COLLABORATION AND ADAPTATION: INSIGHTS INTO THE EXPERIENCES OF PERSONS WITH DISABILITIES

A DISSERTATION

SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY

IN THE GRADUATE SCHOOL OF THE

TEXAS WOMAN'S UNIVERSITY

COLLEGE OF HEALTH SCIENCES

BY

CELIA H. SCHULZ, B.A., M.A.

DENTON, TEXAS

DECEMBER 2006

TEXAS WOMAN'S UNIVERSITY
DENTON, TEXAS

October 25, 2006

To the Dean of the Graduate School:

I am submitting herewith a dissertation written by Celia H. Schulz entitled "Collaboration and Adaptation: Insights into the Experiences of Persons with Disabilities." I have examined this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy with a major in Occupational Therapy.

Gayle I. Hersch, Ph.D., Major Professor

We have read this dissertation and recommend its acceptance:

Director

Accepted:

Dean of the Graduate School

DEDICATION

To the memory of my father,

Richard Frederick Schulz

to the memory of my professor,

Jean Cole Spencer

and to my friend,

Gale Moreland Smith

ACKNOWLEDGMENTS

The author would like to acknowledge the following people:

My dissertation committee chairperson, Gayle I. Hersch, PhD, OTR for her dedication and continued support and encouragement throughout to ensure this project was completed, including assistance with data analysis;

My friend, Virginia K. White, PhD, OTR, FAOTA, Professor Emerita, Texas Woman's University, for her support and encouragement throughout this endeavor; including assistance with coding;

My friend, Kathlyn Reed, PhD, OTR, FAOTA, MLIS for her support and encouragement in this process;

The five individuals who were the participants for this project;

The other members of my dissertation committee; Sally W. Schultz, PhD, OTR, FAOTA, Rebecca I. Estes, PhD, OTR, ATP and Diana Rintala, PhD, for their time and intellectual support during this project;

My sister, Emily K. Schulz, PhD, OTR, CFLE for her time, insight, support, suggestions and assistance with data analysis for this project;

My friend and typist Maggie Jordan for dedicating long hours, flexibility, and her creative curiosity to this project; and

The late Jean C. Spencer, PhD, OTR, FAOTA who originally suggested this line of research and who supported and encouraged me to complete this dissertation.

ABSTRACT

CELIA HOPE SCHULZ

COLLABORATION AND ADAPTATION: INSIGHTS INTO THE EXPERIENCES OF PERSONS WITH DISABILITIES

DECEMBER 2006

This dissertation explored the concept of collaboration by persons with disabilities. Collaboration according to this research is defined as working together to achieve a common goal. Collaboration by persons with disabilities is an important concept as collaboration with others may be considered an alternative method for persons with disabilities to achieve independence in task performance. This line of research included three studies that contribute to the void in the literature on the topic of collaboration by persons with disabilities.

The first study was a literature review which explored and integrated concepts relevant to collaboration by persons with disabilities. The literature supported that collaboration with others can contribute to quality of life for persons with disabilities in a variety of ways.

The second study was a qualitative study conducted to determine the perspectives of persons with disabilities of the experiences with collaboration they have had with others in their lives. The participants clearly identified that collaboration was a necessary feature of their lives. Two forms of collaboration, supporting collaborations and symbiosis, best illustrated how task support

through collaboration promotes participation and is a form of adaptation. Participants' descriptions of supporting collaborations and symbiosis were closely related to concepts of independence and interdependence as described in the Disability Studies literature. Participant's descriptions illuminated ways in which these two forms of collaboration enhance quality of life and self-actualization for people with disabilities.

The third study was a qualitative study of persons with disabilities conducted to examine the phenomenon of collaboration in the marriage relationship for persons with disabilities. The analyzed data fell into five large categories: 1) Practical Considerations; 2) Collaboration on Occupation; 3) Structures and Patterns of Collaboration; 4) Social Considerations; and 5) The Qualities that Make the Marriage Collaboration Special. Data indicated that participants collaborated with their spouses in a variety of ways and that there were qualities in their collaborations with their spouses which indicated a high level of mutual respect and love. Implications for occupational therapy are offered with an emphasis on how to facilitate collaboration by persons with disabilities.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER I

INTRODUCTION

Statement of the Problem

This dissertation explored the concept of collaboration by persons with disabilities through the methods of qualitative research. In this line of research collaboration was defined as working together to achieve a common goal. The significance of this line of research lies in the fact that there appears to be a minimal amount of studies to date on collaboration by persons with disabilities, and the majority are found in the literature of disciplines outside of occupational therapy. This investigation attempted to integrate concepts and literature relevant to this aspect of collaboration specific to occupational therapy. Thus, this line of research has the potential to contribute new and unique insights into the experiences of persons with disabilities regarding the reasons why they collaborate and the value of collaboration.

Collaboration between persons with disabilities and their friends and family is an important notion. Such connections with others could provide a means for persons with disabilities to accomplish tasks or engage in activities that they might not be able to or want to do on their own. These limitations may occur due to barriers in the physical, social, cultural, political, institutional and economic environments (Law, et al., 1996; Smalley, 1990; Taylor, 1991).

Through collaboration with others, persons with disabilities can achieve a level of independence important to them, allowing them to meet their needs through mutual support.

As occupational therapists, it is our role to be flexible and to facilitate improved quality of life for our clients (Lloyd & Samra, 1996). A client-centered approach involves collaboration with the client and provision of experiences which are personally meaningful. As Nelson (1996) states, "after a person finds meaning in a situation, he or she experiences purpose, or the desire to do something about the situation" (p. 777). Collaborative efforts with others can provide considerable meaning in the lives of persons with disabilities (Taylor & McGruder, 1996).

Collaboration, mutuality, facilitating adaptation in a client's own context, and providing opportunities for meaning are all areas of which occupational therapists need to be continually vigilant. We often fall short of these ideals (Meier & Purtilo, 1994; Neistadt, 1995; Spencer, 1991). It is important for occupational therapists to be aware of the value of collaboration among persons with disabilities and of the issues involved around the desire to collaborate. Collaboration with others may be considered an alternative method for persons with disabilities to achieve independence in task performance. Incorporating such awareness into our practice can only contribute to a client-centered approach and to the empowerment of our clients to do what they may be unable to do singly (Ferguson, 1984).

A strength of the qualitative methodology used in this line of research was that it helped to ensure that the information obtained through data analysis and interpretation truly represented the viewpoint of participants. Due to the selection criteria for participants in this research, it became clear that the sample was not representative of the general population of persons with disabilities relative to collaboration. Nevertheless, this research was significant because of the importance for occupational therapists to be aware of issues that may affect the well-being of our clients. Occupational therapists need to be cognizant of new ways in which to facilitate adaptation with those who are served, particularly as the practice of occupational therapy assumes an increasingly significant role in the community.

Statement of Purpose for Research Studies

Using three studies, this dissertation investigated the concept of collaboration by persons with disabilities. The following describes the three studies.

First study. The first study was a literature review which explored literature relevant to the topic of collaboration by persons with disabilities. As there was very little written on this topic, the researcher had to delve into topics which were tangentially related to the topic, not only in the discipline of occupational therapy, but in the disciplines of personality psychology, social psychology, health psychology, physical medicine and rehabilitation, nursing, rehabilitation counseling, gerontology, health promotion, epidemiology, sociology, education,

special education, disability studies, and service animal literature. Other areas which were investigated later in the process included speech pathology and human development. This study answered the question: what is in the literature, both within and outside of occupational therapy, regarding collaboration between persons with disabilities and others; what other concepts and areas are related to this concept of collaboration, and how can this information be integrated into a cohesive review?

Second study. The second study was a qualitative design using interviews and explored the issues relevant to collaboration by persons with disabilities. Many categories emerged from the data resulting in two major themes, Supporting Collaborations and Symbiosis. The connection of these themes to those of independence and interdependence in the disability studies literature were discussed in depth.

Third study. The third study, also of qualitative design, focused on collaboration in the marriage relationship among persons with disabilities. With a focus on collaboration in the marriage relationship, the third study combined excerpted interview data from the second study with data from participant observations from the third. All three studies were submitted to peer-reviewed journals.

Researcher's Perspective

I have always been enthusiastic about phenomenological approaches to research, having already completed and published an earlier study regarding the

survivor interview perspective on helping factors in a peer developed support group for head injury (Schulz, 1994). I am interested in the phenomenology of disability and in drawing out and bringing to light the experience of persons with disabilities.

In 2001, I had surgery to remove a benign brain tumor known as an acoustic neuroma. The surgery and subsequent rehabilitation had a very profound and strong impact on my life. It also enhanced my appreciation of my participants and their lives.

My brain surgery shaped my experience in many ways. In short, I felt I was never able to look at a person with a disability in the same way again. Instead of my pre-surgery, benevolently patronizing approach, I realized that people with disabilities (either ones who are born with or have acquired disabilities) are people. Normal bodies are well-oiled machines, the functioning of which we take for granted. When they stop working, it is not our fault, nor is that a reason to treat us as anything less of a person, or anything less than who we are before that happened.

This awakening affected my approach to understanding my subjects, their data, and their input on my data during member checking. I really started to listen and understand for the first time what they were saying, as if I were the one having the experience. In many cases, what they said seemed to make more sense to me and ring true to my experience. I began to understand how frustrating it must be to be constantly having to explain or justify oneself to others

who just don't understand the disability experience or who look down on people with disabilities, or who are repulsed by them, their appearance, what they do and don't do, and how they do things.

Instead of being an outsider looking at and seeing people with disabilities as having quaint points of view that I qualified in my mind due to their own biases, I saw their experience as something I could relate to and understand as part of my own experience. This change in mind set helped me to be a better listener and to take what they said at face value and not necessarily imbue what my participants said with an underlying meaning that I attributed to what I thought their experience of disability was. If, as an outsider, you are able to change your point of view to seeing people with disabilities as people who are doing their best with a body that doesn't work, you are getting on the right track.

As you can see, I believe that persons with disabilities are experts on their experiences with disability and provide a rich and valuable resource to be tapped through interviews and participant observation sessions. People with disabilities experiencing the phenomenon of collaboration with others can provide insights about and appreciate nuances in data that might be lost to the researcher who has not lived the experience.

CHAPTER II

BACKGROUND

This chapter comprises a review of the literature both within and outside of occupational therapy regarding the topic of collaboration by persons with disabilities. As there has been very little written on this topic, the researcher had to review literature on topics tangential to collaboration by persons with disabilities, such as the client-therapist relationship and collaboration with service animals. In particular, topics that related specifically to collaboration came from the disability studies literature and the literature on collaboration in marriage.

Collaboration

The client-therapist relationship in occupational therapy. The concept of collaboration between the professional and client is a central concept to occupational therapy and to client-centered practice (Baum & Law, 1997; Jongbloed & Crichton, 1990; Law, 1991; Law, Baptiste, & Mills, 1995; Law et al., 1996; Northen, Rust, Nelson, & Watts, 1995; Schultz & Schkade, 1992; Spencer & Davidson, 1998). Rosa and Hasselkus (1996) found that "the give and take of reciprocity between therapists and patients forges connectedness (p. 251) and that "therapist and patient shar[ed] the work and responsibilities of therapy" (p. 251).

However, researchers in the field have noted that collaborative potential in the client-therapist relationship is not often realized, and that professionals often pay lip service to the notion of collaboration between client and therapist, at least in rehabilitative or adult physical disability treatment environments (Neistadt, 1995; Northen, Rust, Nelson, & Watts, 1994). At times, clients and their occupational therapists have conflicting goals (Bates, Spencer, Young & Rintala, 1993).

The relationship between client and attendant. Although some persons with disabilities report positive experiences with attendants in some institutions (Barnes, 1993; Berry, Hitzman, Stewart, & Darwin, 1995; Briggs, 1993, Frank, 1996), others report more negative interactions (Davis, 1993; Oliver, 1993). Some of the concerns that persons with disabilities have in their relationship with attendants have to do with loss of choice and control over how they are cared for, limited time on the part of attendants to provide care, and restrictions on the "range of tasks that professionals can perform...because of professional boundaries, employer requirements or trade union practices" (Oliver, 1993, p. 54). Newsom and Schulz (1998) indicate that caregiving recipients often experience negative reactions to receiving help, including problems with receiving too much help, or not enough help. Another concern is the loss of reciprocity in the relationship between the disabled person and the caregiver, which can have a detrimental effect on both persons involved (Parker, 1993).

Persons with disabilities and service animals. Collaboration with service animals has numerous benefits for persons with disabilities (Eddy, Hart, & Boltz, 1988; Hart, Hart & Bergin, 1987; Mader & Hart, 1989), which may shed some light on the value of collaboration by persons with disabilities with others in their lives. Some of these benefits with service animals include retrieval of dropped objects, increased mobility, being alerted to signals in the environment, and completion of other necessary manual tasks. Service dogs have also been shown to improve opportunities for social interaction for the disabled individual with whom they are working. Service animals can act as a "social lubricant" (Eddy, Hart, & Boltz, 1988, p. 40), influencing increased eye contact, acknowledgment and conversation between people with disabilities and the non-disabled population. In fact, a team comprised of a person with a disability and his or her service animal received more smiles, looks and conversation than a disabled person alone (Eddy, Hart, & Boltz, 1988, p. 42; Mader, Hart & Bergin, 1989; Messent, 1984).

It appears that service animals can affect how a person with a disability is perceived by non-disabled persons in the environment (Mader, Hart, & Bergin, 1989). Such benefits can improve health and increase morale for persons with disabilities (Hart, Hart, & Bergin, 1987; Messent, 1984). Thus, in addition to assistance in the completion of specific tasks, service animals can assist persons with disabilities to: overcome the loneliness and the ostracism, isolation, stigmas and social barriers inherent in society regarding disability; have reciprocal

interactions (rather than unbalanced "helper-helpee" interactions) with members of the non-disabled population; experience increased assistance from non-disabled persons; and increase assertiveness as well as personal security, self-confidence and self-esteem (Eddy, Hart, & Boltz, 1988; Hart, Hart, & Bergin, 1987; Messent, 1984; Powers, 1991). In this manner, the use of service animals by members of the disabled population can be a catalyst for social change. Many of the above-mentioned benefits could follow from collaborative interactions by persons with disabilities as well.

Well-being and structured use of time. Bond and Feather (1988) discuss how having a job provides individuals with goals and tasks to accomplish. According to Bond and Feather (1988) "time structure is related both to role demands and to personality variables" (p. 327). It is unclear if negative personality aspects such as depression, anxiety, and hopelessness bring about a decreased sense of structure and purpose in the individual, or if decreased time structure influences such negative aspects. New routines and purposes are usually introduced through new roles which we either acquire by choice (such as retirement) or which are forced on us (such as disability) (p. 327). Collaboration may be one way in which persons with disabilities can experience increased structure and purpose in their daily lives through the resulting ability to accomplish tasks, enact desired roles, and increase social interaction.

Volunteerism. Meagher, Gregor and Stewart (1987) discuss the value of volunteer-patient dyads in the rehabilitation of individuals after cardiac surgery.

Using a model of support determined by House (1981), Meagher, Gregor and Stewart (1987) found that volunteers who had previously experienced cardiac surgery provided much-needed emotional, informational, instrumental (practical) and appraisal ("affirmation, feedback and social comparison " [p. 833]) support to the recuperating member of their dyad. If the quality of life and the well-being of individuals can be improved through such social support experiences, it would seem that collaborative experiences, as an aspect of social support, could have the same result in providing emotional, informational, practical and appraisal support for those involved in the collaboration (Meagher, Gregor, & Stewart, 1987, p. 833).

One way to facilitate participation in volunteering and empowerment is through programs based on the concept of "Time Dollars" (Cahn & Rowe, 1992). In this concept, hours spent volunteering for others by individuals become an exchangeable commodity which they can "bank" and then "cash in" when they need assistance from others. For example, an individual may read the newspaper to an elderly neighbor in exchange for a ride to the grocery store provided by another neighbor, who in turn has their car tuned by another neighbor, and so on.

These types of exchange mechanisms can exist in the form of formal support programs for elderly persons, but they can also be culturally based or appear informally in neighborhoods. The concept of "Time Dollars" can be

viewed as a form of collaboration which could be applied formally or informally by persons with disabilities with very likely similar benefits.

The Concepts of Dependence, Independence, and Interdependence

Independence. The concept of independence has long been addressed in the Disability Studies literature. They argue that an antiquated definition of independence, stemming from the medical model of disability, still prevails in rehabilitation and in society. This concept of independence focuses on whether or not a person can perform necessary self care tasks and desired daily activities without the aid of another person. Conversely, persons with disabilities are considered dependent if they need assistance from another person throughout their day (DeJong, 1979; Nosek & Howland, 1993). Such dependence is considered undesirable and thus something to be avoided or reduced.

The Disability Rights movement and the Independent Living movement revolutionized the definition of independence. Writers argued that instead of focusing on measures of functional ability, independence should focus on individuals being in control of their choices, their decisions, and their lives, thereby being self-determining (Longmore, 1995; Oliver, 1993; Parker, 1993; Scheer & Luborsky, 1991; Nosek, 1993). Nosek and Fuhrer (1992a, 1992b) provide a hierarchical model of independence with four progressive need stages of "basic survival, material well-being, productivity, and self-actualization" (1992a, p. 5) and developed a profile measuring independence based on the following four non-traditional components of independence: "perceived control over one's

life...psychological self-reliance...physical functioning, and...environmental resources" (1992b, p. 3).

Interdependence. The concept of interdependence is burgeoning among people with disabilities. According to Gill (1995), recognizing interdependence as a part of existence is a central value of the disability community. Longmore (1995) states that persons with disabilities have values which stem from their experience of interdependence, connection to, and affiliation with others. Jacobs (2002) views interdependence as having enormous value to empower people with disabilities because of increased connection and the resulting sharing of information and knowledge.

The Disability Studies literature provides a few examples of interdependence; each involves collaboration as a central component. For example, Scheer and Luborsky (1991, p. 1176) described an elderly woman with disabilities who, upon her husband's demise "lost...a valuable disability ally who helped her maintain physical comfort and functional capacity". French (1993a) discussed a case of interdependence between a social worker with blindness and his or her clients. Scheer and Groce (1988) discuss a community of persons with quadriplegia and paraplegia on Roosevelt Island, New York which became an example of the value of interdependence among persons with disabilities. They provided "...each other support and informal counsel about various issues, from attendant care management, to advice about dating, to equipment repair and purchase" (Scheer & Groce, 1988, p. 35). Many of the residents in this

community formed connections not only among themselves but with people outside the disability community as well. These examples suggest that a variety of forms of collaboration are involved in expressing the value of interdependence. The literature on interdependence provides mostly anecdotal examples, indicating a need to know more about the nature and impact of collaboration.

The Significance of Friendship and Social Support

One way in which people can be interdependent is through friendship and social support, and friendship is one notable vehicle for collaborative efforts. Powers (1991) states that "unlike support relationships that involve helper and helpee, companionship is non-hierarchical" (p. 45). Meier and Purtilo (1994) discuss the need for "mutual respect such as that experienced in friendship" (p. 366). Himes and Reidy (2000) point out that "care exchanges between friends may be an adaptive strategy adopted by women who have few family members nearby" (p. 325)

Rintala, Young, Hart and Fuhrer (1994) studied the relationship between reciprocity in social support relationships and measures of disability, independence and depressive symptoms in individuals with spinal cord injury. Interestingly enough, they found that subjects in their study indicated more often that they were "very satisfied" with relationships when others contributed more in the relationship rather than when they contributed more, or when the contribution of both parties was reciprocal (p. 22). They also found that persons who were physically more mobile, who used their time productively, who were socially more

integrated, and who were more independent economically tended to have more reciprocal social support relationships. They also found that persons who were more physically independent tended to have more social support relationships in which they contributed more than the other person, and that persons who were physically more mobile, who used their time productively, and who were more independent economically tended to have fewer relationships in which the other party contributed more (Rintala et al., 1994, p. 23). Relationships in which the other party contributed more tended to be with professionals and parents. Interestingly enough, symptoms of depression were not correlated with reciprocity or lack of reciprocity in relationships.

Rintala et al. (1994) suggested several models which might explain these findings. It could be that reciprocity in relationships might maintain or increase self-esteem, which in turn improves one's ability to enact social roles in terms of "mobility, productivity, social integration and economic self-sufficiency" (p. 25). It could also be that actively enacting social roles may assist self-esteem, which facilitates the development of reciprocity in relationships. Finally, it could also be that a variable such as good overall health and motivation may encourage social role enactment and reciprocity in relationships (p. 25). According to Rintala, et al. (1994) it is very likely that two or more of such models may be coming into play concurrently.

If such models are truly in operation, Rintala et al. (1994) conclude that rehabilitation professionals could improve quality of life for their clients through

encouraging reciprocity and active involvement in everyday living, as well as facilitating adaptations of the environment and discovering economic resources. Collaboration by persons with disabilities is not only a form of reciprocity in relationships, but also a resource and a form of adaptation to or of the environment that facilitates active involvement in daily living.

The Marriage Relationship

The literature revealed some examples of interdependence as a form of collaboration in the marriage relationship. There is a growing interdependence that develops between spouses during the aging process (Clark & Anderson 1967; Depner & Ingersoll-Dayton, 1985). Oelschlaeger and Damico studied how a man with aphasia used repetition as a form of collaboration in conversation with his wife to compensate (1998b). They also studied a man with aphasia and his wife in the use of joint production in conversation, wherein one member of the conversation starts to speak and then their turn is completed by another person (Oelschlaeger & Damico,1998a).

A recent area of research by a few scholars has been in the area of collaborative cognition among the elderly, which "refers to processes and outcomes that occur when two or more individuals engage jointly in activities such as problem solving or memory" (Strough, Patrick, Swenson, Cheng & Barnes, 2003, p. 44). Most studies on collaborative cognition involve married couples (Strough, et al., 2003). One such study by Berg, Johnson, Meegan and Strough (2003) determined that married couples use a variety of approaches and

patterns in their collaboration within their daily lives, including the division and delegation of tasks.

Parker (1993b) discusses the problems and changing dynamics relative to the independence of both spouses. When one spouse in the marriage becomes disabled, power differences and the balance of exchange within the relationship change. Changes also manifest in other areas such as self-care, financial management, the lives of the children, and the need for assistance from immediate and extended family as well as outside resources. For example, after the onset of disability for the husband, "in all cases where male spouses had taken substantially increased control over household finances carers tended to explain their acceptance of this in terms of giving the spouse something to do." (p. 80). Parker (1993b) also mentions spouses' need for time away from each other. Finally, referring to Duck (1983), Parker (1993b) suggests that "when the fairness or equity of a relationship feels out of balance...one or both partners will re-examine the relationship and make attempts to redress the balance." (Parker, 1993b, pp. 89-90).

Frank (2000) discusses some of the dynamics in the relationship between a woman with congenital limb deficiency and her boyfriend who later became her husband and from whom she was later divorced. For example, she felt her disability hampered her relationship with her boyfriend as she was unable to take care of him as a traditional wife should and she said that her boyfriend did state at one point that her disability was the problem between them. Garee and

Cheever (1992) provide numerous vignettes of married couples wherein one or both members of the couple has a disability and the various coping strategies they use to get through their day, including use of technology, planning of the home environment, focusing on strengths, having realistic expectations of what each other can do and doing what they can, sense of humor, creating their own roles, finding time for oneself, work, awareness of self-care issues, and a strong bond of love.

Adaptation

Adaptation is a phenomenon that is basic to living creatures. In the philosophical base of our profession, adaptation is discussed as a quality of being human, a process that all human beings continuously go through in the experience of living. Individuals continuously adapt until their lives end (American Occupational Therapy Association, 1979, p. 785). "Using their capacity for intrinsic motivation, human beings are able to influence their physical and mental health and their social and physical environment through purposeful activity....Adaptation is a change in function that promotes survival and self-actualization" (American Occupational Therapy Association, 1979, p. 785).

Adaptation involves an interaction between the environment and an individual. (Frank, 1996; Spencer, Davidson, & White, 1996; Spencer, Hersch, Eschenfelder, Fournet and Murray-Gerzik, 1999). When we experience illness or a disability, it causes a change in our relationship with our environment (Spencer, Davidson, & White, 1996). We need to either adapt the environment or our

approach to tasks in order to successfully complete occupations and adapt (Spencer, Davidson, & White, 1996). According to Frank (1996), human beings adopt "adaptive strategies" in order to improve quality of life (p. 51). "Adaptation through mindfully organized action is necessary for the good life" (Frank, 1996, p. 50). Spencer, Daybell, et al. (1998) point out that those who undertake a proactive approach to adaptation probably need "creativity and ability to see things in new ways, flexibility, and willingness to take risks, and a relatively high sense of self-efficacy" (p. 481). Collaboration with others may be seen as a creative way in which persons with disabilities can adapt their environment or the tasks they undertake.

Adaptation also has a self-reinforcing aspect (Frank, 1996; Schultz & Schkade, 1992). Schultz and Schkade (1997) indicate that "while performance of the activity may be a desirable outcome, the more important product is the experience of mastery that follows a successful adaptive response and the effect which that experience has on adaptation " (p. 465). The experience of meaning during a collaborative experience can be synergistic, in which the joy of accomplishment produces joy about collaboration, which encourages further collaboration and accomplishment. This is not unlike the experience of "flow" (Csikszentmihalyi, 1990), in which a just-right match of occupational challenge to individual ability produces a self-perpetuating experience of competence and resulting euphoria. The key to this, however, is that the individuals are adapting in their given environment. There are also social-emotional experiences that

occur during the activity that reinforce the relationship, or cohesiveness, between the collaborating individuals. These experiences also contribute to self-esteem, which in turn reinforce further interaction and collaboration.

