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Mothers with Disabilities: Dispelling the Myths

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MOTHERS WITH DISABILITIES:
DISPELLING THE MYTHS

by

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This Scholarly Project Paper, submitted by Sarah Churchill 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.

Jan Stube

Faculty Advisor

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Date

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CHAPTER I

INTRODUCTION

The majority of women, including myself, hope to someday have a child and become a mother. For many of us, this dream was well-established in our minds as, young girls, we would play with dolls or play “house” with friends, imagining what it would be like to be a parent someday. Envision, however, yourself at twenty years of age, being involved in a motor vehicle accident that left you with a traumatic spinal cord injury and in a wheelchair for the rest of your life. Would that dream of someday having children and becoming a mother simply vanish because you now had a disability?

Like so many women with disabilities, whether they had the disability as a child or acquired it later in life, their desire to have children and become a mother does not simply disappear because they have a disability. Yet the messages these women receive from much of society, including the health care community, is often that it would be irresponsible of them to follow through on this dream since they will be unable to make an adequate parent due to their disability.

This is one of numerous misconceptions regarding women with disabilities and their ability to parent. Misunderstandings have led to these women being discriminated against in society, including by the health care professionals themselves. According to Kirshbaum (as cited in Alexander, 2002) women with disabilities wishing to have children experience a “lack of respect and understanding from medical professionals” (p. 25). Many of these women are encouraged to have an abortion or give their child up for

adoption by their health care providers (Blackford, Richardson, & Grieve, 2000; Killoran, 1994; Kirshbaum, 1988; Kirshbaum & Olkin, 2002). For several other women, the issue of pregnancy and birth control is never brought up in conversation by the health care staff, implying to these women that they should not even consider the possibility of becoming a parent (Killoran, 1994). The negative messages these women receive from the health care community can be detrimental and undermine their confidence and self-esteem in being a parent with a disability (Kirshbaum, 1988).

Despite these negative messages, however, there have been more and more women with disabilities deciding that they too should have the right to have children (Royal College of Midwives (RCM), 2000; Kocher, 1994). According to a 1993 Survey of Income and Program Participation, about “11% of all American families are parented by one or two parents with disabilities” (Kirshbaum & Olkin, 2002, p. 65). Much of this has to do with women with disabilities living longer and more fulfilling lifestyles due to advances made in medicine (Blackford, Richardson, & Grieve, 2000; Grue & Lærum, 2002). Another factor is the Disability Rights movement followed by the Americans with Disabilities Act, which has made it more acceptable and accessible for individuals with disabilities to have the same rights as those individuals without disabilities (Grue & Lærum, 2002; Kocher, 1994).

As more and more women with disabilities decide that they want to have children, the number of healthcare professionals working with these individuals may also increase. As a result, it is imperative that the health care community take an active role in looking at ways they can educate their employees regarding the capabilities women with disabilities have as parents, and examine how they can professionally interact with women with disabilities who either are, or wish to become, parents.

Therefore, in order to meet this critical need I have developed an educational Microsoft® PowerPoint® presentation for my scholarly project that can be shown to healthcare professionals, particularly occupational therapists, who would be working with this population. In this educational presentation, which is based on the available literature, the stereotypes and misconceptions regarding parenting with disabilities will be revealed, along with taking a closer look at the detrimental effects that occurs to clients when healthcare providers question a disabled woman's choice and ability to have children. It will then look at how healthcare providers can overcome these biases and relate professionally towards their clients.

To guide the development of this scholarly project, the theme "client-centered practice" was utilized. Client-centered practice was chosen due to the fact that several of the different healthcare professions are familiar with this term, particularly within the profession of occupational therapy (Restall, Ripat, & Stern, 2003). The main theme of client-centered practice is that healthcare professionals are to be respectful to all clients and to the choices that the clients make (Law & Mills, 1998). This means that if a woman with a disability wants to have a child, then the healthcare professionals need to be respectful of her choice. Further, in the occupational therapy literature, client-centered practice means that the client chooses what occupations he/she would like to work on in therapy (Law & Mills, 1998). According to the American Occupational Therapy Association (AOTA, 2002), the occupation of childrearing, and how a patient performs their life roles, such as the role of parenting, are considered a domain of concern for occupational therapists when working with their clients. Therefore, occupational therapists, in particular, need to be respectful of a woman with a disability who wants to have children in order that they may assist her in fulfilling her occupation of childrearing and help her attain satisfaction in her parenting role.

Despite the fact that healthcare professionals understand what client-centered practice is, many of them find it difficult to adhere to. Often times, this is because the clinician's own values and beliefs are in contradiction with what their client wants and/or needs. According to Restall et al. (2003), "clinicians' behaviors in therapeutic situations are shaped by ingrained beliefs about the world and people" (p. 105). This indicates that healthcare professionals who do not believe women with disabilities can adequately care for their children will, as a result, have great difficulty being respectful towards these woman clients. This may then result in discriminatory actions upon the part of the healthcare professional, either overtly through words and actions, or inadvertently such as simply not bringing up the subject of pregnancy to women who have disabilities.

As a result, it is obvious that in order for healthcare professionals to be client-centered and to be respectful towards their women clients who wish to have a child despite their disability, that they be educated on the numerous misconceptions that are present regarding parenting with a disability and the capabilities that these women have as mothers. As it was stated by Expert Maternity Group in the report Changing Childbirth (as cited in Goodman, 1994, p.228), a lack of education only gives rise to the "prejudice and ignorance of ablebodied professionals". Thus, the educational presentation I have developed for this scholarly project will addresses these highly significant issues in an effort to change the beliefs and attitudes held by many healthcare professionals regarding women with disabilities having children.

Although both men and women with disabilities can face stigmatization by society and healthcare professionals regarding their ability to parent and raise their children, I have chosen to focus the literature review and educational PowerPoint® presentation mainly on the challenges that women with disabilities face in their choice to have children. This was

done primarily because most of the literature found pertained to women with disabilities, but also because women are still considered the primary caregivers when it comes to caring and raising children. Therefore, although the focus of this scholarly project will be primarily on women, it is important to note that these same experiences can happen to men also, and that the adaptive strategies and adaptive equipment mothers with disabilities use for the care of their children can also be applied to fathers with disabilities.

The next chapter consists of the comprehensive literature review that was conducted concerning parenting with a disability. This will be followed by the methodology undertaken to create the product in Chapter III, the actual educational Microsoft® PowerPoint® presentation developed in Chapter IV, and a summary of the findings and areas where more research on this topic is needed will be presented in Chapter V.

CHAPTER II

REVIEW OF LITERATURE

One of the most significant life activities of adulthood is that of becoming a parent and raising a family (Alexander, Hwang, & Sipski, 2001). Farber (2000) states that parenting is a fundamental human occupation, one which gives that individual a great sense of personal meaning. It is often identified as a “life ‘marker’ [as it indicates the] transition from childhood to adulthood” (Llewellyn, 1994, p. 174). Theorist Erick Erikson believed that by being a parent an individual was able to fulfill the stage of generativity vs. stagnation (Peterson, 1993).

