powerpoint presentation - please note however that the babycarrier is available for sale currently only in the UK

Regards

Nina

On 28/02/2011 19:17, Laura Gunderson wrote:

Nina,

This picture would be used in a powerpoint presentation designed for parents with a spinal cord injury. As students, we designed a product (a workshop) to be implemented in practice.

Thanks, Laura

Quoting "Nina Evans" <mpsnme@bath.ac.uk>:

Dear Laura

Please can you clarify how you are wanting to use the photographs is it for a paper presentation or will it be published somewhere?

Regards

Nina Evans

Nina Evans

Research Occupational Therapist, Bath Institute of Medical Engineering (BIME)

The Wolfson Centre

Royal United Hospital

BATH

BA1 3NG

+44 (0)1225 824103

www.bime.org.uk

My name is Laura Gunderson, and I am an occupational therapy student at the University of North Dakota. I am currently working on a scholarly project about parenting with a spinal cord injury. I am writing to ask permission to use photos in the "Who's Carrying a Baby?" article, specifically of the wheelchair baby stroller. If you are willing to give permission, please e-mail me at ldgunderson@medicine.nodak.edu

Thank you for your time,

Laura

Consent #2

Date: Fri, 04 Mar 2011 09:14:31 -0500 [03/04/2011 08:14AM CDT]

From: Rochester Review Mailbox <rochrev@admin.rochester.edu>

To: Laura Gunderson <ldgunderson@medicine.nodak.edu>

Subject: Re: Permission to Use Pictures

Laura,

You must be talking about the photo in this article (link below). Yes, you may use it. Please credit: "Photo courtesy of the University of Rochester." If you need a higher resolution, we may be able to get the original image, but it might take a few more days. It goes back a few years.

Good luck with the project!

<http://www.rochester.edu/pr/Review/V64N1/feature1.html>

Best,

Karen McCally

Karen McCally 02 (PhD)

Associate Editor

Rochester Review

(585) 276-3687

kmccally@admin.rochester.edu

On 2/25/11 4:43 PM, "Laura Gunderson" <ldgunderson@medicine.nodak.edu> wrote:

My name is Laura Gunderson, and I am an occupational therapy student at the University of North Dakota. I am currently working on a scholarly project about parenting with a spinal cord injury. I am writing to ask permission to use photos in the "Engineering for the 21st Century" article, specifically of the modified crib for wheelchair access. If you are willing to give permission, please e-mail me at ldgunderson@medicine.nodak.edu

Thank you for your time,

Laura

Laura Gunderson

Master's of Occupational Therapy Graduate Student - Year 3

University of North Dakota

Consent #3

Date: Wed, 16 Mar 2011 09:54:35 -0700 [03/16/2011 11:54AM CDT]

From: ptweedie <ptweedie@tetrasociety.org>

To: Laura Gunderson <ldgunderson@medicine.nodak.edu>

Subject: RE: Permission to Use Photos

Hi Laura,

There's no problem in your using our photos of those devices - actually, we would be more than pleased.

Please let me know if we can do anything else for you.

Best regards!

Pat

Pat Tweedie

National Program Coordinator

Tetra Society of North America

Phone: 604-688-6464 Ext. 108

Fax: 604-688-6463

ptweedie@tetrasociety.org

-----Original Message-----

From: Laura Gunderson <ldgunderson@medicine.nodak.edu>

Sent: Monday, March 14, 2011 12:44 PM

To: ptweedie@tetrasociety.org

Subject: Permission to Use Photos

My name is Laura Gunderson, and I am an occupational therapy student at the University of North Dakota. I am currently working on a scholarly project about parenting with a spinal cord injury. I am writing to ask permission to use photos specifically of the adapted changing table and wheelchair with carrier attached. If you are willing to give permission, please e-mail me at ldgunderson@medicine.nodak.edu

Thank you for your time,

Laura

PS You will be given recognition if you choose to give permission.

Laura Gunderson

Master's of Occupational Therapy Graduate Student - Year 3

University of North Dakota

Consent #4

Date: Wed, 23 Mar 2011 15:11:52 -0400 [03/23/2011 02:11PM CDT]
From: Janelle LoBello <JLoBello@ChristopherReeve.org>
To: ldgunderson@medicine.nodak.edu
Subject: FW: Permission to Use Resources

Hi there Laura,
Thank you kindly for reaching out about the resources. Surely you can use them, we just ask that proper recognition be given with them.

Thank you!
Janelle

Janelle LoBello
Communications Coordinator
Christopher & Dana Reeve Foundation
636 Morris Turnpike, Suite 3A
Short Hills, NJ 07078
(800) 225.0292 ext. 7111 // (973) 379.2690
(973) 912.9433 fax
JLoBello@ChristopherReeve.org

-----Original Message-----

From: Laura Gunderson [<mailto:ldgunderson@medicine.nodak.edu>]
Sent: Tuesday, March 15, 2011 3:44 PM
To: Janelle LoBello
Subject: Permission to Use Resources

Hello,
My name is Laura Gunderson, and I am a graduate student of Occupational Therapy at the University of North Dakota. I am currently working on a scholarly project about parenting with a spinal cord injury. I am writing to ask permission to use two of your resources, "Spinal Cord Injury Videos" and "Parenting with a Disability". This would be used as a handout for a workshop entitled "Parenting With A Spinal Cord Injury." If you give permission, please send an e-mail to ldgunderson@medicine.nodak.edu.