Spencer, Hersch, et al. (1999) found that elderly individuals who were able to have their basic needs for support fulfilled, who were able to develop new or maintain previously existing social relationships, and who could engage in activities which were meaningful to them were more likely to successfully adapt to returning to the community after hospitalization. According to Spencer, Hersch, et al. (1999), "family members and other caregivers often play a crucial part in successful adaptation to life course disruptions" (p. 168). This researcher believes that spouses, friends, peers, co-workers, and other persons who engage in collaborative interactions with persons with disabilities can equally contribute to such effective and self-reinforcing adaptation, which can be both a short-term and a long-term process (Spencer, Davidson, & White, 1996; Spencer, Daybell, et al., 1998; Spencer, Hersch, et. al, 1999).

CHAPTER III

COLLABORATION BY PERSONS WITH DISABILITIES: A LITERATURE REVIEW

Submitted to *The Canadian Journal of Occupational Therapy,* July 18, 2002.

Introduction

Although the concept of client-therapist collaboration is an important one in client-centered practice, the notion of collaboration by persons with disabilities with other people in their environment has not been directly addressed in the occupational therapy literature or in health care in general. Because collaboration with others may contribute to quality of life in a variety of ways for persons with disabilities, this is an important area to explore. The purposes of this article are to a) review and integrate concepts relevant to collaboration by persons with disabilities found both in the occupational therapy literature and in the literature of other disciplines, and b) to examine the significance of collaboration as a means of adaptation to the environment by persons with disabilities. The categories in this literature review developed from open-ended brainstorming by the author and recommendations from other people about relevant literature and topics; much seems to fall into categories related to roles, occupations and environments. In examining why collaboration is significant for persons with disabilities it is useful to think about it in terms of adaptation.

Collaboration and the Client-Professional Relationship

The concept of collaboration between the professional and client is a central concept to the practice of occupational therapy and to client-centered practice (Baum & Law, 1997; Jongbloed & Crichton, 1990; Law, Baptiste, & Mills, 1995; Northen, Rust, Nelson, & Watts, 1995; Schultz & Schkade, 1992; Spencer & Davidson, 1998; Townsend et al., 2002). Canadian authors describe a client-centered Occupational Therapy Performance Process in which "occupational performance issues are...named, validated and prioritized with the client" (Townsend et al. 2002, p. 62). The main role of occupational therapy is to enable occupation, and "enablement refers to helping approaches that involve people as active agents in learning to help themselves" (Townsend et al., 2002, p. 15). These authors indicate that

> Enabling occupation means collaborating with people to choose, organize and perform occupations which people find useful or meaningful in a given environment....through collaborative partnerships, occupational therapists enable persons to achieve satisfactory performance in occupations of their choice. (p. 30)

In their study of the meaning of therapeutic relationships between occupational therapists and their clients, Rosa and Hasselkus (1996) explore themes of "helping" (p. 249) and "working together" (p. 251) as sub-themes of the concept of "connecting with patients" (p. 247). They found that working together involves a "sense of joining together in mutually supportive partnerships

characterized by compatibility, reciprocity, and rapport" and that "the give and take of reciprocity between therapists and patients forges connectedness" in which "...therapist and patient shar[ed] the work and responsibilities of therapy" (p. 251).

However, researchers in the field have noted that collaborative potential in the client-therapist relationship is not often realized, and that professionals often pay lip service to the notion of collaboration between client and therapist (Neistadt, 1995; Northen, Rust, Nelson, & Watts, 1994). At times, clients and their occupational therapists have conflicting goals (Bates, Spencer, Young & Rintala, 1993). Although some writers in the fields of disability studies and rehabilitation medicine report positive experiences with attendants in some institutions (Barnes, 1993; Berry, Hitzman, Stewart, & Darwin, 1995; Briggs, 1993; Frank, 1996), others tell of more negative interactions (Davis, 1993; Oliver, 1993). Some of the concerns that persons with disabilities have in their relationship with attendants are: loss of choice and control over how they are cared for; limited time on the part of attendants to provide care; and restrictions on the "range of tasks that professionals can perform...because of professional boundaries, employer requirements or trade union practices" (Oliver, 1993, p. 54). Newsom and Schulz (1998) indicate that caregiving recipients often experience negative reactions to receiving help, including problems with receiving too much or not enough help. Another concern is the loss of reciprocity

in the relationship between the person with a disability and the caregiver; this can have a detrimental effect on both persons involved (Parker, 1993).

Collaboration and the Concepts of Dependence, Independence, and Interdependence

Disabling Environments and Dependence

The effects of the environment and the concept of dependence are both significant when discussing collaboration. Dependence on others involves the need for help from others, and this interactive process of asking for, giving and receiving help can require a form of collaboration between the parties involved. Environments can foster dependence in individuals with disabilities. Oliver (1993) points out that the dependent state of persons with disabilities in society is created by industrialization and prevailing beliefs about independence which infiltrate the social, political, medical, and educational environments, affect social and economic policies, and cause an unequal power distribution in the relationship between client and professional. The concept of the disabling environment is also explored by Jongbloed and Crichton (1990) who state that disability is a function of the environment and not seated within the individual. This point of view is probably best advocated by Law (1991), who defines the environment broadly (including physical, social, cultural, socioeconomic and institutional aspects), and considers it to be more changeable than the individual. The environment plays either a supportive or constrictive role in the transaction

of person, environment and occupation, resulting in either maximized or minimized fit or occupational performance (Law, et al., 1996).

Physical barriers in the built environment can encourage dependency in persons with disabilities. In the social environment, disability often carries stigma and has social consequences such as social isolation and economic consequences such as reluctance on the part of employers to hire persons who are disabled (Goffman, 1963; Groce, 1984; Groce & Scheer, 1990; Scheer, 1984; Scheer & Groce, 1988). Collaboration may be one means by which persons with disabilities can transcend such barriers.

Independence and The Independent Living Movement

"An individual who does not possess the physical ability to perform such basic tasks as getting out of bed, tending to personal hygiene, or feeding oneself cannot survive without the assistance of another person" (Nosek & Howland, 1993, p. 789). Such an individual is not considered to be independent or to be able to live independently according to traditional concepts of independence and traditional living models for persons with disabilities (Murphy, Scheer, Murphy & Mack, 1988, p. 235). Scheer and Luborsky (1991) state that people with disabilities can often experience low self-esteem in the face of the strong values of independence and autonomy which prevail in our culture (p. 1175). French (1993b) states:

> Narrowly defined, independence can give rise to inefficiency, stress and isolation, as well as wasting precious time. Striving for independence and

> normality can lead to frustration and low self-esteem....An over-emphasis on physical independence can rob disabled people of true independence by restricting their freedom of thought and action. (p. 47)

The independent living movement developed out of a growing desire on the part of persons with disabilities to be heard, to be de-institutionalized, to take back control of their care, to have opportunities and access previously primarily available only to those without disabilities, and to have more fulfilling lives in general in their communities (DeJong, 1979; Nosek & Fuhrer, 1992a). The independent living movement attempted to eradicate old and dehumanizing models traditionally applied to persons with disabilities (Goffman, 1961; Haller, 1995; Nosek, 1993). According to Scheer and Luborsky (1991), "the independent living and disability rights movement changed the guiding principle of rehabilitation from daily functional independence to self-direction in life decisions" (p. 1174). A recent and significant example of the quest for independent living by persons with disabilities is the 1999 U. S. Supreme Court decision in Olmstead v. L. C., "which requires states to offer appropriate alternatives to institutional placement when reasonably possible" (Harrington & LeBlanc, 2001, p. 27). This can be considered a form of collaboration by people with disabilities, the legal system and the community at large which enables "independent living and greater social participation...(and) enable many to avoid unwanted and unnecessary institutionalization" (Harrington & LeBlanc, 2001, p. 27) (ADAPT, 2002.).

Some humanistic definitions of independence can be found in the disability studies literature. Oliver (1993) states: "disabled people...define independence...as the ability to be in control of and make decisions about one's life, rather than doing things alone or without help" (p. 54). Brisenden (1986) adds: "the most important factor is not the amount of physical tasks a person can perform, but the amount of control they have over their everyday routine" (p. 178).

Nosek and Fuhrer (1992a, 1992b) provide a hierarchical model with four progressive need stages of "basic survival, material well-being, productivity, and self-actualization" (1992a, p. 5) and four non-traditional components of independence- "perceived control over one's life...psychological self-reliance...physical functioning, and...environmental resources" (1992b, p. 3). They developed a profile which measures independence based on these four components. These stages and components are all aspects which can be supported by collaboration with others.

Interdependence

The concept of interdependence is central to the notion of collaboration. Law et al. (1995) define their concept of partnership in a client-centered therapist-client interaction, with the idea that the client and therapist are interdependent, that they can "...achieve together what neither could achieve alone" (p. 252). Meier and Purtilo (1994) suggest that " a comfort level should

develop between persons and their caregivers, which represents intermittent interdependence based upon trust" (p. 366).

Several examples of interdependence as a central component of collaboration are evident in the literature. Depner and Ingersoll-Dayton (1985), citing Clark and Anderson (1967) talk about the growing interdependence that develops between spouses during the aging process (p. 763). Scheer and Luborsky (1991) tell the story of a disabled elderly woman who "lost...a valuable disability ally who helped her maintain physical comfort and functional capacity" upon the death of her husband (p. 1176). Frank (1996) reports a situation in which a woman with a disability developed a relationship with an attendant in which she provided "a sense of home and mothering" (p. 52) to her attendant who in turn provided more and higher quality care for her than what could usually be obtained by normative standards. In one case, a social worker with blindness discussed the value of a partnership with his or her clients in which they were interdependent. "I'll help you, but there are certain ways in which you are going to have to help me" (French, 1993a, p. 204).

In reciprocal relationships, individuals are able to "...have some control of social situations in which they engage...and maintain acceptable adult-level relationships" (Powers, 1991, p. 45). Depner and Ingersoll-Dayton (1985) introduce the concept of "respect as regard" in which there is "the perception that one's thoughts, feelings, and wishes are being considered by the other" (p. 762).

Gage (1997) offers a model of interdependence in which interaction is based on elements such as "seeing the person as a whole", "feeling heard", "knowing each other as people", "mutual trust in competence", and "fostering innovation" (pp. 176-178), and then maintained through "the human touch", "reciprocity", "feeling valued" and "having fun" (pp. 180-181). Invoking such processes through interaction contributes to synergy in relationships (Gage, 1997). These are all qualities that can potentially result from collaborative experiences. It is through such interdependent, collaborative interactions, that a level of independence and accomplishment can be achieved.

The Significance of Friendship and Social Support

One way in which people can be interdependent is through friendship and social support, and friendship is one notable vehicle for collaborative efforts. Powers (1991) states that "unlike support relationships that involve helper and helpee, companionship is non-hierarchical" (p. 45). Meier and Purtilo (1994) discuss the need for "mutual respect such as that experienced in friendship" (p. 366). Jett (2002) indicates that cultural patterns influence ways in which people ask for and receive help from relatives, friends, and neighbors as exemplified in an elderly African-American community.

When friends work together on a project their creative activity, problem solving ability, ability to find resources and ability to reach a consensus increases and they advance cognitively (Zajac & Hartup, 1997, pp. 3-7). One study in the occupational therapy literature (Taylor & McGruder, 1996) explores the

meaningful aspects of a sea kayaking experience for persons with spinal cord injury. In this study, three respondents valued the sociability of the sea kayaking experience. Not only did persons support and encourage each other while kayaking and enjoyed sharing the challenge, but more importantly, they developed friendships out of this experience which served to continue to provide support when taking on other challenges and attempting other activities. When doing the activity of sea kayaking, the emphasis of the social interaction shifted from the disability to the activity itself. Other themes determined from the interviews in this study involved meaningful use of time and an opportunity to define oneself as competent despite social biases to the contrary regarding disability (Taylor & McGruder, 1996).

"...Esteem support, which increases feelings of self-esteem; informational support, which involves providing necessary information; instrumental support, defined as providing assistance with instrumental tasks; and social companionship, which involves various kinds of social activities" (Wills, 1985, pp. 61-62) are all types of support which can result from personal relationships. Collaborative experiences such as the sea kayaking adventure can involve exchanges of these types of support and companionship, and can ultimately contribute to adaptation and self-actualization of the individuals involved.

Another study of the significance of relationships found a connection between the number of reciprocal support relationships a person had and increased physical mobility, productive use of time, greater social integration and

economic independence. Greater physical independence was correlated with fewer relationships wherein the other party contributed more (Rintala, Young, Hart, & Fuhrer, 1994, p. 23). Interestingly enough, they found that participants in their study indicated more often that they were "very satisfied" with relationships in which others contributed more than in relationships in which they themselves contributed more, or where the contribution of both parties was reciprocal. (Rintala et al., p. 22). The authors suggested several models which might explain their findings. It could be that reciprocity in relationships might maintain or increase self-esteem, which in turn improves one's ability to enact social roles "...in terms of mobility, productivity, social integration and economic self-sufficiency" (Rintala et al., p. 25). It could also be that actively engaging in social roles may assist self-esteem, which facilitates the development of reciprocity in relationships. Finally, it could also be that a variable such as good overall health and motivation may encourage social role enactment and reciprocity in relationships. It is very likely that two or more of such models were coming into play concurrently (Rintala et al., p. 25).

Involvement in Leisure, Work and Volunteer Activities

Morgan and Jongbloed (1990) determined that meaningfulness of activities, personal standards for performance of the activity, internal/external control, range of interests, role balance (lack of knowledge about new leisure activities in which one could engage), transportation and distance to recreation facilities were all factors influencing leisure and social activities in the stroke

population. It was found that if an individual had a wide range of interests and was able to find meaningful activities, he or she was more likely to engage in activities. Furthermore, if an individual did an activity for enjoyment (as opposed to viewing the activity as part of his or her identity) and was able to lower his or her standard for performance of the activity, then he or she was more likely to engage than those who kept rigid standards for him or herself. Conversely, persons who had an external locus of control and felt that others were in charge of their lives felt inhibited about engaging independently in activities and therefore tended not to do so. Persons who had limited ability to travel due to loss of driving abilities were constrained in their attempts to engage in activities which were distant. Thus, a willingness to be flexible in attitude towards and how one does activities, a feeling of control over one's life, and ability to overcome environmental barriers such as transportation difficulties could contribute to greater involvement in leisure and social activities. Once again, these are all qualities that can be addressed through collaboration with others.

Bond and Feather (1988) discuss how having a job provides individuals with goals and tasks to accomplish. When individuals are not employed, the resulting lack of purpose and structure can lead to difficulties with how they perceive their use of time. Individuals who are able to fill their time were found to have better mental health (Bond & Feather, pp. 321-322). New routines and purposes are usually introduced through new roles which we either acquire by choice (such as retirement) or which are forced on us (such as disability) (Bond &

Feather, p. 327). Collaboration may be one way in which persons with disabilities can experience increased structure and purpose in their daily lives through the resulting ability to accomplish tasks, enact desired roles, and increase social interaction.

Meagher, Gregor and Stewart (1987) review the extent of support value for the recuperating member of the dyad of volunteer-patient dyads in the rehabilitation of individuals after cardiac surgery. Volunteerism has benefits which are similar to those resulting from collaboration, including increased self esteem, increased will to live and satisfaction with life, personal development, and decreased physical and psychological complaints (Hunter & Linn, 1981; Snyder & Omoto, 1992). Prestby, Wandersman, Florin, Rich and Chavis (1990) state:

> Research suggests that participation in voluntary organizations provides an effective means by which individuals can obtain the skills, knowledge, self-perceptions, political perceptions, and practice necessary for the development and growth of individual empowerment.... The benefits and costs of collective action are directly related to participation level and thereby provide a potentially powerful means by which to facilitate participation and thereby individual empowerment. (pp. 143-144)

One way to facilitate participation in volunteering and empowerment is through programs based on the concept of "Time Dollars" (Cahn & Rowe, 1992). In this concept, hours spent volunteering for others by individuals become an

exchangeable commodity which they can "bank" and then "cash in" when they need assistance from others. These types of exchange mechanisms can exist in the form of formal support programs for elderly persons, but they can also be culturally based or appear informally in neighborhoods. Cahn and Rowe (1992) discuss how such exchange networks can provide important built-in benefits to those participating, including: reconnection of the "old" ways and values which guided how neighbors assisted each other; improved self-esteem; increased motivation and ability to be active and involved in activities of one's choice, having one's needs met; connection to and having a role to enact in one's community; a sense of tradition, history and value in one's community over time; purpose in life; improved health; trusting and caring relationships; being involved in the flow of life again; dignity without feeling beholden to others; security; empowerment; decreased reliance on the impersonal or even mistrusted approach of professionals; contribution of one's abilities and knowledge; recovered identity; involvement with others outside of the self; social acceptance; structure for one's day; saving money; and the opportunity to be involved despite lack of education, disability, or meager finances (Cahn & Rowe, 1992, pp. 152-157). The concept of "Time Dollars" can be viewed as a form of collaboration which could be applied formally or informally by persons with disabilities with similar benefits. Persons with disabilities who collaborate with others in order to accomplish necessary or desired goals in their daily lives can be seen as

contributing to social change through their actions, as they are modeling new views of and approaches to disability, social relationships and the environment.

Collaboration and Adaptation

Adaptation is a phenomenon that is basic to living creatures. In the philosophical base of our profession, adaptation is discussed as a quality of being human, a process that all human beings continuously go through in our experience of living. We continuously adapt until our life ends (AOTA, 1979, p. 785). "Using their capacity for intrinsic motivation, human beings are able to influence their physical and mental health and their social and physical environment through purposeful activity....Adaptation is a change in function that promotes survival and self-actualization" (AOTA, 1979, p. 785).

Adaptation involves an interaction between the environment and an individual (Frank, 1996; Spencer, Davidson, & White, 1996; Spencer, Hersch, Eschenfelder, Fournet and Murray-Gerzik, 1999). When we experience illness or a disability, it causes a change in our relationship with our environment and we need to either adapt our relationship with the environment or our approach to tasks in order to successfully complete occupations and adapt (Spencer et al., 1996). Human beings adopt "adaptive strategies" in order to improve quality of life (Frank, 1996, p. 51). Echoing Morgan and Jongbloed (1990), Spencer et al., (1998) point out that those who undertake a proactive approach to adaptation probably need "creativity and ability to see things in new ways, flexibility, and willingness to take risks, and a relatively high sense of self-efficacy" (p. 481).

Collaboration with others may be a creative way in which persons with disabilities can adapt their environment or the tasks they undertake.

Adaptation also has self-reinforcing aspects (Frank, 1996; Schultz & Schkade, 1997). Schultz and Schkade (1997), in discussing King (1978) indicate that "while performance of the activity may be a desirable outcome, the more important product is the experience of mastery that follows a successful adaptive response and the effect which that experience has on adaptation" (p. 465). The experience of meaning during a collaborative experience can be synergistic, in which the joy of accomplishment produces joy about collaboration, which encourages further collaboration and accomplishment. This is not unlike the experience of "flow" (Csikszentmihalyi, 1990), in which a just-right match of occupational challenge to individual ability produces a self-perpetuating experience of competence and resulting euphoria. There are also social-emotional experiences that occur during the activity that reinforce the relationship, or cohesiveness, between the collaborating individuals and contribute to self-esteem, all of which reinforce further interaction and collaboration.

The relationship between adaptation and occupation is also reciprocal, in which occupational performance influences changes in the individual's developmental structure, which then influences occupational performance (Nelson, 1988; Schultz & Schkade, 1997). Collaboration can be seen as both an adaptation and a type of occupation each of which has influence on an

individual's developmental structure, occupational performance, and successive forms of occupation they engage in.

Persons with disabilities have indicated that connecting to others, especially family, is important in their adaptation processes and their spirituality (Schulz, 2002). Spencer et al. (1999) found that elderly individuals who were able to have their basic needs for support filled, who were able to develop new or maintain previously existing social relationships, and who could engage in activities which were meaningful to them were more likely to successfully adapt to returning to the community after hospitalization. According to Spencer et al. (1999), "family members and other caregivers often play a crucial part in successful adaptation to life course disruptions" (p. 168). This researcher believes that friends, peers, co-workers, and other persons who engage in collaborative interactions with persons with disabilities can equally contribute to such effective and self-reinforcing adaptation and occupation. This can be both a short-term and a long-term process (Spencer et al., 1996, 1998, 1999).

The Potential Value of Collaboration

Collaboration has the potential to facilitate the development of self-esteem, social interaction, involvement in meaningful activities and a sense of belonging, concepts congruent with wellness and quality of life. Adams, Bezner and Steinhardt (1997) define emotional wellness as "possession of a secure self-identity and a positive sense of self-regard, both of which are facets of self-esteem" (p. 211), while spiritual wellness is believed to be associated with "self-

esteem...family togetherness...social skills, coping beliefs, and connectedness" (p. 210). These are all conditions that can result from collaborative experiences.

Collaboration between persons with disabilities and their friends could provide a means for persons with disabilities to accomplish tasks or engage in activities that they might not be able to or want to do on their own due to their own limitations as well as barriers in the physical, social, cultural, political, institutional and economic environments (Law, 1991; Law, et al., 1996; Smalley, 1990; Taylor, 1991). Through collaboration with others, persons with disabilities may be able to achieve a level of independence important to them and meet their own needs through mutual support where they might not have been able to without a collaborator to work with.

In collaboration, there are positive aspects of depending on another person. Through collaboration, a person with a disability may be able to define and develop his or her own culture of flexibility, meaning, and validation of his or her life. Collaboration creates an opportunity for flow- where a balance is struck between the demands of a situation and the combined abilities of the collaborating individuals (Csikszentmihalyi, 1990). There is the enjoyment and synergy that results from working in a non-hierarchical context on a task with an ally who understands (Brown & Gillespie, 1992; Csikszentmihalyi, 1990; Gage, 1997; Meier & Purtilo, 1994: Powers, 1991; Rosa & Hasselkus, 1996: Schulz, 1994). During collaboration, the emphasis of the interaction becomes the activity and the disability can seem to be less of a focus (Taylor & McGruder, 1996).

Not only does collaboration provide an opportunity for the sharing of an experience, but it also provides an opportunity for mutual support and motivation. Collaborative efforts can result in improved self-esteem, self-worth and self-efficacy, as well as enjoyment, creativity, flexibility and adaptation, and increased opportunity. Collaboration can be a means of developing friendships, a way of deepening a previously existing friendship, or a way of adapting one's concept of friendship (Johnson & Troll, 1994). The resulting increased involvement in activity and improved self-esteem due to collaborative interactions with a friend can improve quality of life (Jones & Vaughan, 1990; Rintala, Young, Hart, Clearman & Fuhrer, 1992; Taylor & McGruder, 1996).

Often, the need to collaborate is the result of a major life change, such as a disability with a sudden onset, or when a progressive disability develops to the point where individuals can no longer do what they used to be able to do by themselves and where completing tasks one used to do with ease becomes an adaptive challenge. This is particularly true for the elderly population (Zarb 1993). "When a profound physical disruption is experienced, the relationships between self, body, environment, and daily life have to be redrawn" (Becker, 1993, p. 150). There may be long-term advantages to collaboration which may bring positive changes into the lives of persons with disabilities, and which can be regarded as part of a long-term adaptation process (Spencer et al., 1996, 1998, 1999).

As occupational therapists, it is our role to be flexible and to facilitate improved quality of life (Lloyd & Samra, 1996). A client-centered approach involves collaboration with the client and providing opportunities for clients to have experiences which are personally meaningful to them (Townsend et al., 2002). As Nelson (1996) states, "after a person finds meaning in a situation, he or she experiences purpose, or the desire to do something about the situation" (p. 777).

Collaboration, mutuality, facilitating adaptation in a client's own context, and providing opportunities for meaning are all areas occupational therapists need to be continually vigilant of, as we often fall short of these ideals (Meier & Purtilo, 1994; Neistadt, 1995: Spencer, 1991). It is important for occupational therapists to be aware of issues that may affect the well-being of our clients, and cognizant of new ways in which we can facilitate adaptation in those we serve, particularly as the practice of occupational therapy takes on an increasingly more significant role in the community. The occupational therapy profession supports and has adopted a broad definition of independence which includes the statements:

> Occupational therapy practitioners understand and value not only the independent performance of tasks, but also the use of adaptations or alternative methods to support independent task performance.... Individuals are considered resourceful when they have the needed devices or strategies available to them in their environments to support

> independent functioning....Individuals should not be stigmatized by the use of devices or strategies to support their unique approaches to independence. (Dunn et al., 1995, p. 1014)

Collaboration with others may be considered an alternative method for persons with disabilities to achieve independence. It is important for occupational therapists to be aware of the value of collaboration among persons with disabilities and of the issues involved around the desire to collaborate. Incorporating such awareness into our practice can only contribute to a client-centered approach and to the health and empowerment of our clients (Townsend et al., 2002) to do what they may be unable to do individually (Ferguson, 1984).

CHAPTER IV

SUPPORTING COLLABORATIONS AND SYMBIOSIS: PERSPECTIVES OF PERSONS WITH DISABILITIES

Submitted to *The American Journal of Occupational Therapy - Special Issue on Disability Studies and Its Implications for Occupational Therapy,* March 27, 2005.

Introduction

As an occupational therapy practitioner, the author occasionally observed instances in which clients assisted each other at various tasks in occupational therapy. For example, one client with mental illness and another with both cognitive and visual impairments collaborated and assisted each other on the respective craft projects each was doing. Informal observation suggested that the two clients were able to accomplish more on their projects via collaboration than if they worked on their projects individually. Further they appeared to gain a sense of satisfaction from what they were to accomplish together. Finally, a sense of friendship emerged from their having worked together to attain a goal.

Instances such as this stimulated questions about the broader nature of collaboration by persons with disabilities and how they were manifest beyond the context of therapy. For example, when, why, where, and how do people with disabilities in the community collaborate with others in their lives? Is collaboration by persons with disabilities important to their lives, and, if so, why? The present study explores these questions about collaboration by persons with disabilities.