For the majority of women, deciding to have a child is an “unquestionable right” (Killoran, 1994, p. 122). However, this is not true for women with disabilities who often have to justify their decision to have a child, many times to the healthcare professionals themselves (Killoran, 1994). Women with disabilities are viewed by much of society as ‘unfit’ to parent and it is often thought that their children will have a host of problems because of the parent’s disability (Buck & Hohmann, 1981; Killoran, 1994). Unfortunately, these, and other stereotypes surrounding women with disabilities as mothers remain present in society today, despite growing research that indicates otherwise.

The following review of the literature will address the negative stereotypes faced by women with disabilities and the current research that contradicts those popular beliefs. Next it will focus on the attitudes demonstrated by health professionals and how these attitudes can affect the woman client who is, or is contemplating, having a child. Finally, it will focus

more specifically on the part occupational therapists can play in helping these mothers identify compensatory techniques and adaptive equipment that will make parenting for them as successful as possible. In conclusion, the literature will reveal why health professionals, especially occupational therapists, should not only be respectful, but assist these mothers in their choice to have and raise a family.

Stereotypes

Health Professionals

According to Kirshbaum and Olkin (2002), “Parenting has been the last frontier for people with disabilities and an arena in which parents are likely to encounter prejudice” (p. 67). Prejudicial attitudes and stereotypes toward parenting with a disability are embedded as much in society as they are in the medical community and among the healthcare professionals themselves whom these women are turning to for support and guidance. In fact, within the healthcare community itself it is extensively believed that if a parent has a disability the children will be adversely affected, a result of the limitations that are placed on the parent’s ability to function because of their disability (Buck & Hohlmann, 1981 as cited in Kirshbaum and Olkin, 2002).

As a result of this belief, it is not uncommon for a woman with a disability to have her parenting ability questioned by the medical staff (Blackford, Richardson, & Grieve, 2000; Killoran, 1994; Kirshbaum, 1988; Kirshbaum & Olkin, 2002). In fact, the majority of healthcare professionals, when they learn that a woman with a disability wants to have a child, do not believe she has thought through her decision and, therefore, feel they must warn her of the problems she will face in the future and discuss ‘other’ options.

In a survey done by Maternity Alliance, which is an organization based in London, England supporting parents with disabilities, more than 1/3 of the mothers surveyed reported

that they had been advised not to have their child (Goodman, 1994). A different survey conducted by Through the Looking Glass, a major organization in California that addresses the rights of parents with disabilities, found that the majority of the women had been pressured at some point during their pregnancy to either have an abortion, tubal ligation, or give their child up for adoption because of their disability (Kirshbaum & Olkin, 2002). Killoran (1994) described a nurse practitioner who repeatedly asked his expecting patient, who had a disability, if she knew what she was getting into by having this child, and then explaining to her over and over again how difficult it was going to be for her to raise this child. Yet research reveals that the majority of women with disabilities carefully consider all potential problems and consequences of having a child before they become pregnant (Killoran, 1994; Royal College of Midwives (RCM), 2000). Killoran (1994), as a mother with a disability, mentioned how she and other women with disabilities that she knows, “think extremely carefully before becoming pregnant” (p. 126). So why are healthcare professionals so against the idea of a woman with a disability having children? In order to understand their views it is necessary to take a closer look at the societal stereotypes and misconceptions surrounding women with disabilities as mothers.

Child Development

Society typically views the children who are raised by a parent with a disability as the ‘victim’ in the situation (Kirshbaum & Olkin, 2002). The children are thought to be adversely affected in a number of ways including their personality, interests, the parent-child relationship, and even their sex-role orientation according to literature written before 1980 (Buck & Hohmann, 1981). Early literature supported many of these notions; however, the research was based upon speculation, lacked substantial evidence, and did not use control

groups (Buck & Hohmann, 1981). More recent literature regarding parenting with a disability has been unable to support these beliefs.

A quantitative study conducted by Alexander, Hwang, and Sipski (2002) looked at 88 mothers with a spinal cord injury, their partners and children, and compared them with 84 non-disabled mothers, their partners and children. They concluded that there were no significant differences between the two groups of children in regards to their behavior, affect, or cognition. The study also did not find any significant differences in psychological symptoms between the two groups of children nor any significant difference in the degree of problems the children had with their mothers. Both the children whose mothers had a spinal cord injury (SCI) and the children whose mothers were able-bodied reported that they were satisfied with the parent-child relationship. The results from this study indicated that mothers with a disability do not negatively impact their children in areas of “individual adjustment, self-esteem, attitudes toward their parents, gender roles, or family functioning” (Alexander et al., 2002, p. 28).

Another study conducted by Buck and Hohmann (1981) compared the effects of children who had been raised by a father with a SCI and children who had been raised by an able-bodied father. The results from their study found there was no differences in sex-role orientation between the two groups of children. In addition, both groups of children described their fathers as being more loving than they were rejecting.

Another societal belief is that children will be negatively affected and limited in the number of activities they can participate in due to their parent’s disability. However, in the study conducted by Buck and Hohmann (1981), there were no significant differences between the amount of time the fathers spent with their children or the time spent together on leisure activities. A different study by Westgren and Levi (1994) found mothers with a

spinal cord injury did not perceive that their children had been deprived of participating in normal activities as a result of their disability. In fact, Kocher (1994) described how one mother, confined to a wheelchair, had allowed her daughter to participate in “gymnastics, ballet, swimming, piano lessons, and Girl Scouts” (p. 130). Results from these studies indicate that there are few differences between children raised in a family where the parent has a disability compared to children raised in a family where the parent is able-bodied.

Another aspect of child development which is often overlooked is that of mutual adaptation. A study done by Through the Looking Glass found that babies adapted very quickly to their mothers with a disability (Kirshbaum, 1988). This behavior occurred early and naturally in infants, and was described as a mutual process in that both the mother and the child adapted and learned together (Kirshbaum & Olkin, 2002). An example of this process was described by Kirshbaum and Olkin (2002) where a mother with paraplegia gave her infant light tugs on his clothing to signal that she was going to pick him up and in response the baby would curl up in a ball so that the mother could best lift him.

In addition, work done by Through the Looking Glass found that “babies of disabled parents [often made] early distinctions between able-bodied and disabled parents, [often] behaving less cooperatively, exhibiting fewer adaptations, with able-bodied caregivers” (Kirshbaum, 1988, p. 10). As an example, a baby had learned to lie very still while his blind father diapered him, yet was restless when his sighted mother did the diapering (Kirshbaum, 1988).