Thanks,
Laura

Laura Gunderson
Master's of Occupational Therapy Graduate Student - Year 3
University of North Dakota

Consent #5

Date: Fri, 25 Mar 2011 10:44:56 -0500 [10:44AM CDT]
From: Sobolik, Ana Grace <ana.sobolik@und.edu>
To: ldgunderson@medicine.nodak.edu
Subject: Fwd: Re: Contact form submission from dizABLED:

Date: Fri, 04 Mar 2011 15:24:26 -0800
From: "John Lytle" <jl@johnlytle.com>
To: ana.sobolik@und.edu
Subject: Re: Contact form submission from dizABLED

Hi Ana,

Please feel free to use the strip. Many happy returns,

JOHN R. LYTLE

On Mar 4, 2011, at 12:35 PM, ana.sobolik@und.nodak.edu wrote:

I am sending this in hopes of it reaching John Lytle. I am an occupational therapy student currently in a master's program and completing my scholarly project towards my master's degree. I am creating a workshop to be offered to individuals with spinal cord injuries, and was browsing for positive and appropriate comic strips to include in my presentation. I loved your work and would appreciate the approval to incorporate it into my project.

I would appreciate a response as soon as you are able, as I am on a timeline; but also understand you are busy and am grateful for your time.

Sincerely,
Ana Sobolik

From: Ana Sobolik, Occupational Therapy Student
Email: ana.sobolik@und.nodak.edu

APPENDIX F

Presenter(s)

(PRESENTERS NAME,
CREDENTIALS)

- (PRESENTORS
BACKGROUND
INFORMATION)

(OPTIONAL)

(PRESENTERS NAME,
CREDENTIALS)

- (PRESENTORS
BACKGROUND
INFORMATION)

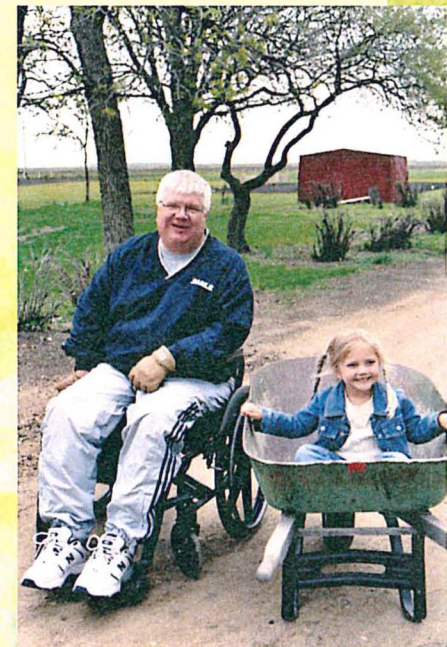
(INSERT COMPANY NAME)

Phone: (INSERT NUMBER)

(ADDRESS LINE 1)
(ADDRESS LINE 2)
(CITY, STATE, ZIP CODE)

(INSERT WEBSITE)

Living with a Spinal Cord Injury: A Workshop for Parenting and Play



(Photo Used with Permission)

Information



(INSERT ORGANIZATION LOGO)

- This 2-part workshop was specially designed for people with a spinal cord injury (SCI) that are parents or thinking of becoming parents in the future.
- The purpose of this workshop is to reduce the fears of parents with a SCI through addressing primary concerns and adapting the environment.
- Special emphasis is placed on adapting children's play activities so the parent can directly interact and participate with their child.

Schedule

(INSERT DATE HERE)

DAY 1

- 8:30-9:40 – Planning, Fertility and Pregnancy, Returning to Parenting
- 9:40-10:00 – Break
- 10:00-11:10 – Adaptive Equipment, Psychological Impact, Family Roles
- 11:10-11:30 – Break
- 11:30-12:00 – Resources, Wrap-up

(INSERT DATE HERE)

DAY 2

- 8:30-9:30 – Introduction, Theory
- 9:30-10:00 – Break
- 10:00-11:10 – Adapted Activities: Birth to 3 years old
- 11:10-11:30 – Break
- 11:30-12:00 – Adapted Activities: 3 Years old to 18 years old – Wrap-up

Location and Accommodations



(Photo Used with Permission)

The workshop will be located at
(INSERT LOCATION)
(ADDRESS LINE 1)
(ADDRESS LINE 2)
(CITY, STATE, ZIP CODE)

This is an accessible location. If you have any other accommodations or questions, please feel free to contact (INSERT PRESENTERS) at:
(PHONE NUMBER)

APPENDIX G

Workshop Implications & Considerations

When conducting this workshop it is important to remember the following for both parts 1 & 2 of the workshop in consideration of the population attending:

- Choosing appropriate dates & times:
 - Recommended that both parts of workshop are offered within the same month or 2-3 week time period
 - Most optimal situation would be a weekend course with both parts
 - Time periods for each part of the workshop average 3-4 hours; depends on attendance, involvement/participation of attendants
 - Decisions should be made on whether morning/afternoon sessions would fit more appropriately with schedules of population.

- Choosing the location:
 - When deciding upon facility appropriate for population. Consider the following:
 - Accessibility (both inside and outside of building)
 - Set-up/layout of building and location of the room used within the building
 - Centralized location (in relation to public transit, accessible streets/sidewalks, level of traffic, parking capabilities, etc.)
 - Technology capabilities/options for method of presentation
 - Adequate space/layout of room to be used (consider handicap accessible tables)

- Additional Considerations:
 - Providing rest breaks/restroom breaks
 - More frequent
 - Longer duration
 - Encourage attendants to take as needed throughout session
 - Encourage attendants to reposition/provide pressure relief as needed
 - Bringing support system
 - Encourage attendants to bring significant others, partners, friends, and/or family with them to assist with transfers in/out building, restroom breaks, asking questions, voicing concerns, writing/taking notes, etc.