Literature Review

The concept of collaboration by persons with disabilities is not directly addressed in the occupational therapy literature or in health care literature in general. However, the phenomenon of collaboration is directly relevant to a contemporary discussion of the concepts of independence and interdependence as they are discussed in the Disability Studies literature.

Independence

The concept of independence has long been addressed in the Disability Studies literature. They argue that an antiquated definition of independence, stemming from the medical model of disability still prevails in rehabilitation and in society. This concept of independence focuses on whether a person can perform necessary self care tasks and desired daily activities without the aid of another person. Conversely, persons with disabilities are considered dependent if they need assistance from another person throughout their day (DeJong, 1979; Nosek & Howland, 1993). Such dependence is considered undesirable and thus something to be avoided or reduced.

The Disability Rights movement and the Independent Living movement revolutionized the definition of independence. Writers argued that instead of focusing on measures of functional ability, independence should focus on individuals being in control of their choices, their decisions, and their lives, thereby being self-determining (Longmore, 1995; Oliver, 1993; Parker, 1993; Scheer & Luborsky, 1991; Nosek, 1993). Nosek and Fuhrer (1992a, 1992b)

provide a hierarchical model of independence with four progressive need stages of "basic survival, material well-being, productivity, and self-actualization" (1992a, p. 5) and developed a profile measuring independence based on the following four non-traditional components of independence: "perceived control over one's life...psychological self-reliance...physical functioning, and...environmental resources" (1992b, p. 3).

Interdependence

The concept of interdependence is burgeoning among people with disabilities. According to Gill (1995), recognizing interdependence as a part of existence is a central value of the disability community. Longmore (1995) states that persons with disabilities have values which stem from their experience of interdependence, connection to, and affiliation with others. Jacobs (2002) views interdependence as having enormous value to empower people with disabilities because of increased connection and the resulting sharing of information and knowledge.

The Disability Studies literature provides a few examples of interdependence; each involves collaboration as a central component. For example, Scheer and Luborsky (1991, p. 1176) described an elderly woman with disabilities who, upon her husband's demise "lost...a valuable disability ally who helped her maintain physical comfort and functional capacity". French (1993a) discussed a case of interdependence between a social worker with blindness and his or her clients. Scheer and Groce (1988) discuss a community of persons

with quadriplegia and paraplegia on Roosevelt Island, New York which became an example of the value of interdependence among persons with disabilities. They provided "...each other support and informal counsel about various issues, from attendant care management, to advice about dating, to equipment repair and purchase" (Scheer & Groce, 1988, p. 35). Many of the residents in this community formed connections not only among themselves but with people outside the disability community as well. These examples suggest that a variety of forms of collaboration are involved in expressing the value of interdependence. That the literature on interdependence mostly anecdotally provides such examples points to the need to know more about the nature and impact of collaboration.

Design and Method

This study employed a phenomenological, qualitative design to explore collaboration. Phenomenology is often used in qualitative research as it provides an insider view on the particular experience being examined (Creswell, 1998; Denzin & Lincoln, 1994; Patton, 2002). The study aimed to illuminate the perspectives of people with disabilities about their experience of collaboration with others.

Participants

The participants in the study were a convenience sample of five (two women and three men). Four of the subjects were professional contacts suggested to the author by a colleague who acted as a gatekeeper by initially

contacting participants about the study and obtaining permission from them for the author to contact them about study participation. The fifth subject was recruited by word of mouth via one of the other study participants. This study was approved by the Human Subjects Review Committee of the Institutional Review Board of Texas Woman's University, Houston. The age range of participants was from 49 to 53 years. All of the participants had a physical disability; two of the participants had quadriplegia, one had paraplegia, one had a head injury, and one had cerebral palsy. All of the participants were living in the community; four of the participants worked at jobs or professional careers and one participant was a hobbyist. Two of the participants had received a high school education; three of the participants had advanced degrees (see Table 1 for demographic information about participants). Four of the participants were married; the fifth participant lived with friends. All of the participants were from the middle or upper socioeconomic class. All were involved in the disability movement during the 1970s in one form or another either through participation in demonstrations or by consciousness raising activities about disability on their college campuses or in the community. Some are still involved in the disability movement today, serving on boards of or as consultants to different community organizations in order to promote disability awareness. As such, the participants in this study were well aware of the disability studies' discussion of the concepts of independence and interdependence. In order to protect confidentiality in the reporting of participant data, the names of the participants for this study have been replaced with

pseudonyms (please refer to Table 1 for pseudonyms and specific demographic information for each participant).

Data Collection

Data were collected through two in-depth interviews, semi-structured interviews that explored instances and the meaning of collaboration. In the first interview, participants were asked open-ended questions about their past experiences with collaboration and in the second interview participants were asked open-ended questions about their current experiences with collaboration. For purposes of the study, collaboration is simply defined as "working together to achieve a common goal", and collaboration in any and all aspects of life with anyone (with or without a disability) was explored. Each participant was interviewed orally and in-person by the researcher on two separate occasions about two weeks apart for one to two hours each time. Interviews were audiotaped. Participants were interviewed either in their homes or in a quiet and private area of a work environment.

Data Analysis

Audiotaped interviews were transcribed and subjected to open coding analysis by the researcher. Following an approach similar to one outlined by Creswell (1998), statements and themes related to collaboration were identified for each participant's interviews and coded according to their properties, until all instances of collaboration in each interview were identified by one or more properties and no new properties about collaboration could be determined. When

possible, if properties could be seen as subsets of a broader category, they were condensed into broader categories for each participant; if a property could not be condensed under another category, it became a category. The researcher then made a list of the categories of collaboration for each participant, making note when categories appeared to be overlapping, related, or contain aspects of each other.

Verification of Data

After data was gathered from the interviews and analyzed, the author used member checking, an approach used in qualitative research (Denzin & Lincoln, 1994; Patton, 2002) to insure greater accuracy of results. In the case of this study, out of five participants, three were involved in the member checking process. One reviewed, corrected and made comments on all of his interview transcripts, all of the properties the researcher had determined via coding them, and all of the categories generated from the properties from the researcher's coding of his interviews; another participant reviewed, corrected and made comments on all of her original transcripts and properties from the coding by the researcher; and a third participant reviewed, corrected and made comments on some of his interview transcripts and all of the categories generated from the properties from the researcher's coding of his interviews.

Findings

Many properties and categories related to collaboration emerged from the data, including categories relevant to collaboration by people in general, as well

as properties and categories specific to collaboration by persons with disabilities. Two categories of collaboration, supporting collaborations and symbiosis, are types of collaborative efforts that best illustrate how task support through collaboration promotes participation and is a form of adaptation. These two forms of collaboration also illustrate the centrality of collaboration in the lives of participants as an expression of interdependence or as a vehicle for greater independence.

Supporting Collaborations

A supporting collaboration involves one individual (or a group of people) assisting the person with a disability with a smaller aspect of a larger occupation. A supporting collaboration provides the opportunity for the person with a disability to participate in a larger leisure, work, or other occupation which would not be possible without the smaller supporting collaboration.

Janice, a 51 year old homemaker with paraplegia, related the following example of a supporting collaboration. She cannot completely supervise and direct a child in her family on the ski slope, but other adult family members take over some of the tasks so that she can participate in a family ski-trip.

> One of the reasons I want to take vacations with [my brother and his family] is because they can actually go on the ski slopes, where I can't, and so I'm...sure that there's an adult around when I take [X] skiing. ...I want to see him ski, but I can't be there for him on the slope...And...my brothers, their wives, their children are all very involved in that type of

collaboration... it's...a type of support group. ...I can't carry skis and push my wheelchair at the same time, and that has always caused a problem...so having my brother and my sister-in-law go with him to pick his skis out is very helpful....So I do have to coordinate with some able-bodied people to get him to ski school and I feel it's a lot safer to have an adult while he's skiing...

While Janice acknowledges that she could just send [X] to ski with her brother, she notes:

I wouldn't have been there, I wouldn't have seen the snow, I wouldn't have seen the fireworks and Santa come down the hill, I wouldn't...see [X]'s face all ruddy from being out in the cold and listen to the fun...times they had had and drink hot chocolate with him and watch him coming down the hill... It's fun to go skiing, even if you don't ski. I wouldn't miss it, that's worth it to me.

Guy, a 52 year old computer programmer with cerebral palsy noted that his life involved a great deal of collaboration: "First of all, I have to collaborate with people just to get there....I also have to ask people to help me go to the bathroom at work, as well as put my lunch out for me..." He also noted that people at work assist him with work tasks as well, and that supporting collaborations help him enjoy social interactions in the work culture:

They'll get [paperwork] off the printer which is in a different room and bring it to my office....When we go to meetings...people push me to the

meeting....Sometimes we'll all go out together, which is a form of collaboration. From figuring out where we're going to conversing about our jobs and our personal lives. Deciding how we're gonna get there [is important] because I always need help getting in and out of a car, and eating.

Karen, a 49 year old attorney with quadriplegia, described the following examples of supporting collaborations which occurred while she was in law school which allowed her to accomplish important work and life role tasks of being a law student and becoming an attorney:

When I would go to school, one of the first things I would do at the beginning of the semester [is] I would go up to the professor and ask the professor if he or she would make an announcement in the class that I needed copies of someone's notes, and that...preferably the person would have legible handwriting, and so the...professor would do that, and I would often get at least 2 or 3 hands...of classmates who would be willing to do that. And so I would work with these classmates on note taking in the...class, they might show me their notes, go over their notes, show me some of the abbreviations that they might use, so that I would be able to interpret what they had written. And in one particular case I remember, there was a student in law school that...not only would she take notes for me, but she sat next to me in class and she would also turn the pages for me so that I could follow along as the professor was reading. ... [A friend]

helped me take my bar exam. She wrote down all my answers, marked all the questions, and...stayed with me during the day and helped me take that exam.

As the quotes illustrate, participants emphasize the life-enhancing role of supporting collaborations in their lives. Supporting collaborations permitted them to participate in important professional, work, school, social and leisure activities and to accomplish important life tasks, such as sharing experiences with children or completing professional exams. Importantly, the supporting collaborations described above achieved their aims in non-obtrusive and natural ways that allowed the participants to preserve the essence and meaning of these life tasks and events.

It is important to note, however, that both participants with quadriplegia in the study, Karen and Michael, were less enthusiastic about supporting collaborations with attendants assisting them with their morning self-care routine, due to the loss of privacy and their requisite nature. As Michael, a 52 year old manager with quadriplegia stated,

> The collaboration I described about my waking up and dressing in the morning involves relationships and people that I couldn't, because of my disability, frankly, I couldn't do it on my own...so that's sort of a forced, you start with the assumption that there is a forced collaboration there, you really need to collaborate...just to get up, and given that then...I think

I've tried to find people...to engage in that collaboration that made the collaboration more relaxed and...more human if not enjoyable.

Karen expressed similar feelings: "The ones at home, they're...I wouldn't say they're pleasant or unpleasant, but it's routine, and it's required. And...some of that can be a little bit tedious."

Despite participants' reactions to these specific types of supporting collaborations, these collaborations were highly important to these participants because they were absolutely required for their functioning and survival and enabled them to be ready to engage in any desired occupations throughout their day.

Symbiotic Collaborations

The term, symbiosis, is used here to describe a collaboration between two individuals (or groups) in which members of each side of the collaboration bring different needs, abilities and/or contributions to the collaboration. In a symbiotic collaboration, each member's differing needs, abilities and/or contributions to the collaboration complement those of the other member, resulting in a mutually beneficial interaction and outcome.

Michael, a 52 year old manager with quadriplegia, described a long-term give-and-take relationship with his personal care assistant, who had a cognitive impairment:

We've ...had a collaboration, a symbiotic relationship that has...enabled both of us to be more independent than we would have been otherwise...I

remind him to take his pills.....reconcile his bank statement, and he works with me and tries to follow the process in turn. I...remind him his doctor told him not to eat so much salt on his meals....By the same token...he helps me getting in the wheelchair... he helps me get a shower. And...the outcome... is that...maybe, from time to time...I am clean and dressed and mobile, and he is...having a sense of accomplishment...for that and also...feeling as though he has shared in a...process for which the reciprocation may be...assistance...paying bills, or...any number of cognitive kinds of needs.

Karen described her work relationship with her secretary as an important symbiosis, the main goal of which was to get work tasks done efficiently. In this symbiosis, Karen provided the cognitive expertise from her training as an attorney and the direction for task completion while her secretary used her own training to carry out Karen's directions and provided task support with the physical aspects of the tasks that needed to be done. Each were also respectful of the other's emotional or personal needs.

...It's ironic that you should notice the symbiosis, or whatever, the symbiotic relationship that you...see because it is very true. Now this doesn't happen at the beginning... This is a relationship that's taken months, even years...to develop, and...that's why it's...so comforting at this stage because you're right, she does anticipate what it is I'm going to

need next. And, you know, we both anticipate each other's, well, maybe, moods, or feelings for that day.

Karen describes how their symbiotic relationship involves a careful orchestration they have learned:

> ...let's say I am reading a letter or reviewing a contract, and I know that it takes me some time to think about what I'm looking at- just to give it thought, for me to just have thought processed, time to do thought processes - that's when I'll have it in front of me and I'll be looking at it, but I'll say, well, you know, there's a quick little e-mail that I can answer in between while I'm thinking about this other stuff. . . So I'll have her pull up the e-mails that are like yes-no type answers, answer real quickly, and then I go back to what I'm thinking about but it's still giving me a little to kind of digest what I'm looking at. Or by the time [X] types it, sends it...creates a file, saves it and does all those things. . .I can be reading and accomplishing something else. So it's all time management.

Karen also describes how symbiotic collaboration requires that they are able to enfold their respective responsibilities together:

> For example, [she] must be available for her children, her husband, and her parents, so oftentimes she'll get calls from her family and I know this, and we've had this...like she knows I'll read through my mail and I'll just make gestures to her to turn a page but she might be...on the phone taking care of some business. And...that's also something we have just

learned and just worked out. Like when I'm on a personal [call] at my...own desk, you know she doesn't really pay attention. She knows that I'm doing something that I need to take care of. But likewise...she may do the same thing. But often times, you know, when she's on [the phone], it will be a[n]...opportunity for me to go through magazines...publications that I just need to kind of skim through, and so, basically what she's doing is turning pages. But she's actually concentrating on something else.

Brian, a 53 year old hobbyist with head injury, enthusiastically described how a symbiotic collaboration with his friend, who also had a physical disability, allowed them both to achieve autonomy that neither could attain without the other.

Without the help I get from this other person I wouldn't be independent and without the help this other person gets from me he couldn't be independent. So we collaborate to achieve independence....I've been helping [him] and...have achieved a lot more than I would have been able to achieve without, if I weren't helping him because I would be institutionalized. For...that's what they do with people who are head injury survivors these days is they put 'em in institutions. 'Cause they don't think they can do anything.

He goes on to explain how each contributes a remaining capacity to compensate for the other's impairment:

> I don't have [a memory] that works well. I'm his arms and legs, is basically the way it works. And, because I've helped him with the physical assistance he needs, he's been able to...go a lot of places he couldn't go otherwise because he...couldn't get out of bed...and into his clothes or into his wheelchair if [he] hadn't had my help. And by the same token, if he hadn't been helping me, I wouldn't have been able to...do any, a lot of the other things that I've done . . .because of the help I have gotten from him. The best way to describe [our] relationship is symbiosis—something that helps both of us....Neither one of us could be as independent as we are without the help of the other... That's why I call it symbiosis. 'Cause of the fact that we do help each other in the way we do....Neither one of us could be as independent as we are without the help of the other, or someone like the other person.

For Michael, Karen and Brian, symbiotic collaboration was an ongoing means to accomplish important life tasks and roles to or achieve a level of independence that would not otherwise be possible. However, symbiotic collaboration had another equally important dimension of mutual benefit achieved by two people working together in close and constant proximity. Some involved in a symbiotic collaboration exchanged cognitive, physical and emotional support in remarkably reciprocal ways. There is also a form of intimacy in this relationship characterized by the unusual extent to which persons must share close physical

space, and orchestrate their respective actions, and share and be considerate of highly personal actions and information.

Discussion

The symbiotic and supporting collaborations described by the participants are closely connected to the concepts of independence and interdependence in the Disability Studies literature. As the participants chose to engage in these collaborations, they further exemplify ways in which people with disabilities choose to be autonomous and in control of their lives. In this regard, collaborations allowed the participants to achieve the kind of independence envisioned by disability scholars (Brisenden, 1996; Longmore, 1995; Nosek, 1993; Oliver, 1993; Parker, 1993; Scheer & Luborsky, 1991). Both types of collaborations are also examples of situations in which people with disabilities were willing to receive or ask for help and saw the positive aspects of depending on others, reflecting the value that members of the disability community place on interdependence.

They also exemplify values of community and connectedness that are espoused by disability activists. As French (1993b, p.47) states, "...giving and receiving help can greatly enrich human experience". The eagerness with which some participants spoke of their collaborative experiences and the ability of such experiences to improve their lives in meaningful ways attest to that richness.

While the participants for the most part spoke positively about collaboration, it should be noted that some participants' enthusiasm for different

types of supporting collaborations existed on a continuum. Some participants viewed the habitual, required supporting collaborations of the morning ADL routine as tedious or involving loss of privacy. Both of the participants Karen and Michael felt that having someone assist them with such tasks who demonstrated a good attitude in the collaboration, or someone that they were compatible with or even friends with enhanced the nature of those specific types of supporting collaborations and made them more enjoyable, a notion substantiated by Roeher Institute (2001).

Also, it is also noteworthy that Karen, who had C1-C2 quadriplegia, stated that she felt that because of her disability she had very little time to herself, or "alone time". Usually, the more disabled a person is, the less alone time he or she has because the more he or she has to collaborate. The need for more alone time appeared to be an issue for some participants and not for others, and seemed to have just as much to do with someone's personality as it had to do with his or her type of disability. For example, the participant, Michael, who had C4-C5 quadriplegia, said that "...for some people...with disabilities...that's one of the worst things about having a disability – is that you don't have privacy, generally speaking. That you are forced to be interdependent with other people and so on...but for me that's a blessing." The notion that interdependence and collaboration are complex issues is supported by Walmsley (1993) who found that receiving and giving care can simultaneously provide sustenance and frustration, and by Roeher Institute (2001) who discuss the need for respectful

interdependence between people with disabilities and providers of support. Further exploration about these topics is warranted.

It is clear that, despite the above issues with lack of alone time and forced or required supporting collaborations, study participants felt overall that symbiosis and supporting collaborations were immensely beneficial to them. Through such collaborations, participants were able to accomplish necessary and desired tasks they would normally not be able to, thereby achieving a better quality of life.

This paper represents a step in examining the phenomena of collaboration by persons with disabilities. The findings are paralleled by Tham and Kielhofner's (2003) observations about collaboration in their study of environmental influences on women with unilateral neglect:

> Those who became collaborating partners for the women had to become comfortable with being used as "instruments" for these women's performance. They had to allow themselves to be incorporated as a kind of unique sensory organ that enabled perception of the left-world, when they provided information about the left world. They also served as instruments when they rearranged objects in the left world at the request of the participants (p. 410).

Taken together their and the present study again suggest that collaboration may be a widespread and complex phenomena worth further exploration in occupational therapy research.

Conclusion

Occupational therapy has adopted the following definition of independence:

> Occupational therapy practitioners understand and value not only the independent performance of tasks, but also the use of adaptations or alternative methods to support independent task performance...Individuals are considered resourceful when they have the needed devices or strategies available to them in their environment to support independent functioning....Individuals should not be stigmatized by the use of devices or strategies to support their unique approaches to independence. (Dunn, 1995, p.1014)

The use of symbiosis and supporting collaborations could also be viewed as a unique adaptive strategy for people with disabilities. As the participant, Brian, stated: "I've chosen to collaborate to achieve the goals I've set that I couldn't have achieved without the collaboration of other people..." It is important for occupational therapists to be aware of the value of collaboration to persons with disabilities as a form of adaptation which can empower them in the attainment of meaningful life goals. Moreover, our own understanding of independence would benefit from a clearer underscoring of the tenets of autonomy and self- determination as well the recognition that they often require a significant measure of interdependence.

Table 1

Participant Demographics

Name	Age	Gender	Disability	Education	Occupation
Guy	52	Male	Cerebral Palsy	Advanced Degree	Computer Programmer
Janice	51	Female	T-8 Paraplegia	High School	Self-Employed /Homemaker
Karen	49	Female	C1 – C2 Quadriplegia	Advanced Degree	Attorney
Michael	52	Male	C4 – C5 Quadriplegia	Advanced Degree	Manager
Brian	53	Male	Head Injury	High School	Hobbyist

CHAPTER V

COLLABORATION IN THE MARRIAGE RELATIONSHIP AMONG PERSONS WITH DISABILITIES

Submitted to *Disability Studies Quarterly*, September 17, 2006.

Introduction

This study explored themes of collaboration in the marriage relationship among persons with disabilities. The types of collaborations in such marriages can help practitioners understand how disability can affect interactions between spouses and how spouses might gauge their collaborations with spouses because of disabilities that they, their spouse or both of them may have. It also appears that certain kinds of collaborations and themes emerged in the marriage relationship for persons with disabilities which were indicative of a high degree of mutual respect and love. For purposes of this study, collaboration was simply defined as "working together to achieve a common goal", and collaboration in any and all aspects of life with spouses (with or without a disability) was explored.

Literature Review

The literature revealed some examples of interdependence as a form of collaboration in the marriage relationship. There is a growing interdependence that develops between spouses during the aging process (Clark & Anderson 1967; Depner & Ingersoll-Dayton, 1985). Scheer and Luborsky (1991) tell the

story of a disabled elderly woman who "lost...a valuable disability ally who helped her maintain physical comfort and functional capacity" upon the death of her husband (p. 1176). Oelschlaeger and Damico studied how a man with aphasia used repetition as a form of collaboration in conversation with his wife to compensate (1998b). They also studied a man with aphasia and his wife in the use of joint production in conversation, wherein one member of the conversation starts to speak and then their turn is completed by another person (Oelschlaeger & Damico,1998a).

A recent area of research by a few scholars has been in the area of collaborative cognition among the elderly, which "refers to processes and outcomes that occur when two or more individuals engage jointly in activities such as problem solving or memory" (Strough, Patrick, Swenson, Cheng & Barnes, 2003, p. 44). Most studies on collaborative cognition involve married couples (Strough, et al., 2003). One such study by Berg, Johnson, Meegan and Strough (2003) determined that married couples use a variety of approaches to and patterns in their collaboration in their daily lives, including the division and delegation of tasks.

Parker (1993b) discusses the problems and changing dynamics relative to the independence of both spouses, power differences and balance of exchange within the relationship, self-care, financial management, effect on children and assistance from immediate and extended family as well as outside resources when one spouse in the marriage becomes disabled. For example, after the

onset of disability for the husband, "in all cases where male spouses had taken substantially increased control over household finances carers tended to explain their acceptance of this in terms of giving the spouse something to do." (p. 80). Parker (1993b) also mentions spouses' need for time away from each other. Finally, referring to Duck (1983), Parker (1993b) suggests that "when the fairness of equity of a relationship feels out of balance...one or both partners will re-examine the relationship and make attempts to redress the balance." (Parker, 1993b, pp. 89-90). Frank (2000) discusses some of the dynamics in the relationship between a woman with congenital limb deficiency and her boyfriend who later became her husband and from whom she was later divorced. Garee and Cheever (1992) provide numerous vignettes of married couples wherein one or both members of the couple has a disability and the various coping strategies they use to get through their day, including use of technology, planning of the home environment, focusing on strengths, having realistic expectations of what each other can do and doing what they can, sense of humor, creating their own roles, finding time for oneself, work, awareness of self-care issues, and a strong bond of love.

There was a minimal amount of literature on the topic of collaboration in marriage, especially for people with disabilities. This would indicate that further research on this topic is needed and this study represents a step in that direction.

Design and Method

This study employed a phenomenological, qualitative design. Phenomenology is often used in qualitative research as it provides an insider view on the particular experience being examined (Creswell, 1998; Denzin & Lincoln, 1994; Patton, 2002). The purpose of this study was to reveal perspectives and experiences of people with disabilities regarding their collaboration with their spouses.

Participants

The study presented in this article was a subset of a larger study on collaboration by persons with disabilities which had five original participants. For the study discussed here, the data from the fifth participant was not included because he was not married. Therefore, the participants in this study were a convenience sample consisting of two men and two women. Three individuals were suggested to the author by a colleague to be participants in the study. This colleague acted as a gatekeeper by initially contacting the participants about the study and obtaining permission from them for the author to contact them about study participation. One of these study participants suggested the fourth study participant, who was then approached by the author about study participation; therefore a "word of mouth" or form of "snowball" sampling was used to recruit the fourth participant. In snowball sampling, new and possible participants are obtained from asking other participants (Patton, 2002, p. 194).

The age range of participants was from 49 to 52 years. All of the participants had a physical disability; two of the participants had quadriplegia, one had paraplegia, and one had cerebral palsy. Three of the four of the participants were married to someone who also had a disability. All of the participants were working and living in the community. One of the participants had received a high school education and three of the participants had advanced degrees. All of the participants were currently married and were of a middle or upper socioeconomic class. In order to protect confidentiality in the reporting of participant data, the names of the participants for this study have been replaced with pseudonyms (please refer to Table 2 for pseudonyms and specific demographic information for each participant). This study was approved by the Human Subjects Review Committee of the Institutional Review Board of Texas Woman's University, Houston, TX.

Data Collection

Data were collected via two methods. The first method was through two audiotaped, in-depth, semi-structured interviews that explored participants' experiences with collaboration and the significance of collaboration for them. In the first set of interviews, participants were asked open-ended questions about their past experiences with collaboration; in the second set of interviews participants were asked about their current experiences with collaboration. Each participant was interviewed by the researcher on two separate occasions about two weeks apart for one to two hours each time. Participants were interviewed

either in their homes or in a quiet and private area of a work environment. For this study, there was a total of eight interviews.