Farber (2000) points out that every family has their own unique way of adapting to the parent’s disability. One of the ways this is often done is by simply changing some of the role obligations (Quigley, 1995). As an example, a mother with a spinal cord injury delegated more of the disciplinary role of parenting to her husband since she was physically

unable to make her child go to his room when he misbehaved. Tuleja and DeMoss (1999) found that for many families in which one of the parents had a disability, the spouses work together as a team to meet the needs of their child. This adaptation process that occurs in the parent-child relationship and the family as a whole reflects what Kirshbaum and Olkin (2002) hypothesized regarding how the parent's disability becomes naturally "incorporated into the family's ways of doing things" (p. 74).

Parentification

Another misconception found in larger society and by many health professionals is that as a result of the mother's disability, the child will be forced to assume the responsibilities that the adult should be doing, a term called 'parentification' (Olkin, 2000 as cited in Alexander et al., 2001 p. 26). It is assumed that the child will be performing a variety of household and care giving tasks at a young age, which are beyond his/her age level (Cohen, 1998 as cited in Kirshbaum, 2002). Despite this widely held belief, in actuality, quite the opposite occurs.

First and foremost, mothers with disabilities do not want their children to view them as being 'needy' or 'dependent', and will, therefore, refrain from asking them to do too many tasks (Quigley, 1995). Another reason is that many mothers with disabilities are afraid that others will think they are taking advantage of their children if they ask them to help with everyday household chores (Grue & Lærum, 2002). Although most able-bodied parents have their children learn responsibility by helping with small jobs around the house, when a parent with a disability asks the same thing of their child it is seen by society much differently (Grue & Lærum, 2002). This fear of being seen as someone taking advantage of their children is genuine. One mother with a disability had someone tell her that it must be nice "to have an assistant around the house" when they noticed her child was performing an

“ordinary household chore” (Grue & Lærum, 2002, p. 679). In a study done by Cohen (as cited in Kirshbaum & Olkin, 2002), parents with a disability were reluctant to ask their children to do even a simple task like taking out the garbage.

However, this unwillingness to have their children help with anything can backfire. One mother with a disability, who had done so well at not asking her child to help with anything at home, was contacted by the school because her child was ‘lazy’ and was not helping to clean-up at school (Grue & Lærum, 2002). Several of the mothers in the study done by Grue and Lærum (2002), found it difficult to keep the balance of wanting to teach their children responsibility, and yet not appearing to others as though they were taking advantage of their children. Mothers in the study also commented how “even if other people shared their opinions about how important it is for children to have certain obligations, they somehow considered it differently when the child helped a disabled mother rather than a non-disabled mother” (Grue and Lærum , 2002, p. 679).

Safety

Perhaps one of the biggest reasons that healthcare professionals are not enthusiastic about a woman with a disability having a baby is that they are concerned about the safety of the child. For health professionals, they have a responsibility to make sure a patient is safe before they can return to their home environment, likewise, an innocent child should not be put in danger. The problem with this thinking is that larger society and health professionals severely underestimate the woman’s skills and determination to be a parent. While it is true that a mother with a disability may not be able to intervene as promptly or as adeptly as ablebodied mothers if their child is in danger (Grue & Lærum, 2002), it is also true that these mothers have found ways that will allow them to care for their children while keeping them safe.

Grue and Lærum (2002) described how one mother, constrained to a wheelchair, allowed her children to have fun at the beach, and yet protected them from drowning, by tying a long rope to her children and to her wheelchair. Although to others this may have seemed cruel, the mother was thinking foremost about the safety of her children while she let them have fun. Other parenting adaptations are expressed in the literature. Kirshbaum (1988) described how using a frontpack could allow a mother with a severe disability to safely hold her child, and Kocher (1994) identified how a parent with a visual impairment could identify where their child was by tying little bells to the child's shoes.

Children can also be taught commands that will help keep them safe. Kocher (1994) described how a mother with quadriplegia taught her child at a young age how important it was to follow her directions. As a result, this mother was able to take her daughter with her to numerous places knowing she would be safe. It is also important to keep in mind that children of able-bodied parents have occasional accidents and get hurt (Grue & Lærum, 2002). Therefore, we, as society, should not be all condemning when this happens to a parent who has a disability.

Changing Perceptions

Different is O.K.

Aside from the stereotypes and misconceptions, healthcare professionals lack visible images of parents with disabilities effectively caring for their children. They often find it “hard to envision the situation of a disabled person caring for a dependent baby” (Kirshbaum, 1988, p. 9). According to Tuleja and DeMoss (1999), although the number of families where at least one of the parents is disabled has been increasing, it is still relatively rare to see and observe a parent with a disability in the community, let alone observe how

they raise and care for their child. As a result, larger society and health professionals do not realize the capability women with disabilities have as mothers (Kirshbaum, 1988).

When a mother has a disability, the parenting tasks often need to be changed or altered to allow successful care of the child. Yet just because a mother with a disability does things differently than an able-bodied mother does not make them any less correct. Killoran (1994) summarized this point when she stated, “Disabled mothers have special ways of caring for [their] children which may look unbearably awkward or slow” (p.123).

Often, childcare tasks do take much longer to complete for a parent who has a disability. For instance, it took one mother with cerebral palsy 20 minutes to change her child’s diaper (Kirshbaum & Olkin, 2002). Despite this extended length of time the mother found it to be a wonderful interaction time to spend with her child, and the child did not appear to mind the length of time this took. Another mother with a visual impairment had to walk to all of her destinations instead of driving (Kirshbaum & Olkin, 2002). Although many would view this as being burdensome, this mother found the walks to be an enjoyable time spent in conversation with her child.

Benefits to the Children

In addition to disputing the belief that children raised by a parent with a disability are adversely affected, the literature supported several ways in which children can benefit from being raised by a parent with a disability. Perhaps the most important is that the children do not consider their parent’s disability to be of any great significance. A study done by Through the Looking Glass discovered that children who are raised in a family where one or both of the parents has a disability consider their parent’s disability normal and are very accepting of it (Kirshbaum, 1988). One young child in this same study even stated that she wanted to be just like her mom, in a wheelchair someday. A different study done by

Westgren and Levi (1994) found that ten out of ten of the children felt that their mom was not different from other moms simply because she had a disability.

In addition, oftentimes these children will have a much greater sensitivity to the needs of others as a result of living in a family in which one of their parents had a disability (Alexander et al., 2002). Buck and Hohmann (1981) discovered that children raised in a family where the dad had a SCI held more positive attitudes towards their father, and were more helpful than the children raised in a family where the dad was able-bodied.

Benefits to the Mothers

Much of larger society, including the healthcare professionals, cannot imagine why a parent with a disability would even consider having a child knowing all the extra difficulties they are sure to encounter as a result (Killoran, 1994). Yet the comments made by mothers who have disabilities do not reflect those negative views. These mothers related how having their child was the best thing that ever happened to them (Grue & Lærum, 2002) and that, despite their disability, they never regretted their decision to have a child (Kocher, 1994). Perhaps this is because mothers with a disability view their parenting role differently than much of the able-bodied culture. This was noted by several mothers including this mother's comment in Kocher (1994):

If we cannot run, chase, throw balls, read the books, or hear the songs of our children, we are made to feel we are not as good a parent as an able-bodied person. This is not true. The essence of parenting is the emotional caring, commitment and closeness, and the guidance and values the parent gives to the child. We can arrange for others to do the physical activities we cannot do. (p.130)

Another mother made the comment, "There's no difference between me and 'Joe Blow' over there, except for I have a little disability. But the disability does not stop me from being

the parent that I am – the good parent that I am” (Farber, 2000, p. 264). Further, Kocher (1994) stated that it is “our relationships with our children [that are] the essence of our parenting, not our physical abilities” (p. 128). Finally, the mothers also described how being able to meet the challenges of parenting associated with their disability gave them a great sense of pride (Farber, 2000).

Mothers in a study by Grue and Lærum (2002) made several comments regarding how having their children benefited them. Several women identified how having their children gave them back the sense of being a woman again; whereas before they had felt like they had no gender and were simply a person with a disability. Other women identified how having their children helped them change how they perceived their bodies. Instead of their body being viewed solely as something that was wrong with them and that doctors could not fix, their body was transformed into something special that had carried their child.

For many women, having a child meant that they felt included to some extent for the first time. No longer were they seen as simply an individual with a disability, but by having their child it made it possible for these women to “‘become known’, not as a disabled woman, but as a mother” (Grue & Lærum, 2002, p. 676). They were able to become included in community activities through their children, and found commonalities with other parents when discussing raising their children (Grue & Lærum, 2002). Farber (2000) noted that mothers with disabilities have many of the same problems raising their children that mothers without a disability have. As an example, one mother in his study stated how relieved she was to find out that other mothers, who did not have a disability, were also having difficulty getting enough sleep after their baby was born (Farber, 2000).

Barriers Facing Women with Disabilities

Despite facing mixed messages, negative stereotypes, and misconceptions from society and the health professionals, women with disabilities also must deal with a lack of knowledge about specific pregnancy and parenting issues from the medical community. According to Blackford et al. (2000), there is a lack of information available to women with disabilities regarding parenting. This was also noted in a survey done by Maternity Alliance where most of the information the women received about having a baby was very general and did not apply to their specific disability (Goodman, 1994). This lack of knowledge by the health professionals was very frustrating for these women. One mother made the comment, “I don’t trust most medical professionals” (Blackford et al., 2000, p. 901), as a result of not receiving adequate advice during her pregnancy. Another mother stated how she “never expected to find such ignorance of [her] condition amongst the medical professions” (Goodman, 1994, p. 227). As a result of the lack of appropriate information women with disabilities receive from much of the medical community many of them end up having to figure things out by themselves (Goodman, 1994). One mother in a study done by Goodman (1994) described her frustration with the health professionals:

Visits from the occupational therapist, midwife, and health visitor discussed briefly how I might manage with lifting, but no one really considered how serious difficulties might be until after the baby was born. I felt I had to ask and work most of it out for myself. (p. 227)

Another disadvantage women with disabilities face is the fact that they have so few role models and other parents like themselves to whom they can talk (Hanna & Edwards, 1988; Kirshbaum, 1988; Kirshbaum & Olkin, 2002; RCM, 2000). One mother who used a wheelchair stated how she had attended numerous events for parents, yet she had only met

one other parent with a disability (Kocher, 1994). According to Kirshbaum and Olkin (2002), there is also a significant lack of media images depicting parents with disabilities. Rarely does an individual see television shows or parenting magazines featuring a parent with a disability caring for his/her child. This lack of role modeling hinders a parent's ability to learn a variety of parenting techniques that could be beneficial to them in caring for their own children (Kirshbaum & Olkin, 2002). As a result, it is even more necessary that parents with disabilities are receiving the help that they need from the healthcare professionals.

Challenging the Perceptions of Health Professionals

As the literature points out, parenting with a disability can be challenging, yet effective and beneficial for both the child and the parent. As in any health professional-client relationship, communication and rapport are paramount to effective outcomes. Therefore, it should not come as a surprise that "the attitudes demonstrated by health professionals can greatly affect the quality of care experienced by disabled women" (RCM, 2000, p. 46). As may be expected, if a health professional questions the capabilities a parent with a disability has in caring for his/her child, the parent will become very offended (Kirshbaum, 1988). Kirshbaum (1988) pointed out that when health professionals, in particular, do not express confidence in the disabled parents' ability to adequately care for their child the parent experience a loss in their self-esteem. A study by Westbrook and Chinnery (as cited in Farber, 2000) found that the women had feelings of guilt about wanting to have a child and misgivings about their ability to parent as a result of having their parenting ability questioned by others.

However, Tuleja and DeMoss (1999) found that health professionals who recognized the rights a woman with a disability has in caring for her child, and who believed in her abilities, greatly increased the woman's self-confidence in being a parent with a disability.

In one of the studies done by Through the Looking Glass, they found that occupational therapists who expressed a positive attitude toward their female client with a disability having a child was seen as “refreshing because such a response to their parenting [had] been so rare” (Tuleja & DeMoss, 1999, p. 75).

In order for health professionals to do this, however, they must first question their own beliefs. One individual who worked in the health field stated, “many of us, especially those who work in maternity where the focus is so much on the elimination of the “abnormal”, are challenged by the idea of disabled people having children” (Goodman, 1994 p. 228). However, the current literature does not support the notion that a woman who has a disability will make an unfit parent, or that her children will be negatively affected. In addition, research has found that parents may have difficulties in their role if there was ever any physical, sexual, or substance abuse in the parent’s past; simply having a disability is not an indicator (Kirshbaum & Olkin, 2002).

Llewellyn (1994) noted that many health professionals need to question what they believe to be satisfactory or unsatisfactory parenting. According to a study done by Espe-Sherwindt (as cited in Llewellyn, 1994), what health professionals consider to be proper parenting is based upon their own unique personal experiences, either of being a parent themselves or recalling how their own parents had raised them. Only when health professionals can question and reflect upon their own beliefs regarding what adequate parenting is, can they be fully accepting of the woman client with a disability who either wants, or is already, a parent.

The Role of the Occupational Therapist

Adaptive Techniques

Occupational therapists, in particular, can play a key role in assisting the disabled mother or

expectant mother by teaching her techniques and adaptations she can use to enhance the care of her child. Kirshbaum and Olkin (2002) described the scenario of a mother who had quadriplegia and had her child taken away from her at birth. During visitations with her child, no one had ever assisted her in being able to care for or interact with her child so the mother just sat there. Due to the ignorance of those involved in the case, they assumed that this mother was “disinterested, psychologically incapable of attachment, and that care was physically impossible” (Kirshbaum & Olkin, 2002, p. 71). However, when a clinician from Through the Looking Glass came in and showed the mother a video of other mothers with physical disabilities caring for their children, she wanted to know how she could care for her baby. With some adaptive strategies, the clinician made it possible “for the mother to hold and feed her baby for the first time, and she immediately engaged lovingly with her baby” (Kirshbaum & Olkin, 2002, p. 71).