The second method of data collection was through participant observation. The term "participant observation" refers to researchers making field observations of a social environment by being around or in that environment in order to analyze it qualitatively (Lofland, 1971, p. 93; Patton, 2002, p. 262). In this study, participants were observed as they collaborated with people in their lives throughout the day- with family members, co-workers, strangers or friends. Participant observations for each participant occurred on two separate occasions about two weeks apart for one to two hours each time. Participants were observed in their homes, at work, at church or while on a family outing.

Data from a total of ten participant observation sessions were used for this study. Six of the participant observation sessions directly involved the participants. For the remaining four participant observation sessions a participant's spouse either contacted them by telephone, fax or e-mail during the observation or the participant spoke about their spouse to others in their environment, and data were excerpted from those parts of the sessions. Data were collected in the form of field notes and noting conversations between participants as accurately as possible.

In addition to the four participants who were interviewed and observed, anyone who was also observed along with them also signed a consent form. In every case, the author was the sole interviewer and observer. In order to protect

confidentiality on the reporting of data, pseudonyms are used for the spouses of participants when they are mentioned in this article.

Data Analysis

Data from audiotaped interviews and participant observations were transcribed and typed. Then, using a method known as open coding, the author coded data from all of the interviews for the concept of collaboration. Following an approach similar to one outlined by Creswell (1998), statements and themes related to collaboration in the interviews were identified for each participant's interviews and coded according to their properties, until all instances of collaboration in each interview were identified by one or more properties and no new properties about collaboration could be determined. When possible, if properties could be seen as subsets of a broader category, they were condensed into broader categories for each participant; if a property could not be condensed under another category, it became a category. The researcher then made a list of the categories of collaboration for each participant, noting when categories appeared to be overlapping, related, or contained aspects of each other.

Excerpts from the original interviews which were relevant to the marriage collaboration were isolated by the author and submitted to a total of three other coders to be coded with open coding analysis relative to the marriage collaboration. Therefore, each piece of data relevant to the marriage collaboration from a total of eight interviews was subjected to open coding by two separate coders including the researcher.

Six participant observations and excerpted data from four additional participant observations relevant to the marriage collaboration were then coded by the researcher and the same other three coders using open coding analysis for the marriage collaboration. Therefore, each piece of data relevant to the marriage collaboration from the participant observations from a total of ten participant observations was subjected to open coding by two separate coders, one of whom was the researcher.

Verification of Data

As described above, selections relative to the marriage collaboration from a total of ten participant observations and eight interviews were individually coded using the open coding method by a total of three other coders in addition to the author, so that each selection was coded by the author and one other coder (with the exception wherein one small set of selected data was coded by the author and all three coders to help determine if there was consistency across coders). Then, working together, the author and one of the coders combined the codes generated by the author and the individual coders from the interview and participant observation data into broader categories. Finally, the author and coder collapsed these broader categories. Most of these categories were further conceptualized into five main groups of data. A follow-up validation of codes and categories involved a second, outside coder in the coding and in the multi-step categorization processes.

Member checking was also used to assist in the validation of the interview data. In the case of this study, of the four participants, two were involved in the member checking process. One reviewed, corrected and made comments on all of his interview transcripts, all of the properties the researcher had determined via coding them, and all of the categories generated from the properties from the researcher's coding of his interviews; and another participant reviewed, corrected and made comments on all of her original transcripts and properties from the coding by the researcher. Finally, the data also have credibility because the researcher was able to enter the world of the participants, and participants allowed that entry.

Findings

Twenty-one major categories relevant to the marriage collaboration by persons with disabilities were generated from the data. Within these 21 categories there might have been anywhere from 1 to 17 codes. Of those original 21 categories and their codes, some were eliminated because of redundancy and/or insignificance, or because they were unrelated to the core issue of the marriage collaboration or because data was insufficient to support them.

Five themes relevant to the marriage collaboration by persons with disabilities emerged from the data, and include: 1) Practical Considerations; 2) Collaboration on Occupation; 3) Structures and Patterns of Collaboration; 4) Social Considerations; and 5) The Qualities that Make the Marriage Collaboration

Special. Please refer to Table 3 for a graphic display of the categories and subcategories.

Practical Considerations

Most of the themes in this category represent an approach to daily tasks which are representative of joint cognitive efforts between the spouses.

Division of tasks and roles according to abilities. One major theme which emerged from the data was division of tasks and roles between the spouses according to abilities. Tasks and roles were divided between the two members of a couple. Sometimes this division of tasks or roles was based on the interest of the individuals but often it was done according to how each of them was equipped (usually physically) to handle the task. For example, Janice (who had paraplegia) drove the van that she and her husband used for transportation while her husband (who had quadriplegia) purchased it. In some cases the roles evolved based on the skills and the abilities of the parties; in other cases the division of labor was discussed and decided on early in the marriage.

In the case of Guy (who had cerebral palsy) and his wife (who did not have a disability), Guy managed their finances on the computer via adaptive equipment which he referred to as a "headfinger" which was a headstick that he wore attached to a band around his head allowing him to press the keys on the keyboard. He described the division of tasks in this manner:

> The way it works around here is I do everything I can do on the computer because there's a lot of physical things that I can't help with. But even

though I might do things on the computer like our finances we collaborate together to decide how that should be handled.

Guy's wife did most of the other physical tasks necessary in the marriage and was usually the one who talked with repairmen as needed because her husband's dysarthria made it difficult for him to communicate. In turn, Guy provided emotional support to his wife, particularly while she was speaking with repairmen, by being with her and helping to talk her through it.

It should be noted that Guy made a distinction between what he referred to as tangibles and intangibles in his marriage:

> We both like to travel but my wife has to handle a lot of the tangibles. However, we both decide what we want to do, and how to do it. And because it's my job to do the finances, I do most of the deciding if we can afford to travel or not.

Guy felt that there was an imbalance in the amount of physical tasks his wife had to do in the marriage as compared to how many he had to do. He said:

> I think she has to do more things than I have to....there's an imbalance in the tangible things. But I think I do a very good job with the intangibles....I usually help out emotionally whenever I can.

Karen and her husband decided early on in their marriage about certain roles they would have. Karen (who had quadriplegia) was to be the breadwinner and work out of the home while her husband (who also had quadriplegia, but a less severe form) would stay home and handle the finances for the couple on the

computer. Another area in which a division of labor was evident was in her description of their collaboration while going to the grocery store:

> For example, when we go grocery shopping. Walter does the driving…he gets us to the store, and goes to the store with me and maybe picks things off the shelf. But usually the decision about what we are going to buy it's probably mostly mine. Except maybe when we get to the meat counter because he likes steaks, so he goes up to the meat counter and tells the butcher what steaks he wants to buy so I kind of let him do his thing there. But I think…for the most part, the meal planning is mine. And then when we go to the store we talk about oh, you know, do you want to have this this week or do you want to have that, and so we certainly jointly decide what we're going to have. But in terms of what ingredients to buy he leaves that up to me, and then of course when we get to the check out counter he pays…the bill. And so that's kind of our typical arrangement there.

Janice also reported that she and her husband often collaborated using lead roles. For example, he would research features and prices of items they wanted to buy, bring the information back to her, and they would decide together what to purchase. He chose this lead role due to his interest in shopping and bargaining.

These are examples of where tasks and roles were mostly divided between the two members of the couple according to physical ability (driving,

taking down items from the shelf, paying the bills) and/or according to knowledge, skill or interest (delineating what ingredients are needed, choosing meats).

Collaboration about the environment. Some notable areas in which participants collaborated were the areas of decision making and planning about and management of their household environment. Some participants collaborated with their spouses on the adaptation of their home environments in order to make it accessible. Another area in which they collaborated were attendant arrangements. For example, during one participant observation session, Guy and his wife collaborated on printing out a flyer to post advertising a job as a part-time caregiver for Guy. Karen discussed at length her collaboration with her husband on the purchase and remodeling of their home:

> When we bought our house...we certainly both had ideas of what...kind of house would work for us...and...we would talk about...what kind of kitchen it had to be, could there be a big center island or not, would hallways work, or...are they too hard to maneuver...if we looked at a hall that had a lot of carpet that might be a little difficult because it's so hard to roll off....And we worked together on remodeling, trying to decide what colors did we want in the bathroom...even though we knew we had to have a roll-in shower, there were still decisions to be made like how big it should be...did we want to knock out any walls and make the bathroom bigger, or just try to make it as small as possible to get by. We had to look

at the height of the sink, and that was his decision because he's the one who rolls under it, so, some of the decisions about how the house got remodeled had to do with who had to use the particular item that was getting remodeled.

Problem solving. Another area of collaboration by people with disabilities in their marriages which emerged in these data was in the area of problem solving. The couples often worked on solving problems together which came up during the course of the day. Most situations had to do with working together on figuring out how to accomplish a certain task considering the disabilities of the individuals involved; some had to do with determining while on the road why a particular piece of adaptive equipment was not working and how to fix it temporarily until they could get home and get it properly repaired. Some had to do with simple navigation on and off of a ramp to a van. One example occurred in a participant observation session with Guy and his wife in which they demonstrated a long-standing routine between them as Guy transferred from his wheelchair after it was in the van into a seat in the van. In this routine, Guy's wife put his hand in a strap (actually a dog leash) which they had affixed to the ceiling of the van. Both of them waited for Guy to position his right hand over his left hand and to get his feet into the right position. Guy then signaled when he was ready by saying "OK" and then his wife grabbed him while he pivoted and landed on the seat.

Another example of problem solving occurred during a participant observation of Karen and her husband as they were leaving to go to a meeting. Karen asked her husband to get her wallet and asked me to carry her water. Her husband started and opened the van with a remote. He then backed his wheelchair into the van. Karen backed in off track and her husband told her how to realign. Then he put her seat belt on her. She and her husband then talked to me about van repair problems. Karen asked me to give her water to her husband so she could sip it. He then held the water for her and put it down when ready.

The use of technology. Another area in which people with disabilities collaborate with their spouses is in the use of technology. They often used various forms of technology to facilitate collaboration and communication with each other throughout their day. These forms of technology included but were not limited to the telephone (cell phone; hands free phone with a headset while driving with hand controls; speaker phone; and fax), the computer (e-mail; fax; "Easy Access" program in order to be independent with use of computer; using the computer and a headstick to do financial management), and driving vans which were equipped with automatic starters, automatic door openers, hand controls, or easy lock devices to lock down wheelchairs. Sometimes "low-tech" items were used; for example, Guy and his spouse came up with the creative idea of using a dog leash which they hung from the ceiling of their van as a strap for him to hook his arm into to provide stability and control while transferring. One excellent example is in the case of Michael who called his wife on his cell phone

from his bedroom down the hall to talk to her about what he wanted to eat for dinner. This approach was far more convenient, efficient and timely than asking his attendant to transfer him out of bed into his chair and wheel down the hall to talk to her.

Collaboration on Occupation

Work. In the area of work, participants were seen to support each other in their desires for careers, work outside the home, work inside the home, work tasks, and work interests in general. In some cases, one spouse supported another in the writing of a resume or calculating figures for work. One of the participants, Janice, was self-employed outside of the home. Her husband was supportive of her interests in that regard in addition to his work outside the home. Karen discussed the decisions she and her husband made together early in their marriage about their work roles:

> Well...since we've been married our roles have been, and this was kind of an agreement that we came to when we first got married as that my role would be...I would continue to work at my job as...an attorney, that I would...go to work during the day and he would be at home, and work all day on the computer, that's what he's done for many, many years and so his job is...more financial planning, doing our budget on the computer, entering checks, looking at...maybe loans, mortgages, how many years it's gonna take to pay that off...just kind of general financial matters...and he would handle all of that. He also takes care of all of our mail, paying all

> of our bills, and my role is the person who leaves the home and goes out and...does my thing...and so this was an agreement but...I think that...we have worked together to make the decision that these would be our respective roles.

Self-care. These types of collaborations with spouses occurred during participant observation sessions and centered mostly around eating. A good illustration of a self-care collaboration occurred between Guy and his wife during a participant observation session while they were attending a meal at their church. In this example, Guy's wife put her purse on his wheelchair and wheeled him in to the dining room. She put a napkin in his pocket. Then she went over to the food buffet carrying two plates (one for each of them). She asked him if he wanted Jell-O. Guy followed her, telling her what he wanted while she filled the plates. She didn't always hear him correctly. He told me he knew she was going to get him water. They pulled up to the table and he asked her to lock his brakes. She fed him while talking to a friend. He listened and waited to eat, leaning in toward her and sitting sideways to the table so as not to get food all over. She wiped his mouth during and after eating. Then she took him to the rest room, holding the door for him and pushing his wheelchair. Guy stated he was hot, so his wife took off his tie, unbuttoned his shirt and took off his jacket.

Structures and Patterns of Collaboration

Some typical and recognizable patterns in the marriage collaboration by people with disabilities emerged from the data. The theme of role division

discussed above was a strong pattern, but there were other patterns that became evident. These had to do with stating one's needs, requesting assistance with a physical task, or anticipating needs of one's spouse.

One example of requesting assistance with a physical task occurred in a participant observation session in which Michael (a man with quadriplegia) and his wife (who had paraplegia) were at home and both working at their computers. Michael asked his wife to do some paperwork and add up some numbers for him. She asked if she had to come over to get the paperwork and numbers. He explained to her how to add them up and make a running tab for him on the data. Michael's wife typed up and printed out an accounting of the airplane ticket coupons he asked her to add up. She went over to him and gave him a printout of the total. He acknowledged it while talking to people on the phone.

Some examples in which Michael stated his needs and/or his wife responded to or anticipated his needs by completing a physical task occurred during two separate participant observation sessions while eating out at restaurant. For example, in these sessions. Michael's wife anticipated his needs by paying for the food, putting lemon in his tea, cutting his food, feeding him bread, toast or a pickle, and pouring capers on his food. Michael stated his needs and requested assistance in asking for butter for bread, asking for tea and for her to stir it, asking for lemon, asking for salt, and asking his wife to bring the plate over closer to him. She responded to his requests.

There was a temporal quality to some of the collaborations in which the spouses engaged. Some of them had invested hours planning about their home environment together. Participants had been married a long time and their collaboration was therefore a long-term one. According to Guy, "I do have a job description now in our marriage. But it's because we have figured out what I'm best at." They had learned and realized over time how to work things out best in their collaboration.

Social Considerations

Helping. Spouses assisted each other. Karen's husband assisted her in safely navigating up the ramp to their van and buckled her seat belt. In a more extreme example, Karen reported how her husband had assisted her in an emergency situation with her ventilator by calling 911. Guy's wife stood in a crouched position while holding the hymnal for him in church so he could see it. She also assisted him in communication by acting as an interpreter for others who had difficulty understanding him. Guy and his wife compensated for each other's deficits. When she talked to repairmen he supported her emotionally through the process. At times Guy would carry his wife's purse in his wheelchair while she pushed it. Other times he would assist her by wheeling his chair himself which, because of his spasticity, would often mean wheeling backwards while watching over his shoulder. At times an exchange of services could be observed between them during participant observations. For example, Guy

brought up and printed out on the computer a flyer advertising for a caregiver for him while his wife explained to me what the job was about.

Making a contribution. This theme was seen primarily in the relationship between Guy and his wife. Guy had a desire to be as independent in areas such as donning the headfinger, and his wife allowed him to do that. Guy and his wife used their skills for the benefit of both parties. For example, one spouse was good at budgeting, the other used technology in the form of the computer to compensate for his physical deficits to manage the finances. His wife did not have dysarthria so she was the one who usually spoke to repairmen. A quote from Guy sums the situation up well:

> We realize that one of us may be better equipped to handle some things than the other and vice versa. And we're comfortable contributing what we can.... I don't know if I would call it fair. But I think we each do what we can to contribute to the marriage.

Alone time. The researcher included a question regarding alone time in the interviews to determine participants' perspective on situations in which they were collaborating with others. Generally speaking, the more severe the disability a participant had, the less alone time they had because of the amount of care or assistance they needed. Michael spoke about the subsequent loss of privacy that comes with disability. Michael did not enjoy alone time because he was concerned for his safety when alone. Karen (who had the most severe disability), in particular, enjoyed alone time because she really could only get it at the end of

the day when she could be alone with her "own thoughts". Janice and Guy responded that they enjoyed alone time because they were in control of what they were doing and when they were doing it. As Janice put it,

> My husband travels and that's one of the reasons I married him, 'cause I knew I could have some alone time....I really enjoy just the peace and quiet, and...the ability to...not do anything, not to have any demands...I mean I don't want it for a very long time, but it's nice to have the break and I enjoy it."

Allowing/Freedom. The themes of allowing and freedom were closely related to each other. Participants were aware of each others' strengths and interests so they allowed each other to make the decisions and follow through on those interests. For example, Karen allowed her husband to choose the meats he wanted for dinner at the meat counter. She also allowed him to be the one to choose certain items they were going to remodel in their home because those items were the ones that pertained to him (such as a sink with wheelchair access). Participants also allowed their spouses to pursue their own work interests outside of the home. These allowances indicated a sense of respect and individual freedom within the relationship.

The themes of allowing and freedom were also closely related to the theme of alone time discussed above. Participants allowed their spouses to pursue their own interests. This was often evident in participant observation sessions in the homes of participants. Often, Michael and his wife would be

working in each other's vicinity but on separate projects on their own computers, such as hobbies on the internet or work from home. Some spouses allowed each other the space and freedom to socialize with others at church. For Guy, allowing and freedom were closely related to alone time and were indicative of a high level of trust in the marriage. Guy said,

> Right now my wife plays piano in a couple of different groups here. So she'll practice once or twice a week. She'll also go out dancing at least once a week and this will give me the alone time that I enjoy. Because I can either read or...I can watch T.V. by myself. I also stay up a lot later than my wife most of the time so I can get a lot of alone time that way, too.

Another quote from Guy seems to sum it up: "We do a lot of things together. But we also know what we need to do some things apart. And I think that is a form of collaboration, too". Spouses gave each other the freedom they needed to be themselves and to "breathe".

The Qualities That Make The Marriage Collaboration Special

Data generated by participants in this study seemed to indicate a variety of qualities in their marriage relationship that pointed to a strong relationship between the spouses. Some of these elements were mentioned by study participants in their interviews but most were observed during participant observation sessions. Some of these elements were best expressed by Karen in one of her interviews:

I think the most obvious to me collaborative effort I've had in my life is with my husband. And that's...certainly a mutual respect for each other, and just desire to be together and spend quality time together.

Certain behaviors on the part of participants indicated the value they put on their relationship. Study participants kept in touch with each other throughout the day via telephone, e-mail and fax. They expressed good feelings about their spouse, shared information about their spouse's current plans, and also shared about their past experiences and demonstrated pride in their accomplishments as a couple to others in their environment. Study participants also supported the emotional needs of their spouses, often putting their spouse's interests first or deferring to their spouse. When working on tasks side by side or separately in their home environment they often connected through dialogue or exchange of tasks. During such times some participants were observed to tap into a stream of mutual knowledge and information in order to perform daily tasks and function.

Some mentioned or demonstrated an orientation towards a future vision of togetherness as they planned their home environment or attendant arrangements. This was well expressed by Karen as she described the process she and her husband went through when they were planning to move into their new home:

When we moved into our home we...spent many, many hours planning on that—how we were going to do it, what it was going to cost us, we also spent a great deal of time looking at houses, looking at what would be

accessible for us, or looking at how much modifications did we have do in that house. So that was certainly a...collaborative effort as husband and wife, to plan for a life together.

Study participants also showed an ability to disagree with each other, or to refuse suggestions when necessary. They used a sense of humor at times while interacting, sometimes as a means of overcoming hurdles in their collaboration. Some expressed that they had learned lessons over the time they had been together - one of which was to be flexible and another was to know when to be apart.

Guy and his wife, in particular, demonstrated a core of love and happiness which was evident in a participant observation session that occurred in their home. In this session, Sally helped Guy with his self-care by wiping his eye while he was managing their finances on the computer. He told me that he does the finances on the computer so that Sally doesn't have to do it, it is easier to work with, and they can get reports. During the time that Guy was doggedly working at the computer, Sally was happily playing the piano and singing along. Guy joked with me about Sally - how she often says she is going to bed early but then doesn't. Before she went in to bed, Sally came in and kissed Guy goodnight on the head. The qualities of mutual respect and love and allowing for individual differences and needs observed in this session were all indicative of the strong connection between them.

Discussion

As very little has been written about collaboration by persons with disabilities, this study helps to begin to fill that gap in the literature. The findings described in the category Practical Considerations and some in the categories Collaboration on Occupation and Structures and Patterns of Collaboration tend to focus on disability as an issue in the marriage collaboration, while the Social Considerations and Qualities that Make the Marriage Collaboration Special categories described qualities in participants' collaborations or interactions with their spouses. The findings of this study indicate that the study participants collaborated with their spouses in a variety of ways in a variety of life areas and environments such as household management, transportation, safety, work, self-care, leisure, finances, communication, and spirituality. It was clear that they saw their spouses as valued long-term partners with whom they planned, decided, problem-solved, managed and delegated tasks in order to function effectively in their environment. Towards that end, they helped each other and were generally supportive of each others' interests, desires and needs while at the same time honing out a place for themselves. Although an imbalance was keenly felt by one participant about his contribution relative to accomplishing necessary physical tasks, it was helpful to him to try to focus on the overall contribution he made to his marriage.

This concept of imbalance and weighing the advantages and disadvantages of one's relationship is discussed in social exchange theory

(Michener, DeLamater & Myers, 2004; Murstein, Ceretto & MacDonald, 1977; Duck, 1983; Cropanzano & Mitchell, 2005). According to social exchange theory, relationships are seen as an exchange between parties as an attempt to increase rewards and reduce costs, and that people evaluate relationships with others via comparing alternatives (Dowd, 1975; Murstein, et al., 1977).

Some of the findings of this study are supported by those of Berg, et al. (2003), who used open-ended interviews with young and old non-disabled married couples to determine how they use collaboration in their relationship. Most couples in that study reported that they collaborate with each other to make decisions and problem solve about managing finances, household repairs, and other major decisions such as where to live. Couples named a variety of patterns they used in their collaboration, such as division of labor due to traditional sex roles, interests, abilities and/or other motivations, or the use of lead roles in the collaboration. Some of those interviewed felt that they complemented each other in their approach. They reported few difficulties in collaboration.

Flexibility and working together seemed to be key elements in the marriage collaboration for people with disabilities. In the marriage collaboration, the person with a disability can try to emphasize and use his strengths and his spouse can fill in in areas in which the person with a disability has limitations. In the case of Guy and his wife, there was flexibility in their decided-on roles and sharing of the responsibility regardless of ability. To quote Guy: "Because we have been able to collaborate on almost everything it has taught me to be open

minded and flexible". An excellent illustration of this is Guy and his wife's ingenious approach towards transferring Guy into their van, an approach in which they used unusual equipment and equally creative maneuvers.

At times, participants' collaborations with their spouses were reminiscent of some of Garee & Cheever's (1992) vignettes of the daily lives of married people with disabilities and the different ways in which they adapt. They also echoed Scheer and Luborsky's (1991) concept of the "disability ally" and notion of the developing interdependence between elderly spouses (Clark & Anderson, 1967; Depner & Ingersoll-Dayton, 1985). They support a concept of independence as being a state in which individuals are self-determining (Longmore, 1995; Oliver, 1993; Parker, 1993a; Scheer & Luborsky, 1991; Nosek, 1993). According to Karen, there are several reasons why people might collaborate:

> The need is the most predominant reason for working with someone else to accomplish some task. But...I think in addition to being just a need, I think also just enjoying life and just enjoying the time that you've had to do things is...part of your reason...certainly if you're with someone that you certainly enjoy being with...even though there's a need I think even beyond that there's a desire to get something done.

Participants used collaboration in their marriages as a vehicle for adaptation to the environment, because they had both a need and a desire to get tasks accomplished. These collaborations were self-reinforcing as they both

strengthened their relationships with their spouses and were a sign of the strength in their relationships with their spouses. They were authentic in their interactions with each other. They had forged a life together. They enjoyed being together.

It should be noted that other than Guy's discussion of the imbalance in the "tangibles" in his marriage, Michael's fear of being alone, and Karen's desire for privacy and time to herself because she had so little due to her disability, participants said very little about difficulties in collaboration with their spouses.

In fact, for Karen and Michael, their concerns were not really voiced relative to their marriage, but to their interactions with all people in their lives. The only minor point that emerged from the observations about difficulties in their collaboration with their spouses was that Sally and Guy told the researcher that they often argue when they are getting ready to go to church, and this was only reported, not observed.

It should also be noted that three of the four participants in this study were married to someone with a disability. This might have influenced the findings by making participants and their spouses more empathetic to each other. This could be one explanation for why the data had so little in it relative to difficulties participants experienced in their collaboration with their spouses.

Conclusion

The purpose of this study was to illustrate ways in which people with disabilities collaborate in their marriages. It also discussed some unique issues in

the marriage collaboration for people with disabilities which can make it difficult for them, such as feelings of imbalance in the contributions to the marriage regarding physical tasks, a need for alone time or - conversely - a fear of being alone. A strength of this study was in the qualitative approach because it allowed the researcher to enter the world of the participants, thereby revealing their perspectives.

A limitation of this study was that the participants comprised a well-educated sample as three out of four persons had advanced degrees; therefore they may not be representative of a typical sample of people with disabilities. Also, all four of the participants were from a middle to upper socio-economic background, and three out of four of them were married to someone who also had a disability. All of the participants had their disability before their marriage; the range of the length of the marriage of the participants at the time of the study was from 17 to 24 years and participants were all middle aged at the time of the study. Finally, because this was a qualitative study with only four participants, the participants in this study do not comprise a representative sample of the population of married people with disabilities. Further studies involving participants from other educational and income levels and with other types and combinations of disabilities or disabled/non-disabled within the marriage are indicated.