Occupational therapists need to look at teaching mothers compensatory techniques and strategies that will allow each mother to effectively interact and care for her child. Examples may include simply holding the child or infant in a different position so that the mother can best feed her baby (Tuleja & DeMoss, 1999); teaching the mother how to cue her child to lift his bottom when the parent is changing his diaper (Tuleja & DeMoss, 1999); or teaching the child how to climb up into the parent’s wheelchair so that the parent does not have to do the lifting (Kirshbaum, 1988). Tuleja and DeMoss (1999) also describe a burping technique that can be taught to parents with limited arm use called the ‘Sit & Lean’ technique. This involves having the baby sit on the parent’s lap facing away from them and the “parent then leans forward, which tilts the baby forward and produces a burp” (p. 76). These and other adaptive techniques and strategies are extremely beneficial for mothers with disabilities to know when caring for their children.

Adaptive Equipment

Another important factor occupational therapists need to consider is to look at what assistive devices are available to aid the mother with a disability in her parenting role. In a study done by Alexander et al. (2001), 88 mothers with a SCI were asked to identify what types of adaptive baby care equipment they used or that they would like to have. The main adaptive devices used included: an adapted baby carrier (31%), adapted baby changing table (30%), adapted crib (29%), and harnesses or straps for their children (24%). Furthermore, adaptive equipment suggested by mothers with SCI included: an adapted baby bathtub (24%), adapted stroller (22%), and an accessible playing surface (18%).

When a parent with a disability uses adaptive baby care equipment, they benefit in a number of ways. By far the most important is that adapted baby care equipment can make the job of parenting feel safer for parents with a disability. Many parents who are wheelchair bound will pick up their child by holding onto the child's clothing. However, by using a lifting harness, which straps around their child, they need not worry about losing a grip on the clothing or the clothes ripping which could result in the child falling during the lift (Kirshbaum & Olkin, 2002).

Another important aspect of using adaptive baby care equipment is that it can help prevent secondary complications to the parent's health. Oftentimes, parents with a disability will "over-stress their own bodies in an effort to avoid stressing their babies during care" (Kirshbaum & Olkin, 2002, p. 72). This can result in the parent developing back pain, repetitive stress syndrome, or other injuries (Kirshbaum & Olkin, 2002). Having the right kind of adaptive baby care equipment can help prevent this from happening. According to Tuleja and DeMoss (1999) and Kirshbaum and Olkin (2002), parents who used adapted baby care equipment experienced decreased fatigue and pain.

In addition, having adapted baby care devices can assist the parent in decreasing many of the environmental barriers, thus giving the parent a fair chance to care for their child (Tuleja & DeMoss 1999). This decrease in environmental barriers makes it easier for the parent to interact with and play with their child (Tuleja & DeMoss, 1999). An example of an assistive baby care device which does just that is a 'Play/Care Center' that was developed to allow mothers who are confined to wheelchair the opportunity to effectively play with their infant and toddler children (Vensand, Rogers, Tuleja, & DeMoss, 2000).

Furthermore, having the right kind of assistive devices can greatly increase a disabled parent's confidence in their ability to care for their child (Tuleja & DeMoss, 1999). Adapted baby care equipment has even been found to help in preventing depression in parents with a disability because it can enable them to care for their child at an improved and more independent level (Kirshbaum & Olkin, 2002). According to Tuleja and DeMoss (1999), many parents with disabilities felt that if they had used assistive devices they would not have needed to rely on family members and others as frequently to help them with tasks pertaining to their children.

A study done by Through the Looking Glass questioned 717 parents with disabilities how having adaptive baby care equipment would have improved their lives (Kirshbaum & Olkin, 2002). Fifty-three percent said it would have made them more independent and decreased their fatigue, 51% stated it would have decreased their time needed to carry out specific baby care tasks, 49% said having adapted equipment would have made the parent feel more confident regarding their child's safety, and 42% said adaptive equipment would have decreased the parent's pain with childcare tasks.

Despite the benefits of adapted baby care equipment to parents with disabilities caring for their children, there are some barriers. The main obstacle is that there is a

considerable lack of adapted baby care equipment available on the market for parents who have physical disabilities (Kirshbaum & Olkin, 2002). As Reid, Angus, McKeever, and Miller (2003) stated, “A perusal of contemporary medical products catalogues finds that they are largely devoid of devices that assist disabled mothers in meeting the needs of their newborn, preschool, and school-aged children” (p. 188). In a study conducted by Through the Looking Glass, 48% of the parents surveyed reported they did not know where they could look to find adapted baby care equipment (Kirshbaum & Olkin, 2002). In this same survey, 50% of the parents reported that they did not have adapted baby care equipment due to the inability to afford it. This addresses an additional barrier of a considerable lack of funding available to help parents with disabilities afford adaptive baby care equipment (Kirshbaum & Olkin, 2002).

It follows that there is also a lack of knowledge by occupational therapists regarding what devices are available to help mothers with disabilities. As Kirshbaum and Olkin (2002) noted, there are currently “very few occupational therapists with the expertise to intervene regarding baby care adaptations” (p. 77). Occupational therapists may recommend basic baby care devices that are commercially available, however, these may lack the needed adaptations that would be optimal for the mother with a disability (Tuleja & DeMoss, 1999). Therefore, it is essential that occupational therapists working with this population rely on their clinical reasoning skills and seek outside resources that will aid them in identifying the type of assistive baby care devices that would be most beneficial to the mother.

Kirshbaum and Olkin (2002) acknowledge that if the parent with a disability has difficulty caring for their child, yet has never been taught adaptive strategies and does not know what adaptive baby care equipment is available, then any resulting problems should be blamed on the environment and not on the parent’s disability. Occupational therapists who

teach parents with disabilities adaptive techniques to care for their child and who assist them in acquiring adaptive baby care equipment are helping to (a) decrease the stress that parents would experience on their own (Kirshbaum, 1988) and (b) allow the mother with a disability a much easier time caring for and interacting with her child (Tuleja & DeMoss, 1999). As one mother stated concerning other disabled mothers like herself, “we need support to find our own unique ways to deal with the physical aspects of parenting that we may not do in the typical ways” (Kocher, 1994, p.132).

Conclusion

After reviewing the present literature, it is obvious that there are many stereotypes surrounding parenting with a disability and a lack of awareness within the medical community regarding the capabilities of women with disabilities as mothers. The literature has also revealed that health professionals, especially occupational therapists who believe in the parents’ abilities to care for their children, play a crucial role in helping them successfully fulfill their parenting role. This may be accomplished through providing a sense of confidence in their parenting abilities, teaching adaptive strategies, and providing instruction on beneficial adaptive equipment for care of their children.