It should be reiterated that this study was a subset of a larger study on collaboration by persons with disabilities, so although there was an original list of

questions for participants, the questions did not focus on collaboration the participants experienced in their marriages. Therefore, the study and data were occupation based and the researcher did not ask participants about intimacy in their marriages. Nor did the researcher ask participants about the history of their marriage relationships. It would be helpful to look at such topics, including difficulties in the marriage collaboration - particularly focusing on times early on in their marriages. Other themes which were present in the data but not elaborated on in this article included concepts of family collaborations and ways in which parenting and child rearing by people with disabilities fit into the scheme of the marriage collaboration. These deserve further attention, development and study.

Table 2

Participant Demographics

Name	Age	Gender	Disability	Education	Occupation
Guy	52	Male	Cerebral Palsy	Advanced Degree	Computer Programmer
Janice	51	Female	T-8 Paraplegia	High School	Self-Employed /Homemaker
Karen	49	Female	C1 – C2 Quadriplegia	Advanced Degree	Attorney
Michael	52	Male	C4 – C5 Quadriplegia	Advanced Degree	Manager

Table 3

Categories and Subcategories About Marriage Collaboration

Categories	Subcategories
1. Practical Considerations	Division of tasks and roles according to abilities
	Collaboration about the environment
	Problem solving
	Use of technology
2. Collaboration on Occupation	Work
	Self-care
3. Structures and Patterns of Collaboration	Stating one's needs
	Requesting assistance with a physical task
	Anticipating needs of one's spouse
	Temporal element
4. Social Considerations	Helping
	Making a contribution
	Alone time
	Allowing/Freedom

Categories	Subcategories
5. The Qualities that Make the Marriage Collaboration Special	Mutual love and respect
	Valuing their relationship
	Support of emotional needs
	Sense of humor

CHAPTER VI

DISCUSSION

This chapter provides a synopsis of this line of research, an overview of how collaboration relates to adaptation, and a discussion of how the findings of this line of research relate to the Occupational Adaptation Model (Schultz & Schkade, 1992; Schkade & Schultz, 1992). It also discusses discoveries made by the researcher in the course of conducting this research, the limitations of this line of research, implications for occupational therapy, models, suggestions for future research, and conclusions.

Synopsis

Using three studies, this dissertation investigated the concept of collaboration by persons with disabilities. The first study was a literature review which explored literature relevant to the topic of collaboration by persons with disabilities. As there was very little written on this topic, the researcher had to delve into topics which were tangentially related to the topic, not only in the discipline of occupational therapy, but in the disciplines of personality psychology, social psychology, health psychology, physical medicine and rehabilitation, nursing, rehabilitation counseling, gerontology, health promotion, epidemiology, sociology, education, special education, disability studies, and service animal literature. Other areas which were investigated later in the

process included speech pathology and human development. This study answered the question: what is in the literature, both within and outside of occupational therapy, regarding collaboration between persons with disabilities and others; what other concepts and areas are related to this concept of collaboration, and how can this information be integrated into a cohesive review?

The second study was a qualitative design using interviews and explored the issues relevant to collaboration by persons with disabilities. Many categories emerged from the data; two significant categories were Supporting Collaborations and Symbiosis. The relationship of these two themes to those of independence and interdependence in the disability studies literature was discussed in depth.

The third study, also of qualitative design, focused on collaboration in the marriage relationship among persons with disabilities. It combined excerpted interview data from the second study with data from participant observations from the third study. All three studies were submitted to peer-reviewed journals.

Collaboration and Adaptation

Adaptation is a phenomenon that is basic to living creatures. In the philosophical base of our profession, adaptation is discussed as a quality of being human, a process that all human beings continuously go through in the experience of living. Individuals continuously adapt until their lives end (American Occupational Therapy Association, 1979, p. 785). "Using their capacity for intrinsic motivation, human beings are able to influence their physical and mental

health and their social and physical environment through purposeful activity....Adaptation is a change in function that promotes survival and self-actualization" (American Occupational Therapy Association, 1979, p. 785).

Adaptation involves an interaction between the environment and an individual. (Frank, 1996; Spencer, Davidson, & White, 1996; Spencer, Hersch, Eschenfelder, Fournet and Murray-Gerzik, 1999). When we experience illness or a disability, it causes a change in our relationship with the environment (Spencer, Davidson, & White, 1996). We need to either adapt the environment or our approach to tasks in order to successfully complete occupations (Spencer, Davidson, & White, 1996). According to Frank (1996), human beings adopt "adaptive strategies" in order to improve quality of life (p. 51). "Adaptation through mindfully organized action is necessary for the good life" (Frank, 1996, p. 50). Spencer, Daybell, et al. (1998) point out that those who undertake a proactive approach to adaptation probably need "creativity and ability to see things in new ways, flexibility, and willingness to take risks, and a relatively high sense of self-efficacy" (p. 481). Collaboration with others may be seen as a creative way in which persons with disabilities can adapt their environment or the tasks they undertake.

Adaptation also has a self-reinforcing aspect (Frank, 1996; Schultz & Schkade, 1992). Schultz and Schkade (1997) indicate that "while performance of the activity may be a desirable outcome, the more important product is the experience of mastery that follows a successful adaptive response and the effect

which that experience has on adaptation " (p. 465). The experience of meaning during a collaborative experience can be synergistic, in which the joy of accomplishment produces joy about collaboration, which encourages further collaboration and accomplishment. This is not unlike the experience of "flow" (Csikszentmihalyi, 1990), in which a just-right match of occupational challenge to individual ability produces a self-perpetuating experience of competence and resulting euphoria. The key to this, however, is that the individuals are adapting in their given environment. There are also social-emotional experiences that occur during the activity that reinforce the relationship, or cohesiveness, between the collaborating individuals. These experiences also contribute to self-esteem which, in turn, reinforce further interaction and collaboration.

Spencer, Hersch, et al. (1999) found that elderly individuals who were able to have their basic needs for support fulfilled, who were able to develop new or maintain previously existing social relationships, and who could engage in activities which were meaningful to them were more likely to successfully adapt to returning to the community after hospitalization. According to Spencer, Hersch, et al. (1999), "family members and other caregivers often play a crucial part in successful adaptation to life course disruptions" (p. 168). This researcher believes that spouses, friends, peers, co-workers, and other persons who engage in collaborative interactions with persons with disabilities can equally contribute to such effective and self-reinforcing adaptation, which can be both a short-term and a long-term process (Spencer, Davidson, & White, 1996;

Spencer, Daybell, et al., 1998; Spencer, Hersch, et. al, 1999).

Application to the Occupational Adaptation Model

The findings of this line of research directly apply to the concept of relative mastery as discussed in the Occupational Adaptation Model (Schultz & Schkade, 1992; Schkade & Schultz, 1992). According to the Occupational Adaptation Model, relative mastery is a "major component of motivation" (Schultz & Schkade, 1992, p. 919) and is "based on the beliefs that each person is endowed with a desire for mastery, that the occupational environment also has a demand for mastery, and that together these internal and external motivational forces provide an interactive press for mastery" (Schultz & Schkade, 1992, p. 919). Relative mastery is evaluated by "efficiency, effectiveness, and satisfaction to self and others" (Schultz & Schkade, 1992, p. 919).

The forms of collaboration by persons with disabilities - such as symbiosis - can be viewed as an occupational response in order to meet an occupational challenge in the environment. The outcome of symbiosis (or other forms of collaboration) is that it enables the individual with a disability to accomplish meaningful tasks, and therefore life roles which they might not otherwise be able to perform.

For example, Karen's symbiosis with her secretary provided her with the ability to effectively and efficiently accomplish her role as an attorney, which was not only deeply satisfying to her as an individual, but also satisfying to society via the clients she served. The efficiency, effectiveness, and satisfaction to herself

and to others which she experienced contributed to her relative mastery which was one of the factors motivating her to engage in the symbiotic collaboration in the first place.

Another way of viewing collaboration by persons with disabilities from an Occupational Adaptation perspective is that part of the personal and social context of the environment was represented by the collaborative relationship; and it is those relationships that support the individual's adaptation process. In their collaborative relationships with their spouses, for example, participants in collaboration with each other continually re-evaluated their experiences, both on a simpler scale such as when backing the electric wheelchair into the van or on a more complex scale of remodeling their home. This directly relates to the "flow of the occupational adaptation process" (p. 832) described by Schkade and Schultz (1992).

In the case of collaboration with a simple task, for example backing into the van, the combination of Karen's desire for mastery and the demand for mastery imposed by the environment caused a press for mastery which brought about an occupational challenge (getting into the van and to the town meeting). This occupational challenge would have been difficult for Karen to meet without the collaboration of her husband, who provided guidance to her on backing into the van which she followed (he evaluating the outcome and she integrating the feedback) until she was able to produce a successful occupational response and back up the ramp and into the van.

Current Literature on the Concepts of Adaptation and Collaboration

An extensive search of the OT database on the search terms "adaptation, physiological OR adaptation, psychological OR adaptation, temporal" as keywords or subject headings yielded about 90 results for publications between the years 2002-2006. Of those publications, the researcher determined that there were only 3 occupational therapy publications which were relevant, some only tangentially, to collaboration by persons with disabilities as discussed in this line of research. A discussion of these three articles and one additional article (Ross, 1994) follows.

Ross (1994) provided a case study to demonstrate how she used the Occupational Adaptation Model (Schultz & Schkade, 1992; Schkade and Schultz, 1992) in the clinic. The case study was about an 82 year old male with stroke who also had high blood pressure and a prior history of prostrate cancer. The patient disclosed that his wife of many years had been diagnosed with terminal lung cancer and had only six months to live. His wife also had a prior history of mastectomy which made it difficult for her to do self-care, cooking and upper extremity dressing. The patient had assisted his wife with such tasks for a long time.

Through interview, the therapist determined that the patient's main goal was to be able to assist his wife and spend as much time with her as possible before she passed away. The therapist, the patient and the patient's wife in collaboration with each other devised a treatment plan which addressed his performance area needs post stroke through addressing his personal goals. For example, part of his

treatment plan was to assist his wife with tasks such as upper extremity dressing and cooking simple meals. The patient and his spouse were satisfied with this approach to treatment. It is clear that this treatment approach facilitated the collaboration between the patient and his spouse and represents an adaptive strategy for them.

Bontje, Kinébanian, Josephsson and Tamura (2004) examined the experiences of elderly people with physical disabilities using qualitative methodology. Participants used several adaptive strategies to surmount the effect of disability on their occupational functioning. Among these were participants obliging others to adapt to their wants. Another strategy was in the form of suggestions from others about answers to "occupational problems" (p.144). For example, one participant's husband helped her overcome her fear of using a wheelchair in public by taking her to an area where she didn't know anyone and encouraging her to try it out. Another strategy was "giving a role to other persons" (p. 145). Some examples of this strategy were asking relatives to help out with adaptations to the home environment; friends or relatives helping with tasks such as opening cans or milk; or receiving recommendations, bolstering and reassurance from others which, in turn, pointed to answers. These adaptive strategies contain elements of or represent forms of collaboration.

Bontje et al. (2004) indicate that occupational therapists need to find a neutral point between giving answers and facilitating clients to devise their own answers. They indicate the need for future research to determine "how persons

recruit resources and rely on experience, how individuals assert their wishes and demands, and how the processes in identifying and creating solutions to problems in occupational functioning are carried out" (p. 147). Again, these are examples of how creativity in collaboration serves as a form of adaptation.

In a study of women with breast cancer and their experiences with dragon boat racing, Unruh and Elvin (2004) found that the women in the study experienced a form of support by working together on a team competing in dragon boat competitions. Competing on a team gave the women an infectious eagerness; the fellowship of being together fostered emotional health. Team members shared information about breast cancer treatments and supported each other in practical ways such as sending food to and through each other when they were ill.

The experience of dragon boat racing fostered a feeling of prevailing over cancer and a feeling of relationship to each other. In this manner, taking part in the occupation of dragon boat racing could be seen as a form of coping which had many significant and meaningful benefits for the participants. The elements of working together, mutual support, well-being and empowerment discussed in this study reinforce the potential qualities emanating from collaboration as discussed in the background and previous literature reviews for this line of research.

Eriksson, Tham and Fugl-Meyer (2005) examined the life satisfaction of both members of couples when one member of the couple was one to five years post acquired brain injury. The authors determined that both members of the couple were satisfied with life in only one third of the couples studied. Satisfaction

in life in both partners was related to daily functioning as well as perceived participation in leisure and social activities, and ability to wash clothes (a complex task for those who have cognitive and motor deficits as a result of head injury). The authors concluded that it is important for rehabilitation professionals to treat the couple as a unit and include the spouse in the treatment process. The authors emphasized that the couple's view of what is difficult for them in their daily life should be a guide for therapists, and that treatment approaches should make the couple's viewpoint a priority and that treatment should be done in an ongoing fashion and continue after discharge through follow up. It is clear that understanding the difficulties couples have adapting to disability provides an excellent opportunity for therapists to promote adaptation in such couples through collaboration.

Discoveries

The researcher made several discoveries while working on this line of research. One of the major discoveries made was that collaboration is a very complex phenomenon. There are many types of collaborations, many structures to collaboration, and many levels to collaboration. Also, there is a time element involved in collaboration, such as if a collaboration has been a long term one or a short term one. It would seem as if a majority of life is some form of collaboration or another.

My literature review revealed mostly positive results of collaboration – how rich and helpful and enjoyable it can be. It also focused on the good aspects of

collaboration and what makes for a good collaboration. As I delved into my observation and interview process, I saw and heard many examples of collaborations that didn't work and why that might be so. It was very helpful to double check these ideas with my subjects, some of whom may not have wanted to discuss where they fell down in their own approaches to collaboration but who were willing to point out how and why collaborations fail.

I also learned that there are many other ways to collaborate other than what was mentioned in the literature review. Many people with disabilities talked about their collaboration with each other as part of the disability movement, or their collaborations with other groups, both friendly and hostile, to bring about changes in how their needs are addressed in the modern world. Much of what was discussed in the literature review was individual collaboration; I found out more about group collaboration and collaboration via technology and public transportation as I progressed through interviews and observations. So I found out not only about new and unexpected, different types of collaboration in which people with disabilities engage, but also that there were very good reasons and needs for such collaborations. Some examples of the many other types of collaborations which emerged in the data not discussed in my articles and which would be interesting to explore further are: hierarchical collaborations and vertical collaborations between institutions or people within institutions.

Another discovery was of a small body of literature discussing the concept of collaborative cognition. The term collaborative cognition refers to situations in

which individuals assist each other with memory and problem solving in their daily lives. There have been several studies on this phenomenon to date, including Strough et al. (2003), and Berg et al. (2003), most of them investigating this phenomenon with married couples, although recently there have been more studies investigating it with the elderly. Another interesting find was a small body of literature about how one married couple collaborated in conversation because one of them had aphasia (Oelschlager & Damico, 1998a).

Limitations

There were several limitations to the studies in this line of research. One limitation is that while the second and third studies were originally planned to be in the participatory research tradition, this approach was abandoned due to time restraints. Instead, for the second study, member checks were done, and for the third study, coders were used to insure accuracy of data. Another limitation is that the third study changed its focus. Instead of relying purely upon participant observation data about collaboration by persons with disabilities, this study focused on collaboration in the marriage relationship by persons with disabilities, combining relevant interview data from the second study with relevant participant observation data from the third study. In some ways, this actually made the study's methodology stronger, as it drew from two different data sets to substantiate findings.

Another important limitation in this line of study to note is that the participants in this study had the financial, educational and cognitive resources to

be able to live in their own homes. As the participants were an unusual cohort, they do not comprise a representative sample of persons with disabilities, so results cannot be generalized.

Implications for Occupational Therapy

Why is it important for occupational therapy to have this knowledge? The knowledge gained from this research is important at many levels.

Contributions to the Research Literature

First, this line of research is significant as there have been minimal studies to date on collaboration by persons with disabilities. For example, a search on the term "collaboration" using the OT Search database of the American Occupational Therapy Association produced 42 studies between the years 2002 and 2006 where the word "collaboration" appeared matched on keywords. There were no studies similar to this one. One study by Tham and Kielhofner (2003) which surfaced in the search had findings which paralleled some of the findings in this line of research; some of those findings are mentioned in the discussion section of study two. This line of research helps fill the gap of research about collaboration by persons with disabilities in the occupational therapy literature.

The findings of this line of research relative to collaboration in the marriage relationship echo the vignettes described by Garee and Cheever (1992). Also, some of the literature regarding spinal cord rehabilitation indicates that spousal support is essential to individuals aging with a spinal cord injury (Holicky & Charlifue, 1999). Although this article was not directly related to the

marriage collaboration, some concluding thoughts are that rehabilitation professionals should look at spouses as a unit and incorporate that concept into their treatment approaches. This can be achieved through education, involvement in the treatment process and making the spouse feel included in the general treatment approach as a whole.

Even more significantly, Rintala's models, wherein self-esteem, reciprocity and engagement in activity are interconnected, support the findings in this line of research (Rintala et al. 1994). It is clear that the participants in this line of research benefited from collaboration as it allowed them to enact social, leisure and work roles and complete tasks which were important to them. This helped them to experience self-actualization and the resulting increased self-esteem.

The findings of this line of research also are supported by the work of Nosek and Fuhrer (1992a, 1992b), who provide a model relating independence to four progressive need stages of "basic survival, material well-being, productivity, and self-actualization" (1992a, p. 5) and four non-traditional components of independence- "perceived control over one's life...psychological self-reliance...physical functioning, and...environmental resources" (1992b, p. 3). The participants in this line of research were able to attain all of these qualities through their collaborative experiences. Not only did their collaborations with others in their lives help them survive, they helped them to self-actualize, be productive, have control over their lives, and function physically.

Finally, the findings of this line of research are supported by the discussion of interdependence in the disability studies literature. Jacobs (2002) views interdependence as having enormous value to empower people with disabilities because of increased connection and the resulting sharing of information and knowledge. Scheer and Groce (1988) discuss a community of persons with quadriplegia and paraplegia on Roosevelt Island, New York which became an example of the value of interdependence among persons with disabilities, as they provided "...each other support and informal counsel about various issues, from attendant care management, to advice about dating, to equipment repair and purchase" (Scheer & Groce, 1988, p. 35). These activities are an indication of the importance that the disability community places on a form of collaboration, and the transformative effect that collaboration can have on and in people's lives. In summary, collaboration by persons with disabilities is important for self-esteem, feeling purposeful, and for being active in one's environment, and can provide a means of accomplishing desired tasks, thereby fostering a form of independence which allows individuals to have control over their lives.

In conclusion, collaboration by persons with disabilities is an important concept for occupational therapists to be aware of because it can provide an alternative means for people with disabilities to accomplish meaningful tasks and achieve independence and self-actualization in their daily lives. One way in which occupational therapists can address this issue is not only to concentrate on the

client to help them become independent, but also to involve the spouse or caregiver in the treatment process. This way the client can accomplish a task even though they may not be independent in the traditional, medical model sense of the word. Another way would be to encourage alternative and innovative means of adaptation through collaboration. Occupational therapy has adopted the following definition of independence:

> Occupational therapy practitioners understand and value not only the independent performance of tasks, but also the use of adaptations or alternative methods to support independent task performance...Individuals are considered resourceful when they have the needed devices or strategies available to them in their environment to support independent functioning....Individuals should not be stigmatized by the use of devices or strategies to support their unique approaches to independence. (Dunn, 1995, p.1014)

It is important for occupational therapists to be aware of the value of collaboration to persons with disabilities as a form of adaptation which can empower them in the attainment of meaningful life goals.

Contributions to Varied Practice Environments

In this section, discussion will focus on how therapists could pursue this line of research on collaboration by persons with disabilities ("collaborative intervention") in the practice arena and how they could implement it in the clinic, at home, and in the community. This section will also look at the impact of

collaborative intervention on occupational therapy, and how therapists could study the effectiveness of collaborative intervention, including identifying some of the obstacles they might encounter.

In order to implement collaborative intervention in the practice arena, the therapist would have to start out with small studies with a few clients at first to see how the interaction would progress. Starting in the clinic, the therapist could match two clients who seem to get along with each other, who indicate an interest in working with and helping others as well as receiving assistance from others, and whose strengths and deficits complement each other's. This could be determined through a combination of informal observation of clients in the clinic, chart review, and formal evaluation of strengths and deficits in performance skills. This type of intervention would probably not work well with clients who had strong social skill deficits such as seen in clients with personality disorders or severe thought disorders. This intervention may work better when pairing up, for example, clients with cognitive disorders and clients with depression who are ready to interact with others.

For example, in the psychiatric clinic arena, the therapist could provide them with a craft activity which they could both work on together and through which both client's goals could be addressed. This could be done either in a group environment or a dyad situation. Although safety is always a concern, the clinic is a controlled environment and safety would be less of a concern as the therapist would be supervising the interaction of the clients. If a dyad appeared to

be working out particularly well in the clinic, the therapist might encourage further collaboration between them on the unit (after having made staff aware that they were a collaborating dyad).

If the environment were an acute care hospital the therapist should again choose clients who are ready and willing to interact with others and have the skills to do so. The therapist should choose clients whose strengths and deficits complemented each other's. Again, staff and family would need to be informed. Initially, a facilitated collaboration between them might just involve an initial meeting to say "hi" to each other and get to know each other, and maybe talk about how their reasons for being in the hospital. If the clients were in a rehabilitation hospital, the therapist might introduce them, and if they were willing, encourage them to interact and collaborate with each other between treatment sessions or to even be present during each other's treatment sessions. If clients seemed to be benefiting from their collaboration, the therapist could encourage them, the staff, and their family members to encourage collaboration between the dyad as much as possible after discharge.

In the community environment, collaboration between appropriate clients would also need to be understood and sanctioned by the families of the dyads if indicated. It would need to be established with the staff that the dyad is a collaborating dyad. The dyad would collaborate with each other throughout the day as appropriate to the setting and the treatment goals of one or both members of the dyad (it would depend upon the environment and the treatment needs). In

a community setting, the dyad would have to be able to function safely while at the community setting as an independent unit unless proper supervision could be provided. A well functioning collaborating dyad could collaborate on getting to and from the community setting (a day program, an outpatient program, etc.); i.e. their collaboration could extend beyond just beginning and ending at the community setting.

In the home setting, as in any of these other environments, the therapist could grade the approach to establishing a collaborating dyad. The therapist could introduce clients (or even better, they might know each other from a treatment setting before discharge home) and initially encourage them to collaborate on small tasks in one or the other's homes, for a short period of time during the day. If their collaboration went well, the time and nature of their collaboration could be expanded.

In any setting, it would be very important to let staff know that a particular dyad with whom the therapist was working was a collaborating dyad. In a hospital setting, some obstacles therapists might encounter would be resistance on the part of staff to a new approach as it might have an effect on the status quo of the milieu. There might also be concerns regarding hospital rules, concerns about client privacy, and the schedules of various activities, groups and individuals throughout the day. These areas of resistance would have to be ironed out (this is one reason why the therapist should start out with one dyad and see how it worked). There also might be resistance on the part of some occupational

therapists who might have a difficult time stepping back and letting clients find their own way in a collaboration. In a home setting, family members might resist a family member having a new acquaintance and the changes that might bring in their lives and lifestyle. In the community setting, there would probably be resistance from all of these areas- family, occupational therapists, and other staff. Once the therapist had some successes with the collaborative intervention approach, the therapist could probably do an in-service for staff on the approach and its value in treatment.

One way to teach collaborative intervention to students is through example and demonstration. Students could observe this approach through either simulation in the classroom or observation of the faculty/therapist implementing the technique in the clinic. The faculty/therapist should then have the students write in a journal about and reflect on their experiences. The faculty/therapist should teach the students treatment models which stress a client-centered approach and support this with appropriate readings from the occupational therapy literature as well as disability studies. The faculty/therapist should ground the students in strong evaluation skills as well as sound clinical reasoning and judgment.

One way to study the effectiveness of collaborative intervention would be to determine if the clients involved were meeting the goals which the collaborative intervention was addressing. Another way would be to elicit feedback from the collaborating dyads about their collaborations through

surveys, interviews or a phenomenological approach to see how satisfied they were with the intervention or the areas in which they would like to see improvement. This could be coupled with survey feedback from the client's caseworkers, family members or other staff to round out the picture.

Models

This section will discuss some models remove devised to illustrate some concepts of collaboration which emerged in the data from the second study in this line of research. The models will illustrate the concepts of symbiosis and supporting collaborations and how they might "plug in" to the Occupational Adaptation Model (Schultz & Schkade, 1992; Schkade & Schultz, 1992).

The definition of symbiosis is a collaboration between two individuals or groups in which members of each side of the collaboration bring different needs, abilities and/or contributions to the collaboration. In a symbiotic collaboration, each member's differing needs, abilities and/or contributions to the collaboration complement those of the other member, resulting in a mutually beneficial interaction and outcome.

Figure 1 is a general visual representation of the above definition. The two individuals in the symbiosis, Person A and Person B, are each represented by a differently shaded circle; one light, one dark. Each circle is divided into two sections; one representing the needs of that individual and the other representing the contributions of that individual. The contributions of one individual meet the needs of the other individual; this relationship is represented by the horizontal

arrows. The two individuals become an interlocking unit and as a result become "Person A/B" which is represented by the large oval encompassing the system. The shading of the oval is of medium intensity to indicate the merging of the shading of the two circles. The downward pointing arrow indicates that the outcome of the symbiosis is mutually beneficial to the individuals on both sides of the collaboration (see Figure 1).