Farber (2000) pointed out that mothers with disabilities face unique challenges to overcome compared to mothers without disabilities. Prejudicial attitudes and actions demonstrated by the healthcare professionals should not be one of these additional challenges. It is evident through this literature review that healthcare professionals are in need of educational training regarding the stereotypes and misconceptions surrounding women with disabilities as parents and their capabilities. It is also evident that healthcare professionals, particularly occupational therapists, would benefit greatly from learning how they can help a mother with a disability care for her child.

CHAPTER III

METHODOLOGY

When deciding what I wanted to choose for the topic of my scholarly project, I came across a journal article I had read awhile back called “*Home is where their wheels are: Experiences of women wheelchair users*” (Reid, D., Angus, J., McKeever, P., & Miller, K-L., 2003). The article discussed barriers and adaptations women who used wheelchairs had to deal with in order to perform their homemaking, community, and work tasks. There was also a section in the article that pertained to the aspect of parenting from a wheelchair. It was this section on parenting that was of great interest to me. I was curious regarding how women with disabilities managed certain aspects of caring for their children and was interested in learning more on this topic.

My original topic proposal focused on women with spinal cord injury and their role as parents. However, after a literature review was conducted, it was evident that although there was some literature available on this topic, there was not enough to get a complete picture of what this phenomenon was like for mothers with a spinal cord injury. As a result, the topic was broadened to include mothers with *any* physical disability caring for their children.

After conducting this comprehensive literature review and discovering the issues of prejudice and discrimination, it appeared evident that healthcare professionals were in need of education regarding the negative stereotypes affecting women with disabilities as parents and the capabilities that these women have as mothers. It was also evident that occupational

therapists would benefit from learning about adaptive techniques and adaptive equipment in order to help their women clients with a disability who are interested in becoming a mother, or who may already be a mother, best care for their child.

Several of the articles I had reviewed for this project referred to an organization called Through the Looking Glass. One such article mentioned a book that had been developed pertaining to specific adaptive equipment mothers with disabilities could use when caring for their children. I went to Through the Looking Glass' website at www.lookingglass.org and decided it would be a worthwhile investment for me to purchase the book "*Adaptive baby care equipment: Guidelines, prototypes and resources*" in order to use some of the information in my scholarly project, and also to use as a practicing occupational therapist. The book also contained several pictures of parents with disabilities caring for their children and so I again contacted them to ask for permission to use some of these pictures in my scholarly project and poster presentation. They responded back to me and gave their permission (see Appendix).

Several theories and frames of reference were discussed as being possible guides for the development of this scholarly project, including an educational model. However, in the end it was decided that the philosophy of client-centered practice was the most appropriate and provided the best overall fit. The philosophy of client-centered practice was selected because it is highly valued in the occupational therapy literature and due to the fact that all healthcare professionals are familiar with this term and what it means. It was also chosen because healthcare professionals cannot be truly client-centered if they have certain beliefs and stigmatizations against a specific group of people. Therefore, the goal of my scholarly project was to change the attitudes of healthcare professionals so that they would recognize the capabilities women with disabilities have as parents and, as a result, provide a better

healthcare experience for these women and demonstrate more effective client-centered practice.

Once all the necessary information had been gathered and the overall goal of my product was identified, I discussed with my advisor the best method of developing this product so that healthcare professionals could be educated regarding this highly important topic area of parenting with a disability. In the end, it was decided that a Microsoft® PowerPoint® presentation would be the most effective means of accomplishing that goal. An outline was established addressing the main points that needed to be covered in this educational presentation. The current literature on this topic served as a guide to developing the outline and the product. I then worked closely with my advisor to get the educational presentation to flow in an organized and professional manner so that it might be widely viewed and accepted by healthcare providers.

The educational PowerPoint® presentation that was developed highlights common misconceptions regarding parenting with a disability and the capabilities these women have as parents, how healthcare professionals attitudes impact the woman's healthcare experience and sense of self-worth, and specific adaptive techniques and adaptive equipment of interest to occupational therapists for informing their women clients to assist them in caring for their children. Chapter IV of this document is the educational PowerPoint® presentation and audience handout.

CHAPTER IV

PRODUCT

Prejudicial attitudes and stereotypes exist in society, including within the healthcare community, towards women with disabilities having and raising children. The following product is an educational presentation designed to inform healthcare professionals, particularly occupational therapists, regarding the capabilities women with disabilities have as mothers and to contradict negative attitudes health professionals may have towards these individuals.

The educational product developed is in the form of a Microsoft® PowerPoint® presentation. It consists of a handout questionnaire, common stereotypes regarding parenting with a disability, reasons why healthcare professionals may have difficulty being accepting towards women with disabilities wanting to have children, and finally, ways that occupational therapists can assist these women in caring for their children by teaching them compensatory techniques and informing them about what adaptive equipment is available.

The Microsoft® PowerPoint® presentation is designed to last approximately 50 minutes, after which a brief 12 minute video titled “Adaptive Baby Care Equipment” will be shown depicting parents with various disabilities caring for their children. It will then conclude with a discussion and time for question and answers. The entire educational presentation is designed to last 90 minutes. It is the intention that this product will be shown to a variety of healthcare professionals at major hospitals, and also presented at the American Occupational Therapy Association (AOTA) Conference where multiple

occupational therapists would be informed regarding this highly significant topic. Although the information presented in this product pertains mainly to women with disabilities as parents, much of the information presented can also be generalized to fathers with disabilities as well.

Mothers with Disabilities: Dispelling the Myths

Sarah Churchill, MOTS
Department of Occupational Therapy
University of North Dakota

Demographics

- There are over 10 million families in the United States where the child's parent has a disability



- National Institute on Disability and Rehabilitation as cited in Kirshbaum & Olkin, 2002

“Many of us, especially those who work in maternity where the focus is so much on the elimination of the “abnormal”, are challenged by the idea of disabled people having children”

- Goodman, 1994, p. 228

Many healthcare professionals find it difficult to “envision the situation of a disabled person caring for a dependent baby”

- Kirshbaum, 1988, p. 9

For healthcare professionals, not only do mothers with disabilities challenge their attitudes, but they can also affect the way they behave and act towards them

Discrimination by Health Professionals

- Pressure woman client
 - Abortion
 - Tubal Ligation
 - Adoption
- Question the woman's choice

Clients' Interpretation of Healthcare Professionals

- "I never expected to find such ignorance of my condition amongst the medical professionals" - Goodman, 1994, p. 227
- "I don't trust most medical professionals" - Blackford, Richardson, and Grieve, 2000, p. 901