Figure 2 is a general visual representation of how a symbiotic collaboration might "plug in" to the Occupational Adaptation Model (Schultz & Schkade, 1992; Schkade & Schultz, 1992). In the top left hand corner of the model for the person element I have placed the circles representing both Person A and Person B in the symbiosis. The shading of the circles is consistent with the previous model. The effect of each individual person's desire for mastery on the press for mastery in the interaction element, and the effect of the press for mastery on each individual's desire for mastery are represented by two curvy, dotted lines for each individual. The dotted and curvy lines represent the frustration of the individuals in their desire for mastery and their ability to respond to the press for mastery because of their specific disabilities. The solid black lines emanating from each individual which connect between them and form a single downward arrow pointing to the shaded oval labeled "Person A/B" indicate the decision on the part of both individuals to engage in a symbiotic collaboration. Once they engage in a symbiosis, they become "Person A/B" and are able to generate an adaptive response to the occupational challenges and roles at hand.

The oval representing "Person A/B" is appropriately shaded to indicate the merging of the two shaded circles representing the individuals (see Figure 2).

Figure 3 is a general visual representation of a supporting collaboration. A supporting collaboration involves one individual (or a group of people) assisting the person with a disability with a smaller aspect of a larger occupation. A supporting collaboration provides the opportunity for the person with a disability to participate in a larger leisure, work, or other occupation which would not be possible without the smaller supporting collaboration.

In Figure 3, the person with a disability is represented by the lightly shaded circle on the left labeled Person A. A part of the circle is missing indicating need for assistance with a smaller task which is part of a larger occupation. The darker shaded circle on the right labeled Person B represents the individual providing task support. The horizontal arrow traveling from Person B to Person A represents Person B providing the needed task support. In this case, the circles are shaded differently only for contrast. The system of this collaboration is represented by the shaded oval encompassing the interaction of Person A and Person B. The outcome of the system is represented by the downward pointing arrow indicating the resulting ability of Person A to participate in a larger leisure, work or other occupation which would not have been possible without the task support of Person B in the smaller task (see Figure 3).

Figure 4 is a general visual representation of how a supporting collaboration might "plug in" to the Occupational Adaptation Model (Schultz &

Schkade, 1992; Schkade & Schultz, 1992). In the top left hand corner of the model in the person element we have Person A's desire for mastery represented by the shaded oval. Their decision to engage in a supporting collaboration with Person B is represented by the solid black arrow emanating from the shaded oval and pointing down to the system of the supporting collaboration of Person A and Person B. The circles representing the individuals in the supporting collaboration are shaded similarly to those in Figure 3. As in Figure 3, the horizontal arrow going from Person B to Person A indicates the task support Person B provides to Person A during a smaller task. The outcome of the supporting collaboration is that Person A is able to generate an adaptive response and therefore meet occupational challenges and occupational roles. They would not be able to meet these occupational challenges and occupational roles without task support from Person B in the smaller task (see Figure 4).

Future Research

As mentioned earlier, many themes about collaboration emerged from the data, particularly in the second study. It would be interesting to further explore some of these themes of collaboration in future research projects with a different focus or purpose and a different methodology. For example, it would be interesting to choose a theme about collaboration, such as "long-term collaboration", and explore it in depth in focus groups with participants. It would be interesting to study in depth the structures and patterns involved in some of these types of collaborations. Hopefully, the focus groups would generate data

which would allow a task analysis of the type of collaboration in question. Then models could be developed for the specific types of collaboration studied. Another important change in the methodology would be to employ more coders because that would strengthen the data analysis process and the validity of the findings.

Many different words are used in the literature for collaboration or processes similar to collaboration. Some examples of terms used for or similar to collaboration include: reciprocity, cooperation, and joint-activity. One future research project might be to use a standardized tool such as a mutuality scale to measure collaboration in a relationship between a person with a disability and a significant other or spouse, or to even develop such a tool.

Another approach would be to expand the participant pool to include individuals of different backgrounds, age groups and/or disabilities, or combinations of disabilities. This would shed light on any differences that may exist between the sample of participants in this line of research and other people with disabilities relative to collaboration.

The participants in the third study appeared to be very happy in their marriages. As the sample for this study was limited to only 4 participants, it would be interesting to further investigate on a larger scale how many marriages end in divorce versus how many marriages remain intact in couples with disabilities and make comparisons to the non-disabled population. As 3 out of 4 of the participants in this line of research had spinal cord injury, one pertinent area to

examine would be the incidence of divorce for people with acquired disabling conditions such as spinal cord injury and compare that to the rate of divorce among the non-disabled population.

According to Garee and Cheever (1992) the divorce rate among non-disabled persons is 50% and the divorce rate for persons with disabilities is 80 to 85%, while 85% of marriages that occur after the onset of disability remain intact (Garee & Cheever, 1992). Information about the incidence of divorce for people with spinal cord injury seems to conflict with this information in some areas. According to the DeVivo, Richards, Stover and Go (1991), the divorce in married couples during the first few years following a spinal cord injury rate appears to peak and surpass the divorce rate of the general population, but by five years post injury the divorce rate appears to again approach that of the general population. According to DeVivo, Hawkins, Richards and Go (1995), despite a higher divorce rate as compared to the general population, most post injury marriages remain intact (after five years, 74.3% of study participants were still married; after ten years 58.6% of study participants were still married). The effect of spinal cord injury appears to be almost the same for pre-existing marriages and post-injury marriages. In both pre and post injury marriages the likelihood of success for the marriage is a little bit lower than in the non-injured population (NSCISC, 2006).

According to Garee and Cheever (1992) the sex of the person who is disabled, sexual difficulties as a result of the disability and the financial situation

of the couple are all factors which can affect the success of marriage for people with disabilities. According to DeVivo, Richards, et al. (1995), among the risk factors for divorce for people with spinal cord injury are being female, being young, being of African-American descent, prior divorce, having no children, and inability to ambulate. According to DeVivo, Hawkins, et al. (1995), for people who married after the onset of spinal cord injury, the divorce rate was higher for men and previously divorced people than for women or people in first marriages. Also, among people who married after the onset of spinal cord injury, divorce rates were higher among those who did not have a college education and were lower for people with lower level injuries (such as in the lumbar region). As conflicting or incomplete information exists in the literature regarding risk factors affecting the success of marriages of persons with spinal cord injuries, further study is needed on these factors. Further studies about collaboration in the marriage relationship using cohorts with differing characteristics such as discussed above are necessary and would provide important insights into the differences between differing cohorts and their collaborations.

Involving the non-disabled spouse in the rehabilitation process, the ability for the members of a couple to accept a disability, and good quality communication between the couple would facilitate success for the marriage. Also, it is helpful to train more than one family member to provide care for the persons with a disability, or to hire an attendant (if possible) to relieve the spouse of some of the responsibility for care (Garee & Cheever, 1992). Counseling and

support for both the person with a newly acquired disability and the caregiving spouse are important for the health of the marriage. Flexibility in the relationship and a mutual interest in meeting the needs of one's spouse are central to the success of such a marriage (Garee & Cheever, 1992). Many of these qualities for the success of a marriage after onset of disability can be fostered by or are central to a healthy collaboration process.

Conclusion

A minimal amount of studies exist to date on collaboration by persons with disabilities. This line of research is significant because it helps fill that gap in the literature.

Collaboration by persons with disabilities is a complex phenomenon, involving many different types, levels, structures, dynamics and patterns- as well as a temporal element. Collaboration by persons with disabilities is an important concept as collaboration with others may be considered an alternative method for persons with disabilities to achieve independence in task performance. Individuals with disabilities may experience higher states of relative mastery as a result of using collaboration as an adaptive strategy. It is important for occupational therapists to be aware of the value of collaboration to persons with disabilities as a form of adaptation which can empower them in the attainment of meaningful life goals.

Figure 1. Model of Symbiosis

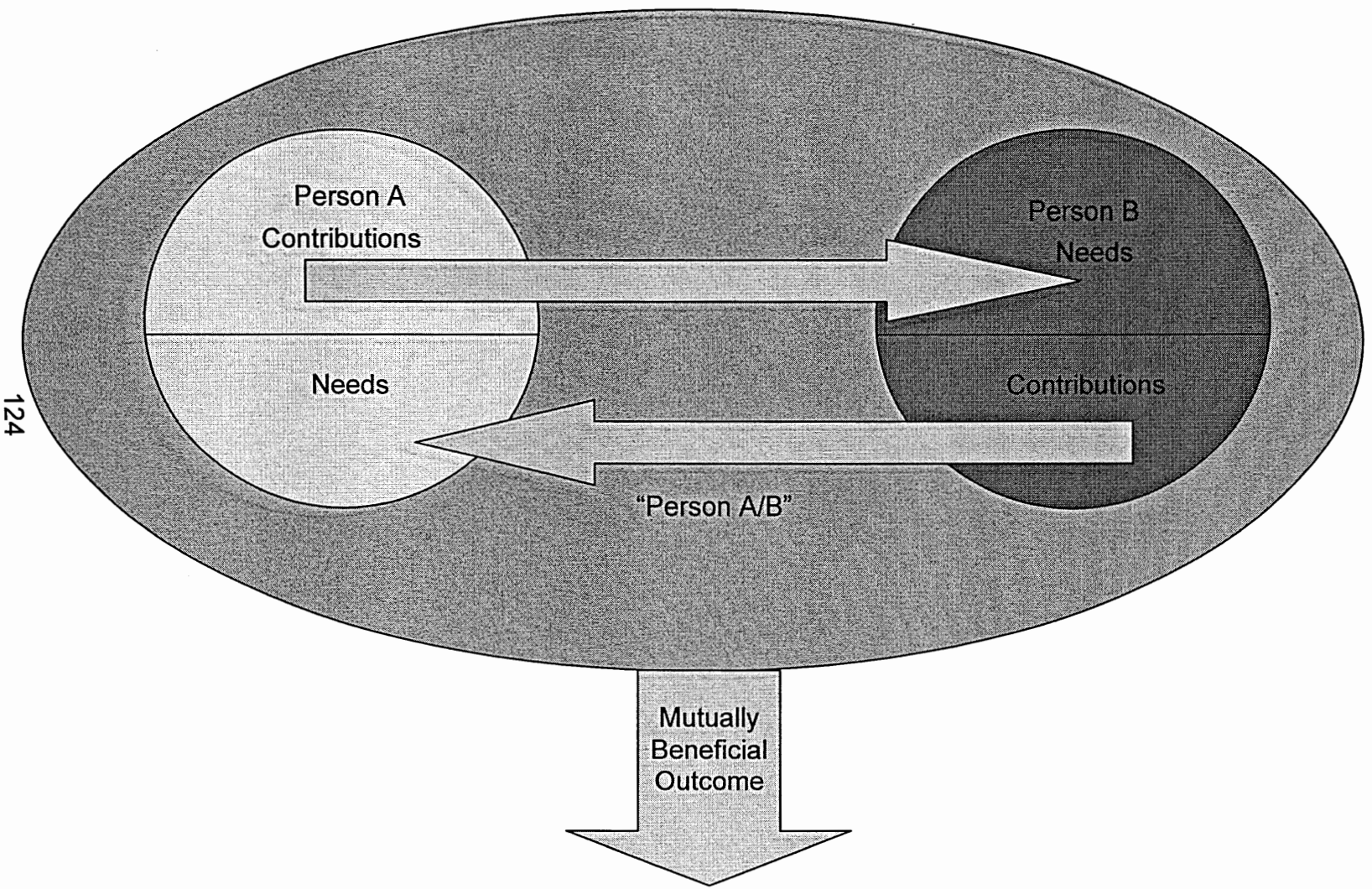


Figure 2. Model of Symbiosis and Occupational Adaptation (Schkade & Schultz, 1992)

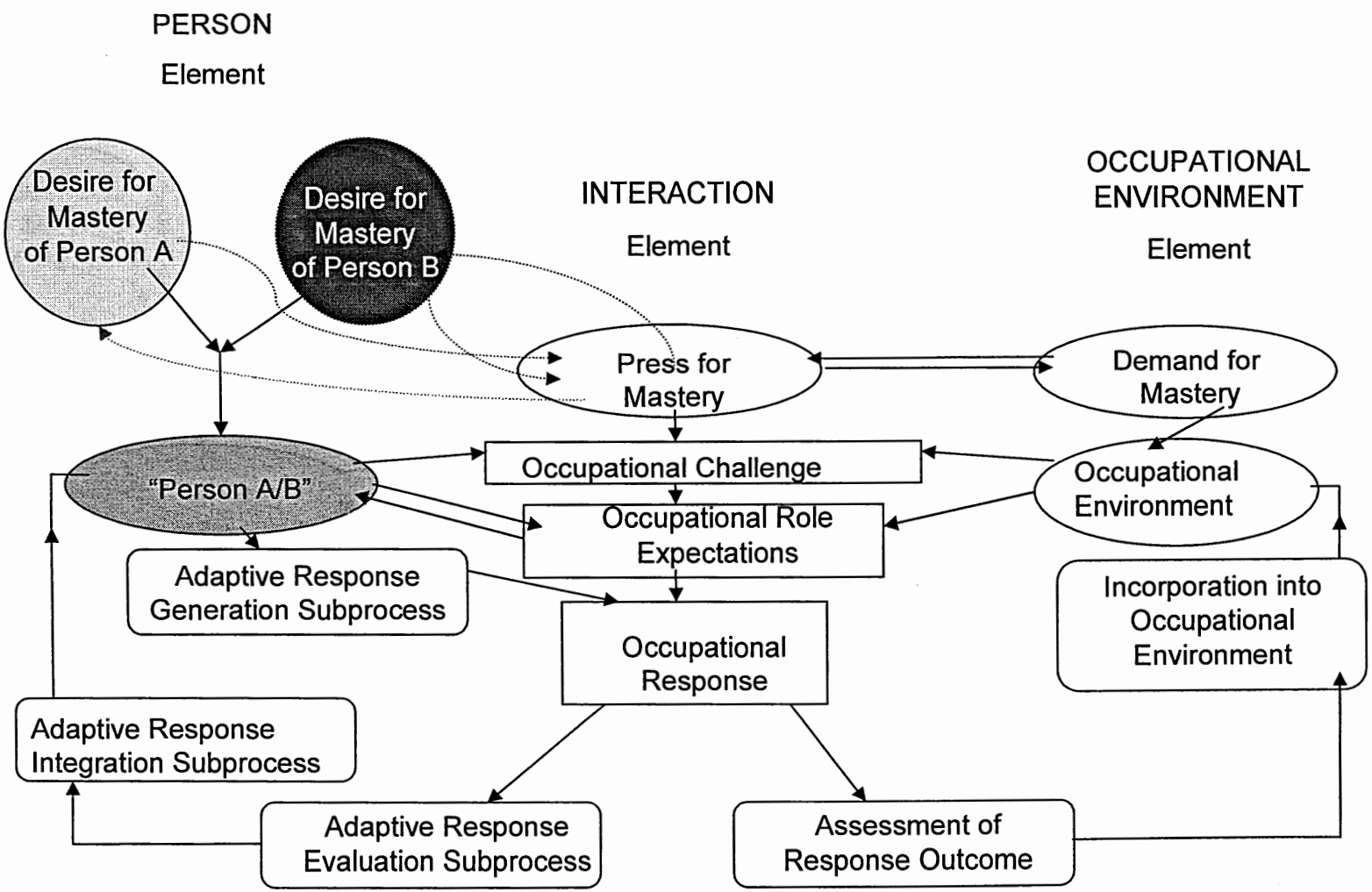


Figure 3. Model of Supporting Collaboration

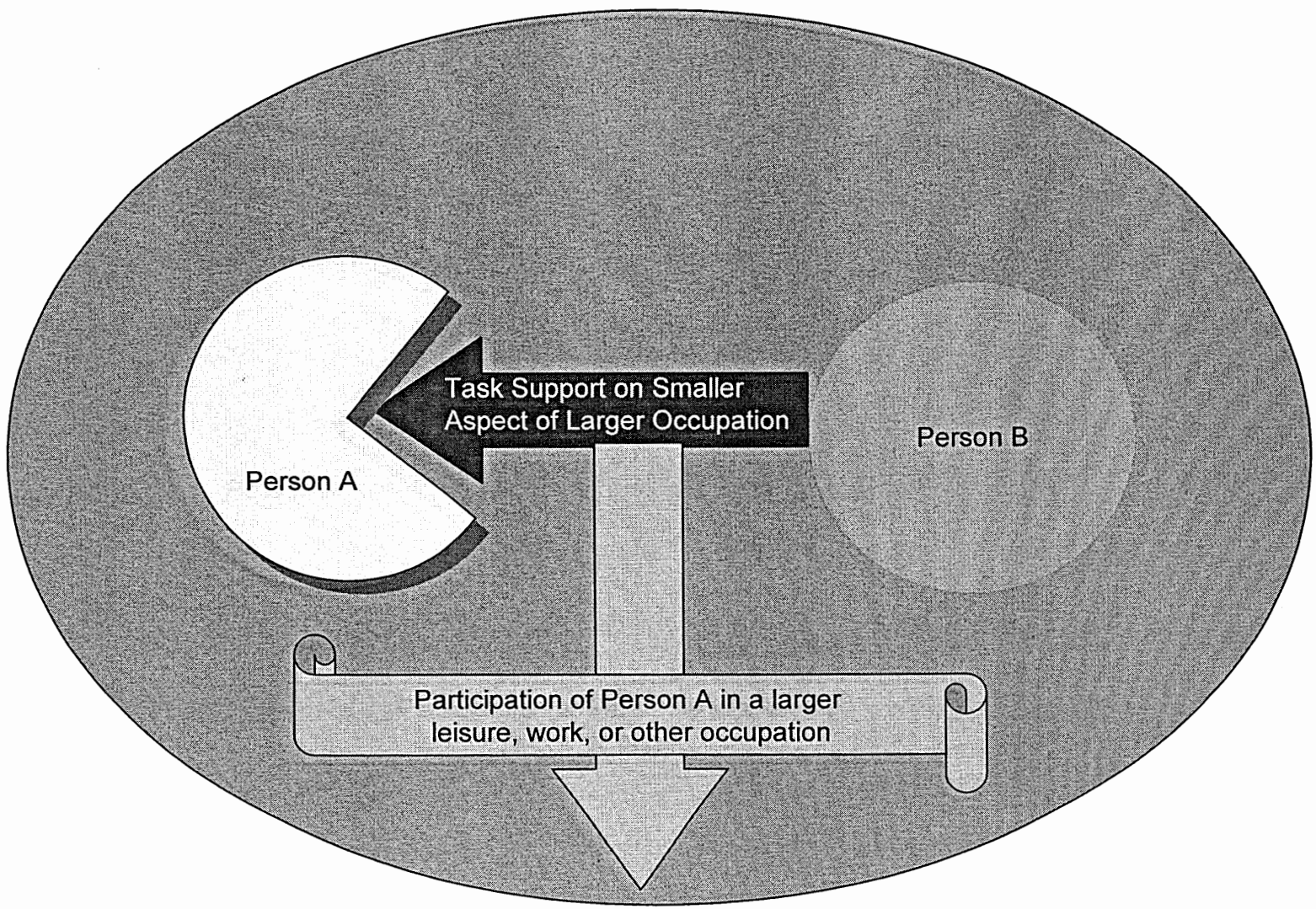
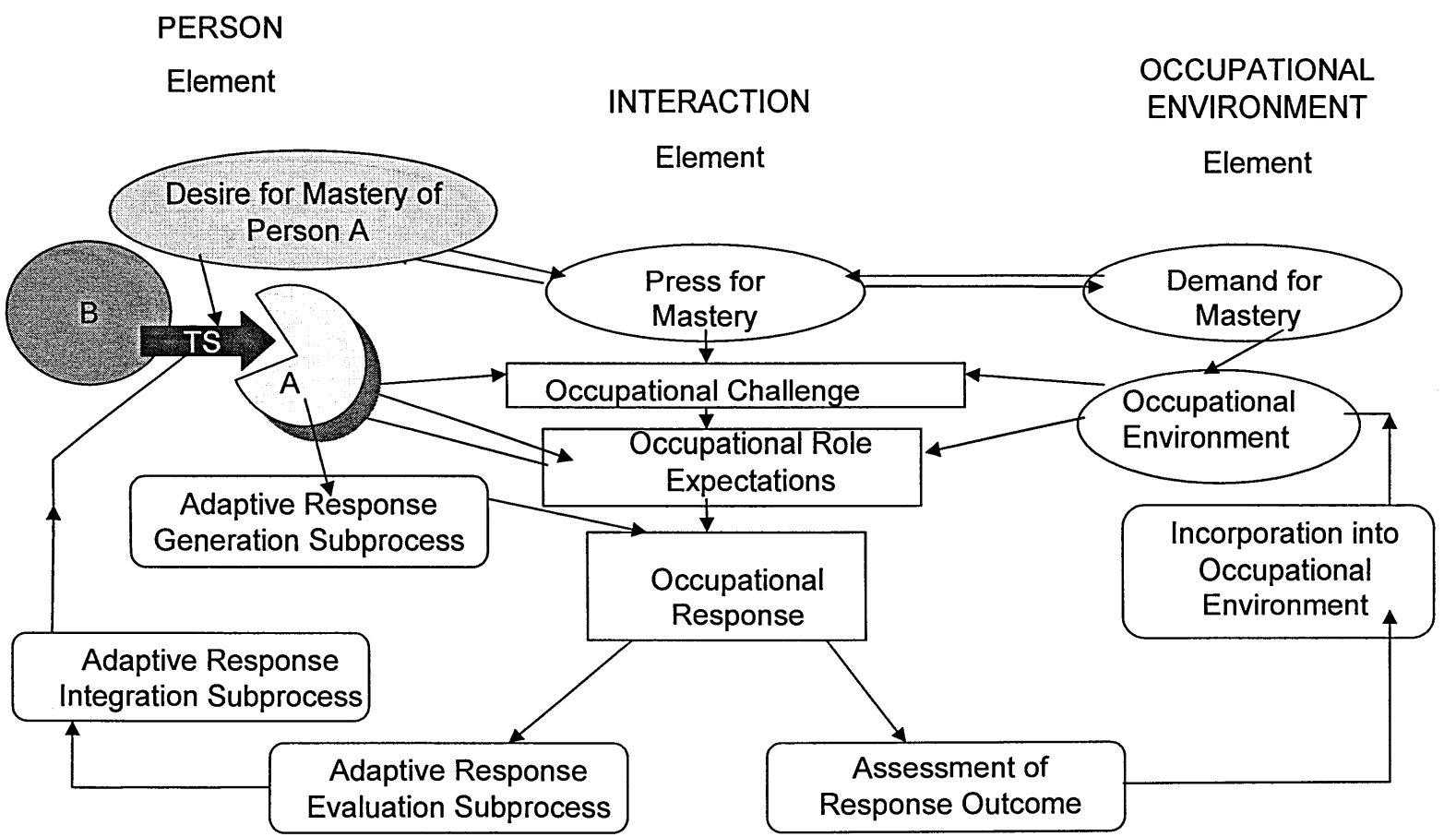


Figure 4. Model of Supporting Collaboration and Occupational Adaptation (Schkade & Schultz, 1992)



REFERENCES

Adams, T., Bezner, J., & Steinhardt, M. (1997). The conceptualization and measurement of perceived wellness: Integrating balance across and within dimensions. *The American Journal of Health Promotion, 11,* 208-218.

American Disabled for Attendant Programs Today. (2002). Segregation and the medical model thrive in the independent living movement's cradle. *Incitement, 18,* 1-32.

American Occupational Therapy Association. (1979). Statement of philosophy. *The American Journal of Occupational Therapy, 33,* 781-813.

Barnes, C. (1993). Participation and control in daily centres for young disabled people aged 16 to 30 years. In J. Swain, V. Finkelstein, S. French, & M. Oliver (Eds.), *Disabling barriers-Enabling environments* (pp. 169-177). London: Sage.

Bates, P. S., Spencer, J. C., Young, M. E., & Rintala, D. H. (1993). Assistive technology and the newly disabled adult: Adaptation to wheelchair use. *The American Journal of Occupational Therapy, 47,* 1014-1021.

Baum, C. M., & Law, M. (1997). Occupational therapy practice: Focusing on occupational performance. *The American Journal of Occupational Therapy, 51,* 277-288.

Becker, G. (1993). Continuity after a stroke: Implications of life-course disruption in old age. *The Gerontologist, 33,* 148-157.

Berg, C.A., Johnson, M. M. S., Meegan, S. P. & Strough, J. (2003). Collaborative problem-solving interactions in young and old married couples. *Discourse Processes, 35,* 33-58.

Berry, J. F., Hitzman, S., Stewart, G. W., & Darwin, P. (1995). A survey of attendant care arrangements in indigent persons with spinal cord injury. *SCI Psychosocial Process, 8,* 112-117.

Bond, M. J., & Feather, N. T. (1988). Some correlates of structure and purpose in the use of time. *Journal of Personality and Social Psychology, 55*, 321-329.

Bontje, P., Kinébanian, A., Josephsson, S., & Tamura, Y. (2004). Occupational adaptation: The experiences of older persons with physical disabilities. *The American Journal of Occupational Therapy, 58,* 140-149.

Briggs, E. (1993). Striving for independence. In J. Swain, V. Finkelstein, S. French, & M. Oliver (Eds.), *Disabling barriers- Enabling environments* (pp. 129-135). London: Sage.

Brisenden, S. (1986). Independent living and the medical model of disability. *Disability, Handicap, and Society, 1,* 173-178.

Brown, K., & Gillespie, D. (1992). Recovering relationships: A feminist perspective of recovery models. *The American Journal of Occupational Therapy, 46,* 1001-1005.

Cahn, E. S., & Rowe, J. (1992). *Time dollars: The new currency that enables Americans to turn their hidden resource—time—into personal security and community renewal.* Emmaus, PA: Rodale Press.