Clinician Attitudes

- > Personal Values
- > Personal Beliefs
- > "Clinicians' behaviors in therapeutic situations are shaped by ingrained beliefs about the world and people" - Restall, Ripat, & Stern, 2003, p. 105

Misconception #1: Pregnancy is a mistake

- > "The disabled mothers I know...think extremely carefully before becoming pregnant"
- > "I wish everyone would think as carefully as I did before having children"

Killoran, 1994, p. 126

Misconception #2: Children are negatively affected

- > Child are the 'victim'
- > Personality is affected
- > Decreased athletic interests
- > Confusion in sex-role orientation
- > Parent-Child relationship suffers

Group Comparison Study by Buck and Hohmann (1981)

- > Compared adult children who had been raised by a father with a SCI and children who had been raised by a father who was able-bodied
- > No significant difference in sex-role orientation
- > No significant difference on time parent spent with child or time spent together in leisure
- > Both groups of children participated in a variety of activities/ leisure interests

Comparative Study by Alexander, Hwang, and Sipski (2002)

- > Quantitative study comparing 88 mothers with a SCI, their partners, and children with 84 able-bodied mothers, their partners, and children
- > No significant differences in psychological symptoms between the two groups of children
- > No significant differences in problems with parent-child relationship

Misconception #3: Parentification Occurs

- > Child assumes adult responsibilities
 - Household Tasks
 - Care Giving Tasks

Contrary Evidence

- > Mothers do not want their children and others to think they are 'needy' or 'dependent'
- > Afraid others will think they are taking advantage of their children
- > Mothers go to the opposite extreme

"Even if other people shared their opinions about how important it is for children to have certain obligations, they somehow considered it differently when the child helped a disabled mother rather than a non-disabled mother"

- Grue and Laerum, 2002, p. 679

Misconception #4: Child's Safety is at Risk

- > Mothers with disabilities put their children's safety first!
- > Verbal Commands
- > Adaptive Equipment
 - Parent-Child Seat Belt
 - Adapted Walking Security Strap



Family Adjustment

- Babies adapt to their mothers with a disability
- Process occurs early and naturally
- Children can make distinctions between their disabled and able-bodied parent
- Each family has their own unique way of adapting

- Kirshbaum, 1988

Different is O.K.

- > "Disabled mothers have special ways of caring for [their] children which may look unbearably awkward or slow"
 - Killoran, 1994, p. 123
- > Tasks take longer
 - 20 minutes to diaper child
 - Walking to destinations

“If we cannot run, chase, throw balls, read the books, or hear the songs of our children, we are made to feel that we are not as good a parent as an able-bodied person. This is not true. The essence of parenting is the emotional caring, commitment and closeness, and the guidance and values the parent gives to the child”

- Kocher, 1994, p. 130

Positive Outcomes for Children

- > Parent's disability is normal
- > Increased sensitivity towards others
- > More positive attitudes toward parents

A Grown Child's Perspective

“I have benefited greatly from watching and participating in the survival of a family where life depends on strength and courage”

- Buck and Hohmann, 1981, p. 436

Advantages to the Woman

- > Sense of Pride
- > Achieve womanhood
- > Perception of their body
- > Included in the community

“I instantly felt more like a woman when my son was born. During my whole life I had felt like a person without gender. The process I went through during pregnancy and afterwards made me more conscious of my identity and my worth as a human being. My child made it possible for me to say... see, I am the same as you”

- Grue and Laerum, 2002, p. 676

Health Professionals' Attitudes Make a Difference!

- > Decreased self-esteem
- > Feelings of guilt
- > Become offended

“visits from the occupational therapist...discussed briefly how I might manage with lifting, but no one really considered how serious difficulties might be until after the baby was born. I felt I had to ask and work most of it out for myself”

- Goodman, 1994, p. 227

Health Professionals' Attitudes Make a Difference!

- > Increased self-esteem
- > Increased self-confidence
- > It's refreshing!

Occupational Therapists

Compensatory Techniques

- > Tying little bells on shoes
- > Sit and Lean Technique
- > Cueing Up Technique
- > Slide Down Transfer

Adaptive Equipment

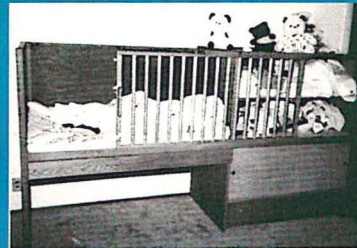
Bottle Wrap - This allows a mother with little to no grasp feed her baby a bottle.



Arms Reach Bassinet -

This is a bassinet that can attach to the parent's bed, thus eliminating the need for the parent to get out of bed.

Adapted Crib



Play/Care Center



Concluding Remarks

"It is our relationship with our children [that is] the essence of our parenting, not our physical abilities"

- Kocher, 1994, p. 128

"Ultimately parenting is about loving, guiding, and nurturing, disability status aside"

- Kirshbaum & Olkin 2002

Resources

- Parents with Disabilities Online: The Internet's One-Stop Resource for Parents with Disabilities
 - Information on books, web resources, organizations for parents with a disability, including networks available to parents with a disability and where to access such items.
 - Available at: www.disabledparents.net
 - Book: *Mother to Be: A Guide to Pregnancy and Birth for Women with Disabilities*. By Judi Rogers and Molleen Matsumura.
 - Book: *The Baby Challenge: A Handbook on Pregnancy for Women With a Physical Disability*. By Mukti Jain Campion.
 - Web Resources: MS Moms, Parenting with a Disability Network (PDN), The DisAbled Women's Network (DAWN).

Resources Cont.

- Through the Looking Glass
 - Nationally recognized nonprofit organization. Provides research, training, and services for families in which a parent has a disability
 - *Web site:* www.lookingglass.org
 - *Phone:* 1-800-644-2666
 - *Address:* Through the Looking Glass
2198 Sixth Street, Suite 100
Berkeley, CA 94710-2204
 - **Book:** *Adaptive Baby Care Equipment: Guidelines, Prototypes & Resources*. By Kris Vensand, Judith Rogers, Christi Tuleja, Anitra DeMoss
 - **Periodical:** *Parenting with a Disability* available for free to all members on the mailing list

Mothers with Disabilities:

Dispelling the Myths

Sarah Churchill, MOTS

Demographics of parents with a disability

- There are more than 10 million families in the United States with a parent having a disability

Ways healthcare professionals can discriminate against a woman with a disability becoming a mother

- Pressure her to have an abortion or give her child up for adoption
- Question her decision and ability to have and care for a child

Common misconceptions regarding mothers with a disability

- The woman became pregnant by mistake or is incapable of making an informed decision about motherhood
- The children will be adversely affected due to the parent's disability
- The children will be forced to carry out a variety of adult responsibilities at a young age; referred to as 'parentification'
- The child's safety will be compromised as a result of the parent's disability