Clark, M. M., & Anderson, B. G. (1967). *Culture and aging: An anthropological study of older Americans.* Springfield, IL: Charles C. Thomas.

Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five traditions.* Sage: Thousand Oaks, CA.

Cropanzano, R., & Mitchell, M. S. (2005). Social exchange theory: An interdisciplinary review. *Journal of Management, 31,* 874-900.

Csikszentmihalyi, M. (1990). *Flow: The psychology of optimal experience.* New York: Harper & Row.

Davis, K. (1993). The crafting of good clients. In J. Swain, V. Finkelstein, S. French, & M. Oliver (Eds.), *Disabling barriers- Enabling environments* (pp. 197-200). London: Sage.

DeJong, G. (1979). Independent living: From social movement to analytic paradigm. *Archives of Physical Medicine and Rehabilitation, 60,* 435-446.

Denzin, N. K. and Lincoln, Y. S. (1994). *Handbook of qualitative research.* Sage: Thousand Oaks, CA.

Depner, C. E., & Ingersoll-Dayton, B. (1985). Conjugal social support: Patterns in later life: *Journal of Gerontology, 40,* 761-766.

DeVivo, M. J., Hawkins, L., Richards, J. S., & Go, B. K. (1995). Outcomes of post-spinal cord injury marriages. *Archives of Physical Medicine and Rehabilitation, 76,* 130-138.

DeVivo, M. J., Richards, J. S., Stover, S. L., & Go, B. K. (1991). Spinal cord injury: Rehabilitation adds life to years. *Western Journal of Medicine, 154,* 602-605.

Dowd, J. J. (1975). Aging as exchange: A preface to theory. *Journal of Gerontology, 30,* 584-594.

Duck, S. (1983). *Friends, for life: The psychology of close relationships.* New York: St. Martin's Press.

Dunn, W., Foto, M., Hinojosa, J., Schell, B. A. B., Thomson, L. K., & Hertfelder, S. D. (1995). Position paper: Broadening the construct of independence. *The American Journal of Occupational Therapy, 49,* 1014.

Eriksson, G., Tham, K., & Fugl-Meyer, A. R. (2005). Couple's happiness and its relationship to functioning in everyday life after brain injury. *Scandinavian Journal of Occupational Therapy, 12,* 40-48.

Ferguson, K. E. (1984). *The feminist case against bureaucracy.* Philadelphia: Temple University Press.

Frank, G. (1996). The concept of adaptation as a foundation for occupational science research. In R. Zemke & F. Clark (Eds.), *Occupational Science: The evolving discipline* (pp. 47-55). Philadelphia: F. A. Davis.

Frank, G. (2000). *Venus on wheels: Two decades of dialogue on disability, biography and being female in America.* Los Angeles: University of California.

French, S. (1993a). Experiences of disabled health and caring professionals. In J. Swain, V. Finkelstein, S. French, & M. Oliver (Eds.), *Disabling barriers- Enabling environments* (pp. 201-210). London: Sage.

French, S. (1993b). What's so great about independence? In J. Swain, V. Finkelstein, S. French, & M. Oliver (Eds.), *Disabling barriers- Enabling environments* (pp. 44-48). London: Sage.

Gage, M. (1997). The Muriel Driver Lecture: From independence to interdependence: Creating synergistic health care teams. *The Canadian Journal of Occupational Therapy, 64,* 174-183.

Garee, B. & Cheever, R. (Eds.). (1992). *Marriage and disability: An accent guide.* Bloomington, Illinois: Cheever Publishing.

Gill, C. S. (1995). A Psychological View of Disability Culture. *Disability Studies Quarterly, 15,* 16-19.

Goffman, E. (1961). *Asylums: Essays on the social situation of mental patients and other inmates.* Garden City, NY: Doubleday.

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity.* New York: Simon & Schuster.

Groce, N. (1984). Anthropology and the handicapped: The need for a cross-cultural perspective. In S. Hey, G. Kiger & J. Seidel (Eds.), *The 25th*

Annual Conference of the Western Social Science Association, Sociology Division: Sessions on Chronic Disease and Disability (pp. 197-203). Salem, OR: The Society for the Study of Chronic Illness, Impairment and Disability and Willamette University.

Groce, N. & Scheer, J. (1990). Introduction. *Social Science and Medicine, 30,* V-VI.

Haller, B. (1995). Rethinking models of media representation of disability. *Disability Studies Quarterly, 15,* 26-43.

Harrington, C. & LeBlanc, A. J. (2001). Medicaid Home and Community-based Services. *Disability Statistics Report (16)*. Washington, D.C.: U. S. Department of Education, National Institute on Disability and Rehabilitation Research.

Holicky, R. & Charlifue, S. (1999). Ageing with a spinal cord injury: The impact of spousal support. *Disability and Rehabilitation, 21,* 250-257.

Hunter, K. I., & Linn, M. W. (1981). Psychological differences between elderly volunteers and non-volunteers. *International Journal of Aging and Human Development, 12,* 205-213.

Jacobs, P. G. (2002). Potential Maximization: Toward a Micro-Sociological Approach in Disability Studies. *Disability Studies Quarterly, 22,* 59-73.

Jett, K. (2002). Making the connection: Seeking and receiving help by elderly African Americans. *Qualitative Health Research, 12,* 373-387.

Johnson, C. L., & Troll, L. E. (1994). Constraints and facilitators to friendships in late late life. *The Gerontologist, 43,* 79-87.

Jones, D. C., & Vaughan, K. (1990). Close friendships among senior adults. *Psychology and Aging, 5,* 451-457.

Jongbloed, L., & Crichton, A. (1990). A new definition of disability. Implication for rehabilitation practice and social practice. *The Canadian Journal of Occupational Therapy, 57,* 32-58.

King, L. J. (1978). Toward a science of adaptive responses. *The American Journal of Occupational Therapy, 32,* 429-437.

Law, M. (1991). The Muriel Driver Lecture: The environment: A focus for occupational therapy. *The Canadian Journal of Occupational Therapy, 58,* 171-179.

Law, M., Baptiste, S., & Mills, J. (1995). Client-centred practice: What does it mean and does it make a difference? *The Canadian Journal of Occupational Therapy, 62,* 250-257.

Law, M., Cooper, B., Strong, S., Stewart, D., Rigby, P., & Letts, L. (1996). The person-environment-occupation model: A transactive approach to occupational performance. *The Canadian Journal of Occupational Therapy, 63,* 9-23.

Lloyd, C., & Samra, P. (1996). Healthy Lifestyles: A community programme for chronically mentally ill people. *The British Journal of Occupational Therapy, 59,* 27-32.

Lofland, J. (1971). *Analyzing social settings.* Belmont, CA: Wadsworth.

Longmore, P. K. (1995). The second phase: From disability rights to disability culture. *Disability Rag & Resource, 16,* 4-11.

Meagher, D. M., Gregor, F., & Stewart, M. (1987). Dyadic social-support for cardiac surgery patients: A Canadian approach. *Social Science and Medicine, 25,* 833-837.

Meier, R. H., III, & Purtilo, R. B. (1994). Ethical issues and the patient-provider relationship. *American Journal of Physical Medicine & Rehabilitation, 73,* 365-366.

Michener, H.A., DeLamater, J.D. & Myers, D. J. (Eds.). (2004). *Social psychology*. Belmont, CA: Wadsworth.

Morgan, D., & Jongbloed, L. (1990). Factors influencing leisure activities following stroke: An exploratory study. *The Canadian Journal of Occupational Therapy, 57*, 223-229.

Murphy, R. F., Scheer, J., Murphy, Y., & Mack, R. (1988). Physical disability and social liminality. A study in the rituals of adversity. *Social Science and Medicine, 26,* 235-242.

Murstein, B. I., Cerreto, M., & MacDonald, M. G. (1977). A theory and investigation of the effect of exchange-orientation on marriage and friendship. *Journal of Marriage and the Family, 39,* 543-548.

National Spinal Cord Injury Statistical Center. (2006, June). Spinal cord injury-Facts and figures at a glance- June 2006. Retrieved November 1, 2006, from http://www.spinalcord.uab.edu/show.asp?durki=21446.

Neistadt, M. E. (1995). Methods of assessing clients' priorities: A survey of adult physical dysfunction settings. *The American Journal of Occupational Therapy, 49,* 428-436.

Nelson, D. L. (1988). Occupation: Form and performance. *The American Journal of Occupational Therapy, 42, 633-641.*

Nelson, D. L. (1996). Therapeutic occupation: A definition. *The American Journal of Occupational Therapy, 50,* 775-782.

Newsom, J. T., & Schulz, R. (1998). Caregiving from the recipient's perspective: Negative reactions to being helped. *Health Psychology, 17,* 172-181.

Northen, J. G., Rust, D. M., Nelson, C. E., & Watts, J. H. (1995). Involvement of adult rehabilitation patients in setting occupational therapy goals: *The American Journal of Occupational Therapy, 49,* 214-220.

Nosek, M. A. (1993, April/May/June). A response to Kenneth R. Thomas' commentary: Some observations on the use of the word "consumer". *Journal of Rehabilitation,* 9-10.

Nosek, M. A., & Fuhrer, M. J. (1992a). Independence among people with disabilities: I. A heuristic model. *Rehabilitation Counseling Bulletin, 36,* 6-20.

Nosek, M. A., & Fuhrer, M. J. (1992b). Independence among people with disabilities: II. Personal Independence Profile: *Rehabilitation Counseling Bulletin, 36,* 21-36.

Nosek, M.A., & Howland, C. A. (1993). Personal assistance services: The hub of the policy wheel for community integration of people with severe physical disabilities. *Policy Studies Journal, 21,* 789-800.

Oelschlaeger, M. L., & Damico, J. S. (1998a). Joint productions as a conversations strategy in aphasic. *Clinical Linguistics and Phonetics, 12,* 459-480.

Oelschlaeger, M. L., & Damico, J. S. (1998b). Spontaneous verbal repetition: A social strategy in aphasic conversation. *Aphasiology, 12,* 971-988.

Oliver, M. (1993). Disability and dependency: A creation of industrial societies. In J. Swain, V. Finkelstein, S. French, & M. Oliver (Eds.), *Disabling barriers-Enabling environments* (pp.49- 60). London: Sage.

Parker, G. (1993a). A four-way stretch? The politics of disability. In J. Swain, V. Finkelstein, S. French, & M. Oliver (Eds.), *Disabling barriers- Enabling environments* (pp.249- 256). London: Sage.

Parker, G. (1993b). *With this body: Caring and disability in marriage.* Philadelphia: Open University.

Patton, M. Q. (2002). *Qualitative research & evaluation methods.* Thousand Oaks, CA: Sage.

Powers, B. A. (1991). The meaning of nursing home friendships. *Advances in Nursing Science, 14,* 42-58.

Prestby, J. E., Wandersman, A., Florin, P., Rich, R. and Chavis, D. (1990). Benefits, costs, incentive management and participation in voluntary organizations: A means to understanding and promoting empowerment. *American Journal of Community Psychology, 18,* 117-149.

Rintala, D. H., Young, M. E., Hart, K. A., Clearman, R. R., & Fuhrer, M. J. (1992). Social support and the well-being of persons with spinal cord injury living in the community. *Rehabilitation Psychology, 37,* 155-163.

Rintala, D. H., Young, M. E., Hart, K. A., & Fuhrer, M. J. (1994). The relationship between the extent of reciprocity with social supporters and measures of impairment, disability, and handicap in persons with spinal cord injury. *Rehabilitation Psychology, 39,* 15-27.

Roeher Institute (2001, February). *English*: *Publications: Alphabetical List: Disability Related Support Arrangements: Policy Options and Implications for Women's Equality.* Retrieved March 13, 2005 from the Status of Women Canada Website: http://www.swc-cfc.gc.ca/pubs/0662653238/200102_0662653238_e.pdf

Rosa, S. A., & Hasselkus, B. R. (1996). Connecting with patients: The personal experience of professional helping. *The Occupational Therapy Journal of Research, 16,* 245-260.

Ross, M. M. (1994). Focus: Acute care: Applying theory to practice. *OT Week, 8,* 16-17.

Scheer, J. (1984). Social adjustment of impaired and disabled people. In S. Hey, G. Kiger & J. Seidel (Eds.), *The 25th Annual Conference of the Western Social Science Association, Sociology Division: Sessions on Chronic Disease and Disability* (pp. 197-203). Salem, OR: The Society for the Study of Chronic Illness, Impairment and Disability and Willamette University.

Scheer, J., & Groce, N. (1988). Impairment as a human constant. Cross-cultural and historical perspectives on variation. *Journal of Social Issues, 44,* 23-37.

Scheer, J., & Luborsky, M. L. (1991). Post-Polio sequelae: The cultural context of polio biographies. *Orthopedics, 14,* 1173-1181.

Schkade, J. & Schultz, S. (1992). Occupational adaptation: Toward a holistic approach for contemporary practice, part 1. *The American Journal of Occupational Therapy, 46,* 829-837.

Schultz, S. & Schkade, J. K. (1992). Occupational adaptation: Toward a holistic approach for contemporary practice, part 2. *The American Journal of Occupational Therapy, 46,* 917-925.

Schultz, S. & Schkade, J. (1997). Adaptation. In C. Christiansen & C. Baum (Eds.), *Occupational therapy: Enabling function and well-being* (2nd ed.). Thorofare, NJ: Slack.

Schulz, C. H. (1994). Helping factors in a peer-developed support group for head injury: Survivor interview perspective. *The American Journal of Occupational Therapy, 48,* 305-309.

Schulz, E. K. (2002). *The meaning of spirituality in the lives and adaptation processes of individuals with disabilities*. Unpublished doctoral dissertation, Texas Woman's University, Denton.

Smalley, S. (1990). Chronic illness and codependence: The caring role. *Occupational Therapy Practice, 2,* 1-8.

Snyder, M. and Omoto, A. M. (1992). Volunteerism and society's response to the HIV epidemic. *Current Directions in Psychological Science, 1,* 113-116.

Spencer, J., Daybell, P. J., Eschenfelder, V., Khalaf, R., Pike, J. M., & Woods-Petitti, M. (1998). Contrasting perspectives on work: An exploratory qualitative study based on the concept of adaptation. *The American Journal of Occupational Therapy, 52,* 474-484.

Spencer, J., Hersch, G., Eschenfelder, V., Fournet, J., & Murray-Gerzik, M. (1999). Outcomes of protocol-based and adaptation-based occupational therapy interventions for low-income elderly persons on a transitional unit. *The American Journal of Occupational Therapy, 53,* 159-170.

Spencer, J. C. (1991). An ethnographic study of independent living alternatives. *The American Journal of Occupational Therapy, 45,* 243-251.

Spencer, J. C., & Davidson, H. A. (1998). The community adaptive planning assessment: A clinical tool for documenting future planning with clients. *The American Journal of Occupational Therapy, 52,* 19-30.

Spencer, J. C., Davidson, H. A., & White, V. K. (1996). Continuity and change: Past experience as adaptive repertoire in occupational adaptation. *The American Journal of Occupational Therapy, 50,* 526-534.

Strough, J., Patrick, J. H., Swenson, L. M., Cheng, S., & Barnes, K. A. (2003). Collaborative everyday problem solving: Interpersonal relationships and problem dimensions. *International Journal of Aging and Human Development, 56,* 43-66.

Taylor, M. C. (1991). Stigma: Theoretical concept and actual experience. *The British Journal of Occupational Therapy, 54,* 406-410.

Taylor, L. P. S., & McGruder, J. E. (1996). The meaning of sea kayaking for persons with spinal cord injuries. *The American Journal of Occupational Therapy, 50,* 39-46.

Tham, K. & Kielhofner, G. (2003). Impact of the social environment on occupational experience and performance among persons with unilateral neglect. *American Journal of Occupational Therapy, 57,* 403-412.

Townsend, E., Stanton, S., Law, M., Polatajko, H., Baptiste, S., Thompson-Franson, T., et al. (2002). *Enabling occupation: An occupational therapy perspective* (Rev. ed.) (E. Townsend, Ed.). Ottawa, ON: CAOT Publications ACE.

Unruh, A. M., & Elvin, N. (2004). In the eye of the dragon: Women's experience of breast cancer and the occupation of dragon boat racing. *The Canadian Journal of Occupational Therapy, 71,* 138-149.

Walmsley, J. (1993). Contradictions in caring: reciprocity and interdependence. *Disability, Handicap & Society, 8,* 129-141.

Wills, T. A. (1985). Supportive functions of interpersonal relationships. In C. Chen & L. Syme (Eds.), *Social support and health* (pp. 61-82). Orlando, FL: Academic Press.

Zajac, R. J., & Hartup, W. W. (1997). Friends as coworkers: Research review and classroom implications. *The Elementary School Journal, 98,* 3-13.

Zarb, G. (1993). The dual experience of ageing with a disability. In J. Swain, V. Finkelstein. S. French, & M. Oliver (eds.), *Disabling barriers- Enabling environments* (pp. 186-195). London: Sage.

APPENDIX A

Institutional Review Board Approval and Renewal Forms

TEXAS WOMAN'S UNIVERSITY
DENTON DALLAS HOUSTON
Institutional Review Board
1130 John Freeman Blvd., Houston, Texas 77030 713/794-2074

MEMORANDUM

TO: Gayle Hersch
Celia Schulz

FROM: IRB

DATE: April 18, 2006

SUBJECT: Renewal of currently approved proposal

Proposal Title: Interview perspectives on collaboration by persons with disabilites

Your request for renewal of your IRB approved protocol, has been approved.

Your renewal request is attached.

Please note that this approval lasts for 1 year. If your study extends beyond April 18, 2007, you will need to resubmit your application to the IRB for renewal.

Gretchen Gemeinhardt
Chairperson

TEXAS WOMAN'S UNIVERSITY
DENTON DALLAS HOUSTON
HUMAN SUBJECTS REVIEW COMMITTEE - HOUSTON CENTER

HSRC APPROVAL FORM

Name of Investigator(s) Celia H. Schulz

Social Security Number(s) 135-38-1583

Name of Research Advisor(s): Jean C. Spencer, Ph. D.

Address: 2007 Teasley Lane #117
Denton, TX 76205

Dear: Celia

Your study entitled: "Interview Perspectives on Collaboration by Persons with Disabilities"

(The applicant must complete the top portion of this form)

has been reviewed by the Human Subjects Review Committee - Houston Center and it appears to meet our requirements in regard to protection of the individual's rights.

Please be reminded that both the University and the Department of Health and Human Services regulations typically require that signatures indicating informed consent be obtained from all human subjects in your study. These are to be filed with the Human Subjects Review Committee Chairman. Any exception to this requirement is noted below. Furthermore, according to HHS regulations, **another review by the HSRC is required if your project changes or if it extends beyond one year from this date of approval.**

Any special provisions pertaining to your study are noted below:

Renewal approved 4/12/2006

The filing of signatures of subjects with the Human Subjects Review Committee is not required.

Other: see attached sheet.

No special provisions apply.

Renewal approved April 28 2005

modifications approved 5-16-01

Sincerely,

Gayle Hersch, Ph.D.
Chairperson, HSRC - Houston Center

renewal approved on 6-11-02
William P. Hanten

Renewal approved on 6-2-03
William P. Hanten

Renewal approved on May 9, 2004
William P. Hanten

TEXAS WOMAN'S UNIVERSITY
DENTON · DALLAS · HOUSTON
HUMAN SUBJECTS REVIEW COMMITTEE - HOUSTON CENTER

HSRC APPROVAL FORM

Name of Investigator(s) Celia H. Schulz

Social Security Number(s) 135-38-1583

Name of Research Advisor(s): Jean C. Spencer, Ph. D.

Address: 2007 Teasley Lane #117
Denton, TX 76205

Dear: Celia

Your study entitled: "Interview Perspectives on Collaboration by Persons with Disabilities"

(The applicant must complete the top portion of this form)

has been reviewed by the Human Subjects Review Committee - Houston Center and it appears to meet our requirements in regard to protection of the individual's rights.

Please be reminded that both the University and the Department of Health and Human Services regulations typically require that signatures indicating informed consent be obtained from all human subjects in your study. These are to be filed with the Human Subjects Review Committee Chairman. Any exception to this requirement is noted below. Furthermore, according to HHS regulations, **another review by the HSRC is required if your project changes or if it extends beyond one year from this date of approval.**

Any special provisions pertaining to your study are noted below:

The filing of signatures of subjects with the Human Subjects Review Committee is not required.

Other: see attached sheet.

No special provisions apply.

Sincerely,

Gayle Hersch, Ph.D.
Chairperson, HSRC - Houston Center

1-26-01

HUMAN SUBJECTS REVIEW COMMITTEE REPORT FORM

APPLICANT'S NAME: Celia H. Schulz

SOCIAL SECURITY NUMBER: 135-38-1583

PROPOSAL TITLE: "Interview Perspectives on Collaboration by Persons with Disabilities"

Applicant must complete top portion of this form)

DATE:

William P. Hunter
Disapprove Approve

Disapprove Approve
Sharon L. Olson
Disapprove Approve

Jeanette Krumb
Disapprove Approve

Susan Lawson
Disapprove Approve

1-26-01

TEXAS WOMAN'S
UNIVERSITY
DENTON/DALLAS/HOUSTON

SCHOOL OF OCCUPATIONAL THERAPY
1130 M.D. Anderson Blvd.
Houston, TX 77030-2897
Phone: 713/794-2128
Fax: 713/794-2122

CONSENT TO RECORD
(to be used in addition to the written consent when the voice and/or image of an individual are to be recorded).

Texas Woman's University
"INTERVIEW PERSPECTIVES ON COLLABORATION
BY PERSONS WITH DISABILITIES"

I consent to the recording of my voice and/or image by Celia H. Schulz, acting under the authority of the Texas Woman's University, for the purposes of the research project entitled " Interview Perspectives on Collaboration by Persons with Disabilities". I understand that the material recorded for this research may be made available for educational, informational, and/or research purposes; and I hereby consent to such use.

_____ _____
Participant Date
(Guardian or nearest relative must sign
if participant is a minor or has a guardian)

The above form was read, discussed, and signed in my presence. In my opinion, the person signing said consent form did so freely and with full knowledge and understanding of its contents.

_____ _____
Authorized representative Date
of the Texas Woman's University

TEXAS WOMAN'S
UNIVERSITY
DENTON / DALLAS / HOUSTON

SCHOOL OF OCCUPATIONAL THERAPY
1130 M.D. Anderson Blvd.
Houston, TX 77030-2897
Phone: 713/794-2128
Fax: 713/794-2122

INFORMED CONSENT FOR PARTICIPANT

"Interview Perspectives on Collaboration by Persons with Disabilities"

I agree to participate in a study that will be made by Celia Schulz. The purpose of the study is to find out about the experiences people with disabilities have when they work together with other people. I will allow Celia Schulz meet with me so that she can ask me questions to learn about my past and present times working together with other people on things I have to do during my day. We will meet at a place and time that I want to. First I will fill out a personal information form which will take about 20 minutes of my time. Then and we will meet for one to two hours after that at 2 separate times. The second time we meet will be one or two weeks after the first time we meet. I know that these meetings will take no more than 4 hours of my time. I understand that these 2 meetings will be tape recorded by Celia Schulz.

I also agree to then help Celia Schulz by reading, talking about and organizing the information from the meetings she has with me. We will be trying to put the information into different groups of topics. I can decide when I want to start doing this and when I want to stop. We will meet at a place and time I want to. I understand that when I meet with her that we will spend no more than 2 hours at a time, and that we will have no more than 10 of these meetings. This equals to about 20 hours of my time in addition to the 4 hours when she will be meeting with me to ask me

questions and the 20 minutes to fill out the personal information form. The total amount of time needed for my participation in the study will be 24 hours and 20 minutes.

I understand that participating in these meetings might have the following risks for me: these talks and meetings might interrupt my day, the conversations may make me feel uncomfortable and tired, I may become embarrassed, and other people may learn some private things about me or things that are private to me that I talk about. I understand that I can stop meeting with Celia Schulz at any time, and that it will be all right if I do. I understand that Celia Schulz will protect my identity by not using my name. I understand that tape recorded and handwritten information from all the meetings will be kept in a locked cabinet at the School of Occupational Therapy at Texas Woman's University once this study is finished. I understand that the material recorded for this research may be made available for educational, informational, and/or research purposes; and it is all right with me for it to be used that way.

If I have any questions about the study or about my rights as a participant, I should ask Celia Schulz or contact Dr. Jean Spencer at 713-794-2131. If I have questions later, or I want to report a problem, I may contact Celia Schulz at 940-898-2808 or the Office of Research and Grants Administration at 940-898-3375.

_____ _____

Participant Signature Date

TEXAS WOMAN'S
UNIVERSITY
DENTON/DALLAS/HOUSTON

SCHOOL OF OCCUPATIONAL THERAPY
1130 M.D. Anderson Blvd.
Houston, TX 77030-2897
Phone: 713/794-2128
Fax: 713/794-2122

INFORMED CONSENT FOR GUARDIAN

"Interview Perspectives on Collaboration by Persons with Disabilities"

As guardian for_____, I consent for my relative to participate in a study conducted by Celia Schulz. The purpose of this study is to find out about the experiences of persons with disabilities in collaborating with others around them, and the issues involved in such collaboration. I consent for my relative to fill out a personal information sheet, which will take about 20 minutes, and for Celia Schulz to then interview my relative. I understand that she will first meet with my relative 2 different times at a time and place of my relative's choice in order to obtain information about my relative's past and present experiences collaborating with other people. The second meeting will take place one or two weeks after the first meeting. I understand that both visits will last from 1 to 2 hours, for a total of 4 hours. I understand that these interviews will be tape recorded by Celia Schulz.