Facts regarding women with disabilities as parents

- The family and children naturally adapt to the parent's disability
- Mothers with a disability are similar to mothers without a disability
 - Different methods of care, same purpose
 - There is more to parenting than simply the physical abilities, including the emotional caring, support, and guidance they provide to their children

Benefits children have being raised by a parent with a disability

- They consider their parent's disability 'normal'
- They have an increased sensitivity to the needs of others
- They have more positive attitudes toward their parents

Advantages women with a disability have from being a mother

- Gives her a sense of pride and accomplishment
- Helps her achieve a sense of 'womanhood'
- Results in a positive change in the perception of her body
- They feel included in society as a result of being a mother

Professionals' attitudes make a difference in the healthcare experience perceived by women with disabilities

- Professionals' attitudes that are negative and disapproving of the woman's choice results in decreased self-esteem, decreased confidence, and feelings of guilt
- Professionals' perceptions that are positive and optimistic of the woman having a child results in increased self-esteem and confidence and is encouraging to the woman client

Occupational Therapist's Role

Compensatory Techniques

- Various positioning adaptations can allow a parent with a severe disability hold, feed, and care for their child (Kirshbaum & Olkin, 2002)
- Tying little bells on the baby's/child's shoes can allow a parent who is blind the ability to know the location of their child. (Kocher, 1994)
- Sit and Lean – This is a burping technique where the child is sitting on the parent's lap and the parent leans forward to get the baby to burp. Used for a parent who has poor upper extremity control (Vensand, K., Rogers, J., Tuleja, C. & DeMoss, A., 2000).
- Cueing up – This is a method of teaching the child to lift his/her bottom while the parent is changing the diaper. Used for parents with poor strength or motor control (Vensand, K., Rogers, J., Tuleja, C. & DeMoss, A., 2000).

Adaptive Equipment

- Arms Reach Basinet – This is a basinet that is connected to the parents bed thus eliminating the need for timely and exhausting transfers in the middle of the night for a parent who uses a wheelchair or other mobility device
- Bottle Wrap – This simple adaptive device allows a parent with limited or no grasp to successfully feed their baby
- Adapted Baby Cribs – These allow a parent with a disability to get their wheelchair up next to the crib and/or safely place their child in/out of it
- Modified Play/Care Center – This is a raised play area where a parent who is in a wheelchair can effectively care for and play with her child
- Adapted Hooks and Latches – These allow a parent with limited hand function the ability to successfully carry out a number of daily childcare tasks including, but not limited to, the latching system of highchair trays, safety gates, cribs, and car seat fasteners.

Adaptive Equipment Reference: Vensand, K., Rogers, J., Tuleja, C. & DeMoss, A., 2000.

Resources

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2. Parents with Disabilities Online: The Internet's One-Stop Resource for Parents with Disabilities. Information on a variety of books, web resources, and organizations for parents with disabilities. Available at: <http://www.disabledparents.net>.

“Ultimately parenting is about loving, guiding,
and nurturing, disability status aside”

Kirshbaum and Olkin, 2002, p. 78

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CHAPTER V

SUMMARY

Women who have disabilities face attitudinal barriers in their choice to have and raise children. This occurs in larger society, but also by many healthcare professionals. Often times, healthcare professionals are not even aware of their own attitudinal biases, which are resulting in discriminatory behavior towards their women clients, such as encouraging her to have an abortion or questioning her choice to have a child. Therefore, it was the intention that through this educational PowerPoint® presentation, developed specifically for healthcare professionals, that they would come to realize the capabilities women with disabilities have as parents, and to recognize their own biases and how this is affecting the patient care and treatment experienced by these women.

Another area where future research on this topic is needed is in regards to educating the general public. The educational presentation that was developed in this scholarly project focuses on educating healthcare professionals and is not aimed at educating the general public. Yet there is an enormous need for this. Mothers with disabilities face all kinds of discrimination and attitudinal barriers from larger society. It is only through fervent education of the general public that mothers with disabilities can hope to be treated equally in society.

After completing this scholarly project, it is evident that there is a need for future research to be conducted in the area of parenting with a disability. One such area involves looking at the types of compensatory techniques and adaptive equipment that is beneficial

and recommended for parents with a particular disability. For example, what techniques and adaptive equipment would assist a mother with a right upper extremity amputation care for her child compared to a mother who suffered from multiple sclerosis? It could also then address new ways to adapt as the child developed. This type of handbook would be extremely helpful and valuable for occupational therapists working with this population and also for the woman client herself.

Finally, there is a need for women with disabilities to be informed of the capabilities they have of being a mother despite their medical condition. Often times, women with disabilities do not even realize they have the option of becoming a parent, and healthcare professionals seldom bring this topic up in discussion. Therefore, informing these women of their abilities might be accomplished through developing educational pamphlets or through training workshop specifically for individuals who have disabilities.

There were some limitations to this scholarly project. First of all, it mainly focused on mothers who had disabilities with very little attention being paid to the role that fathers with disabilities play in the development and care of their children. Secondly, it focused only on parents who had physical disabilities and did not take into account those parents who suffer from psychological conditions, or combinations of cognitive and physical disabilities.

Women who have a disability have every right to become a parent. Although the methods they use to raise and care for their children may be different than how an able-bodied parent would perform the task, this does not make them any less capable. Through this scholarly project it has been revealed just how capable women with a disability can be in their role of parent.

APPENDIX

X-Sieve: CMU Sieve 2.2
X-Sender: ppreston@lookingglass.org@pop.lookingglass.org
Date: Mon, 28 Feb 2005 11:13:58 -0800
To: sarah.churchill@und.nodak.edu
From: Paul Preston <ppreston@lookingglass.org>
Subject: Photo permission
Cc: jstube@medicine.nodak.edu, judi_rogers@lookingglass.org
X-Scanned-By: MIMEDefang 2.37

Hello Sarah--

Your email regarding using some photos from our Adaptive Babycare Equipment was forwarded to me. It would be fine for you to scan the photos you suggested. Here's what we'd like to have you do as far as citing our work:

1. Photos are from "Adaptive Baby Care Equipment: Guidelines, Prototypes & Resources" and reproduced with permission from Through the Looking Glass, the National Resource Center for Parents with Disabilities. Contact information:

Through the Looking Glass
2198 Sixth Street, Suite 100
Berkeley, CA 94710-2204
U.S. (800) 644-1666
U.S. (800) 804-1616 (TTY)
email: tlg@lookingglass.org
website: www.lookingglass.org

I've also attached a Powerpoint slide that has this contact information on it in case somehow this is easier to incorporate.

2. After your presentation, we'd really appreciate it if could you send us a brief follow up regarding: summary and date of your presentation (mostly this is what you've already sent to us), approximately how many people attended, and any notable feedback or questions that came up. You can send this to me.

If you have any questions, please let me know.

thanks for your interest -- and, also, thanks for asking for permission.

Good luck!

Paul Preston, Ph.D.
Director, National Resource Center for Parents with Disabilities

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