I also agree for my relative to then help Celia Schulz with the coding, analysis and interpretation of the information she obtains from these meetings. I understand that my relative can decide at what point and how he or she would like to contribute to this data analysis process. I understand that these meetings will be held at a convenient place and time for my relative. I have been told that each of these meetings will take no more than 2 hours, and that there will be no more than 10 of these meetings, for

a total of 20 hours in addition to the 4 hours of interviews and the 20 minutes to fill out the personal information sheet. The total amount of time needed for my relative's participation in the study will be 24 hours and 20 minutes.

I understand that participation in this study involves the following risks for my relative: these talks might interrupt my relative's day, the conversations may make my relative feel uncomfortable and tired, my relative could become embarrassed, and my relative could experience some loss of privacy. I understand that all interviews with my relative will be coded to protect his or her identity, and that tape recorded and written materials from the interviews will be kept in a locked cabinet at the School of Occupational Therapy at Texas Woman's University once this study is completed. I understand that the material recorded for this research may be made available for educational, informational, and/or research purposes; and I hereby consent to such use.

I understand that I can withdraw my relative's participation in the study at any time without penalty. If I have any questions about the research or about my relative's rights as a participant, I should ask Celia Schulz, who can be reached at 940-898-2808, or contact Dr. Jean Spencer at 713-794-2131. If I have questions later, or I wish to report a problem, I may contact the researcher or the Office of Research and Grants Administration at 940-898-3375.

_____ _____

Participant Guardian Signature Date

TEXAS WOMAN'S
UNIVERSITY
DENTON/DALLAS/HOUSTON

SCHOOL OF OCCUPATIONAL THERAPY
1130 M.D. Anderson Blvd.
Houston, TX 77030-2897
Phone: 713/794-2128
Fax: 713/794-2122

INFORMED CONSENT FOR INTERPRETER

"Interview Perspectives on Collaboration by Persons with Disabilities"

I agree to participate in a study that will be made by Celia Schulz. I agree to act as interpreter during the study for _____. The purpose of the study is to find out about the experiences people with disabilities have when they work together with other people. I will allow Celia Schulz to meet with us so that she can ask _____ questions to learn about his past and present times working together with other people on things he has to do during his day. We will meet at a place and time that we want to. First we will fill out a personal information form which will take about 20 minutes of his and my time. Then we will meet with Celia Schulz for one to two hours after that at 2 separate times. The second time we meet will be one or two weeks after the first time we meet. I know that these meetings will take no more than 4 hours of my time. I understand that these 2 meetings will be tape recorded by Celia Schulz.

I also agree to then help Celia Schulz by interpreting what

_____ says as he reads, talks about and organizes the information from the meetings she has with us. The purpose of this will be trying to put the information into different groups of topics. We can decide when we want to start doing this and when we want to stop. We will meet at a place and time we want to. I understand that when we meet with her that we will spend no more than 2 hours at a time, and that we will have no more than 10 of these meetings. This equals to about 20 hours of my time in addition to the 4 hours when she will be meeting with us to ask _____ questions and the 20 minutes to fill out the personal information form. The total amount of time needed for my participation in the study will be 24 hours and 20 minutes.

I understand that participating in these meetings might have the following risks for me: these talks and meetings might interrupt my day, the conversations may make me feel uncomfortable and tired, or I may become embarrassed. I understand that I can stop meeting with Celia Schulz at any time, and that it will be all right if I do. I understand that Celia Schulz will protect my identity by not using my name. I understand that tape recorded and handwritten information from all the meetings will be kept in a locked cabinet at the School of Occupational Therapy at Texas Woman's University once this study is finished. I understand that the material recorded for this research may be made available

for educational, informational, and/or research purposes; and it is all right with me for it to be used that way.

If I have any questions about the study or about my rights as a participant, I should ask Celia Schulz or contact Dr. Jean Spencer at 713-794-2131. If I have questions later, or I want to report a problem, I may contact Celia Schulz at 940-898-2808 or the Office of Research and Grants Administration at 940-898-3375.

_____ _____

Interpreter Signature Date

TEXAS WOMAN'S UNIVERSITY
DENTON DALLAS HOUSTON
Institutional Review Board
1130 John Freeman Blvd., Houston, Texas 77030 713/794-2074

MEMORANDUM

TO: Gayle Hersch
Celia Schulz

FROM: IRB

DATE: April 18, 2006

SUBJECT: Renewal of currently approved proposal

Proposal Title: Participant observation perspectives on collaboration by persons with disabilities

Your request for renewal of your IRB approved protocol, has been approved.

Your renewal request is attached.

Please note that this approval lasts for 1 year. If your study extends beyond April 18, 2007, you will need to resubmit your application to the IRB for renewal.

Gretchen Gemeinhardt
Chairperson

TEXAS WOMAN'S UNIVERSITY
DENTON DALLAS HOUSTON
HUMAN SUBJECTS REVIEW COMMITTEE - HOUSTON CENTER

HSRC APPROVAL FORM

Name of Investigator(s) Celia H. Schulz

Social Security Number(s) 135-38-1583

Name of Research Advisor(s): Jean C. Spencer, Ph. D.

Address: 2007 Teasley Lane #117
Denton, TX 76205

Dear: Celia

Your study entitled: "Participant Observation Perspectives on Collaboration by Persons with Disabilities"

(The applicant must complete the top portion of this form)

has been reviewed by the Human Subjects Review Committee - Houston Center and it appears to meet our requirements in regard to protection of the individual's rights.

Please be reminded that both the University and the Department of Health and Human Services regulations typically require that signatures indicating informed consent be obtained from all human subjects in your study. These are to be filed with the Human Subjects Review Committee Chairman. Any exception to this requirement is noted below. Furthermore, according to HHS regulations, **another review by the HSRC is required if your project changes or if it extends beyond one year from this date of approval.**

Any special provisions pertaining to your study are noted below:

The filing of signatures of subjects with the Human Subjects Review Committee is not required.

Other: see attached sheet.

✓ No special provisions apply.

Renewal approved April 28 2005

Sincerely,

Renewed approved on Aug 11, 2004 William P. Hensley

Gayle Hersch, Ph.D.
Chairperson, HSRC - Houston Center

Renewed approved on 6-14-02 William P. Hensley

Renewed approved on 6-2-03 William P. Hensley

Renewal approved April 18 2006

TEXAS WOMAN'S UNIVERSITY
DENTON DALLAS HOUSTON
Institutional Review Board
1130 M. D. Anderson Blvd., Houston, Texas 77030 713/794-2114

MEMORANDUM

TO: Celia Schulz
Cc: Dr. Jean Spencer

FROM: IRB

DATE: May 16, 2001

SUBJECT: Modification to currently approved proposal

Proposal Titles: "Participant Observation Perspectives on Collaboration by Persons with Disabilities " and "Interview Perspectives on Collaboration by Persons with Disabilities "

Your modifications to the currently IRB approved protocols have been approved. Specifically, your applications have been amended to allow for the inclusion of an interpreter to aid in the data gathering process for one of the study subjects. I understand that the appropriate consent documents have been modified to reflect these changes.

Please note that this approval lasts your initial approval date. If your study extends beyond February, 2002 you will need to resubmit your applications to the IRB for renewal.

Thank you for your patience and cooperation in awaiting this decision. Should you have any further questions about your application, please contact me at 713-794-2360.

Julieann Sakowski, Ph.D.
Chairperson

HSRC APPROVAL FORM

Name of Investigator(s) Celia H. Schulz

Social Security Number(s) 135-38-1583

Name of Research Advisor(s): Jean C. Spencer, Ph. D.

Address: 2007 Teasley Lane #117
Denton, TX 76205

Dear: Celia

Your study entitled: "Participant Observation Perspectives on Collaboration by Persons with Disabilities"

(The applicant must complete the top portion of this form)

has been reviewed by the Human Subjects Review Committee - Houston Center and it appears to meet our requirements in regard to protection of the individual's rights.

Please be reminded that both the University and the Department of Health and Human Services regulations typically require that signatures indicating informed consent be obtained from all human subjects in your study. These are to be filed with the Human Subjects Review Committee Chairman. Any exception to this requirement is noted below. Furthermore, according to HHS regulations, **another review by the HSRC is required if your project changes or if it extends beyond one year from this date of approval.**

Any special provisions pertaining to your study are noted below:

The filing of signatures of subjects with the Human Subjects Review Committee is not required.

Other: see attached sheet.

No special provisions apply.

Sincerely,

Gayle Hersch, Ph.D.
Chairperson, HSRC - Houston Center

HUMAN SUBJECTS REVIEW COMMITTEE REPORT FORM

APPLICANT'S NAME: Celia H. Schulz

SOCIAL SECURITY NUMBER: 135-38-1583

PROPOSAL TITLE: "Participant Observation Perspectives on Collaboration by Persons with Disabilities"

Applicant must complete top portion of this form)

DATE:			
	William P. Hunter	Disapprove	Approve
	Jean Boisaubin	Disapprove	Approve
	Doris E. Wyatt	Disapprove	Approve
	Jeanette Kennedy	Disapprove	Approve
	Susan Lawson	Disapprove	Approve

gh 1-26-0

TEXAS WOMAN'S
UNIVERSITY
DENTON/DALLAS/HOUSTON

SCHOOL OF OCCUPATIONAL THERAPY
1130 M.D. Anderson Blvd.
Houston, TX 77030-2897
Phone: 713/794-2128
Fax: 713/794-2122

INFORMED CONSENT FOR PARTICIPANT

"Participant Observation Perspectives On Collaboration By Persons With Disabilities"

I agree to participate in a study that will be made by Celia Schulz. The purpose of the study is to observe people with disabilities working together with other people and what happens between them. I will allow Celia Schulz to watch me as I do daily activities with other people. She will observe me doing activities that I agree to. She will observe me on days and at times that I agree to. One of her visits will be on a weekday and the other will be on a weekend. She will visit no more than 2 times. I know that each of the times she visits and observes me will take at least 2 hours but no more than 8 hours. I understand that Celia Schulz will make some notes during and after each visit. I know that I will spend at the most 16 hours total that I will be observed by Celia Schulz while I do daily activities with other people.

I also agree to then help Celia Schulz by reading, talking about and organizing the information from the visits she has with me. We will be trying to put the information into different groups of topics. I can decide when I want to start doing this and when I want to stop. We will meet at a place and time I want to. I understand that when I meet with her we will spend no more than 2 hours at a time, and that we will have no more than 10 of these meetings. This equals to about 20 hours of my time in addition to the 16 hours when she will be visiting

me to watch me do daily activities with other people. The total time needed for my participation in the study will be 36 hours.

I understand that participating in these meetings might have the following risks for me: these visits may interrupt my day and make me feel uncomfortable and tired, I may become embarrassed, and other people may learn some private things about me or things that are private to me. I understand that I can tell Celia Schulz when I need a break at any time. And if I want, I may stop at any time, and I know that that will be all right. I also know that Celia Schulz will protect my identity by not using my name. I understand that written information from all the meetings will be kept in a locked cabinet at the School of Occupational Therapy at Texas Woman's University once this study is finished. I understand that the material from this research may be made available for educational, informational, and/or research purposes, and it is all right with me for it to be used that way.

If I have any questions about the study or about my rights as a participant, I should ask Celia Schulz or contact Dr. Jean Spencer at 713-794-2131. If I have questions later, or I want to report a problem, I may contact Celia Schulz at 940-898-2808 or the Office of Research and Grants Administration at 940-898-3375.

_____ _____

Participant Signature Date

TEXAS WOMAN'S
UNIVERSITY
DENTON / DALLAS / HOUSTON

SCHOOL OF OCCUPATIONAL THERAPY
1130 M.D. Anderson Blvd.
Houston, TX 77030-2897
Phone: 713/794-2128
Fax: 713/794-2122

INFORMED CONSENT FOR COLLABOREE

"Participant Observation Perspectives On Collaboration By Persons With Disabilities"

I agree to participate in a study that will be made by Celia Schulz. The purpose of the study is to observe people with disabilities working together with other people and what happens between them. I will allow Celia Schulz to watch me together with another participant in her study as we do daily activities together. Celia Schulz will watch me and the other participant as we do daily activities together at least one time on a day and at a time that I agree to. She may come back for a second time, but it will be on a different day. She will visit no more than 2 times. I know that each of the times she visits and observes us will take at least 2 hours but no more than 8 hours. I understand that Celia Schulz will make some notes during and after each visit. I know that I will spend at the most 16 hours total that I will be observed by Celia Schulz while doing daily activities with the other study participant. The total amount of time needed for my participation in this study will be 16 hours.

I understand that participating in this study may have the following risks for me: these visits may interrupt my day and make me feel uncomfortable and tired, I may become embarrassed, and other people might learn some private things about me or things that are private to me. I understand that I can tell Celia Schulz when I need a break at any time. And if I want, I may stop at any time, and I know that that will be all

INFORMED CONSENT FOR COLLABOREE

"Participant Observation Perspectives On Collaboration By Persons With Disabilities"

right. I also know that Celia Schulz will protect my identity by not using my name. I understand that written information from the visits will be kept in a locked cabinet at the School of Occupational Therapy at Texas Woman's University once this study is finished. I understand that the material from this research may be made available for educational, informational, and/or research purposes, and it is all right with me for it to be used that way.

If I have any questions about the study or about my rights as a participant, I should ask Celia Schulz or contact Dr. Jean Spencer at 713-794-2131. If I have questions later, or I want to report a problem, I may contact Celia Schulz at 940-898-2808 or the Office of Research and Grants Administration at 940-898-3375.

_____ _____

Collaboree Signature Date

TEXAS WOMAN'S
UNIVERSITY
DENTON/DALLAS/HOUSTON

SCHOOL OF OCCUPATIONAL THERAPY
1130 M.D. Anderson Blvd.
Houston, TX 77030-2897
Phone: 713/794-2128

INFORMED CONSENT FOR PARTICIPANT GUARDIAN

"Participant Observation Perspectives on Collaboration by Persons with Disabilities"

As guardian for_____, I consent for my relative to participate in a study conducted by Celia Schulz. The purpose of this study is to observe people with disabilities collaborating on tasks with other people and observe what occurs during that interaction. I will allow Celia Schulz to observe my relative as they do daily activities of their choice with other people. I understand that she will observe my relative 2 different times at a time and place of my relative's choice. I understand that both visits will last from 2 to 8 hours, for a total of 16 hours. I understand that Celia Schulz will make some notes during and after each observation session.

I also agree for my relative to then help Celia Schulz with the coding, analysis and interpretation of the information she obtains from these meetings. I understand that my relative can decide at what point and how he or she would like to contribute to this data analysis process. I understand that these meetings will be held at a convenient place and time for my relative. I have been told that each of these meetings will take no more than 2 hours, and that there will be no more than ten of these meetings, for a total of 20 hours in addition to the 16 hours of observation. The total amount of time needed for my relative's participation in the study will be

36 hours.

I understand that participation in this study involves the following risks for my relative: that these meetings might interrupt my relative's day, the conversations may make my relative feel uncomfortable and tired, that my relative may become embarrassed, and that my relative could experience some loss of privacy. I understand that all interviews with my relative will be coded to protect his or her identity, and that written materials from the interviews will be kept in a locked cabinet at the School of Occupational Therapy at Texas Woman's University once this study is completed. I understand that the material recorded for this research may be made available for educational, informational, and/or research purposes; and I hereby consent to such use.

I understand that I can withdraw my relative's participation in the study at any time without penalty. If I have any questions about the research or about my relative's rights as a participant, I should ask Celia Schulz, who can be reached at 940-898-2808 or contact Dr. Jean Spencer at 713-794-2131. If I have questions later, or I wish to report a problem, I may contact the researcher or the Office of Research and Grants Administration at 940-898-3375.

_____ _____

Participant Guardian Signature Date

TEXAS WOMAN'S
UNIVERSITY
DENTON/DALLAS/HOUSTON

SCHOOL OF OCCUPATIONAL THERAPY
1130 M.D. Anderson Blvd.
Houston, TX 77030-2897
Phone: 713/794-2128

INFORMED CONSENT FOR COLLABOREE GUARDIAN

"Participant Observation Perspectives on Collaboration by Persons with Disabilities"

As guardian for_____, I consent for my relative to participate in a study conducted by Celia Schulz. The purpose of this study is to observe people with disabilities collaborating on tasks with other people and observe what occurs during that interaction. I will allow Celia Schulz to observe my relative together with another participant in her study as they do daily activities together. I understand that she will observe my relative at least one time and then may return on a different day to observe once more. She will visit and observe no more than two different days. I understand that visits will last from 2 to 8 hours, for a total of 16 hours. These visits will occur at a time and place of my relative's choice. I understand that Celia Schulz will make some notes during and after each visit.

I understand that participation in this study involves the following risks for my relative: that these visits might interrupt my relative's day, the conversations may make my relative feel uncomfortable and tired, my relative may become embarrassed, and my relative could experience some loss of privacy. I understand that all interviews with my relative will be coded to protect his or her identity, and that written materials from the visits will be kept in a locked cabinet at the School of Occupational Therapy at

Texas Woman's University once this study is completed. I understand that the material from this research may be made available for educational, informational, and/or research purposes, and I hereby consent to such use.

I understand that I can withdraw my relative's participation in the study at any time without penalty. If I have any questions about the research or about my relative's rights as a participant, I should ask Celia Schulz, who can be reached at 940-898-2808, or contact Dr. Jean Spencer at 713-794-2131. If I have questions later, or I wish to report a problem, I may contact the researcher or the Office of Research and Grants Administration at 940-898-3375.

_____ _____

Collaboree Guardian Signature Date

TEXAS WOMAN'S
UNIVERSITY
DENTON/DALLAS/HOUSTON

SCHOOL OF OCCUPATIONAL THERAPY
1130 M.D. Anderson Blvd.
Houston, TX 77030-2897
Phone: 713/794-2128
Fax: 713/794-2122

INFORMED CONSENT FOR INTERPRETER COLLABOREE

"Participant Observation Perspectives On Collaboration By Persons With Disabilities"

I agree to participate in a study that will be made by Celia Schulz. The purpose of the study is to observe people with disabilities working together with other people and what happens between them. I will allow Celia Schulz to watch me together with another participant in her study as we do daily activities together. I agree to act as interpreter for the other participant to make it clear to Celia Schulz what the other participant is saying. Celia Schulz will watch me and the other participant as we do daily activities together at least one time on a day and at a time that I agree to. She may come back for a second time, but it will be on a different day. She will visit no more than 2 times. I know that each of the times she visits and observes us will take at least 2 hours but no more than 8 hours. I understand that Celia Schulz will make some notes during and after each visit. I know that I will spend at the most 16 hours total that I will be observed by Celia Schulz while doing daily activities with the other study participant. The total amount of time needed for my participation in this study will be 16 hours. I understand that another interpreter will be present when the

information gathered is analyzed.

I understand that participating in this study may have the following risks for me: these visits may interrupt my day and make me feel uncomfortable and tired, I may become embarrassed, and other people might learn some private things about me or things that are private to me. I understand that I can tell Celia Schulz when I need a break at any time. And if I want, I may stop at any time, and I know that that will be all right. I also know that Celia Schulz will protect my identity by not using my name. I understand that written information from the visits will be kept in a locked cabinet at the School of Occupational Therapy at Texas Woman's University once this study is finished. I understand that the material from this research may be made available for educational, informational, and/or research purposes, and it is all right with me for it to be used that way.

If I have any questions about the study or about my rights as a participant, I should ask Celia Schulz or contact Dr. Jean Spencer at 713-794-2131. If I have questions later, or I want to report a problem, I may contact Celia Schulz at 940-898-2808 or the Office of Research and Grants Administration at 940-898-3375.

_____ _____

Interpreter Collaboree Signature Date

TEXAS WOMAN'S
UNIVERSITY
DENTON/DALLAS/HOUSTON

SCHOOL OF OCCUPATIONAL THERAPY
1130 M.D. Anderson Blvd.
Houston, TX 77030-2897
Phone: 713/794-2128
Fax: 713/794-2122

INFORMED CONSENT FOR INTERPRETER SPOUSE OF PARTICIPANT

"Participant Observation Perspectives On Collaboration By Persons With Disabilities"

I agree to participate in a study that will be made by Celia Schulz. I agree to act as interpreter during the study for my husband, who is the participant. The purpose of the study is to observe people with disabilities working together with other people and what happens between them. I will allow Celia Schulz to watch my husband and I as we do daily activities by ourselves or with other people. She will observe us doing activities that we agree to. She will observe us on days and at times that we agree to. She will visit on a weekend. I know that the times she visits and observes us will take at least 2 hours but no more than 8 hours. I understand that Celia Schulz will make some notes during and after each visit. I know that I will spend at the most 16 hours total in which my husband and I will be observed by Celia Schulz while we do daily activities with each other or other people.

I also agree to then help Celia Schulz by interpreting what my husband says as he reads, talks about and organizes the information from the visits she has with me and my husband and other people. My husband will be

trying to put the information into different groups of topics. My husband and I can decide when we want to start doing this and when we want to stop. My husband and I will meet at a place and time we want to. I understand that when we meet with her we will spend no more than 2 hours at a time, and that we will have no more than 10 of these meetings. This equals to about 20 hours of my time in addition to the 16 hours when she will be visiting me and my husband to watch us do daily activities by ourselves or with other people. The total time needed for my participation in the study will be 36 hours.

I understand that participating in these meetings might have the following risks for me: these visits may interrupt my day and make me feel uncomfortable and tired, I may become embarrassed, and other people may learn some private things about me or things that are private to me. I understand that I can tell Celia Schulz when I need a break at any time. And if I want, I may stop at any time, and I know that that will be all right. I also know that Celia Schulz will protect my identity by not using my name. I understand that written information from all the meetings will be kept in a locked cabinet at the School of Occupational Therapy at Texas Woman's University once this study is finished. I understand that the material from this research may be made available for educational, informational, and/or research purposes, and it is all right with me for it to be used that way.
If I have any questions about the study or about my rights as a participant,

INFORMED CONSENT FOR INTERPRETER SPOUSE OF PARTICIPANT

"Participant Observation Perspectives On Collaboration By Persons With Disabilities"

I should ask Celia Schulz or contact Dr. Jean Spencer at 713-794-2131. If I have questions later, or I want to report a problem, I may contact Celia Schulz at 940-898-2808 or the Office of Research and Grants Administration at 940-898-3375.

_____ _____

Interpreter Spouse Signature Date

APPENDIX B

Data Collection Tools

DEMOGRAPHIC INFORMATION SHEET

(Please fill in as much information as you feel comfortable disclosing):

Today's Date_____

Initials_____

Date of Birth_____ Place of Birth_____

Town and State you currently reside in_____

Gender M_____ F_____

Ethnic/Cultural/Religious background_____

_____

Level of Education_____

Employment Status_____

Description of Job_____

Interests and Hobbies_____

Marital Status_____

Number of Brothers_____

Number of Sisters_____

Number of Children_____

Number of Grandchildren_____

What is your
disability?_____

How long have you had the disability you mention above?_____

Do you require assistance from others because of the disability?_____

What device or devices do you use as an aid to mobility and/or function?____

_____

Do you have experience collaborating with others?_____

_____

Comments_____

_____

_____

_____

_____

SAMPLE QUESTIONS

Semi Structured Interview Questions For 1st Interview Study (Study #2)

1. Let's first talk about the meaning of the word "collaboration". What does the word "collaboration" mean to you?

    Possible probe:

        What do you think of when you think of the word "collaboration"?

2. Please tell me about your past experiences with collaboration.

    Possible probes:

    Are there any people in your past that you can remember collaborating with on anything? What sort of relationship did you have with this person? Did this person have a disability?

    Where did these collaborations take place?

    What were you doing that you would call collaboration?

    Was there any particular task involved that you collaborated on? Please tell me about it. What, if any, were the smaller tasks involved in the larger task?

3. Please tell me about the different types of collaborations you have done with other people.

    Possible probes:

    How do you interpret the different types of collaborations you have done?

    Please tell me about the similarities and differences in the types of collaborations you have done.

4. Please tell me about some of the different roles you have had when collaborating with others, and their roles with you.

    Possible probes:

What sort of role were you in with that individual or in that environment when you were collaborating? What sort of role did you take on during the collaboration? What sort of role did they have? Did your roles seem to change at any point?

Please tell me about the different types of environments in which you have collaborated with others.

5. Please tell me about how your experiences in the disability movement influenced your experiences with collaboration at the time.

6. Tell me some thoughts you have about collaboration with others- why you have done it in the past. What is the value in doing it?

Possible probes:

Please tell me about some of the reasons why you chose to collaborate with someone at a particular time.

7. In the past has it been possible for you to have "down time" where you are alone? Please tell me your thoughts about your past experiences with such "alone "time.

Semi Structured Interview Questions For 2nd Interview Study (Study #2)

1. Let's first talk about the meaning of the word "collaboration". Do you have anything to add from the last interview about what the word "collaboration" means to you?

Possible probes:

What do you think of when you think of the word "collaboration"?

2. Please tell me about your current experiences with collaboration.

Possible probes:

Are there any people in your current life that you collaborate with on anything? What sort of relationship do you have with this person? Does this person have a disability?

Where do these collaborations take place?

What do you do that you would call collaboration?

Is there any particular task involved that you collaborate on? Please tell me about it. What, if any, are the smaller tasks involved in the larger task?

3. Please tell me about the different types of collaborations you do with other people.

Possible probes:

How do you interpret the kinds of collaborations you do?

Please tell me about the similarities and differences in the types of collaborations you do.

4. Please tell me about some of the different roles you have when collaborating with others, and their roles with you.

Possible probes:

What sort of role are you in with that individual or in that environment when you collaborate? What sort of role do you take on during the collaboration? What sort of role do they have? Do your roles seem to change at any time?

Please tell me about the different types of environments in which you collaborate with others.

5. Tell me some thoughts you have about collaboration with others- why you do it, do you like doing it? What is the value in doing it?

Possible probe:

Please tell me about some of the reasons why you choose to collaborate with someone at that particular time.

6. Is it currently possible for you to have "down time" where you are alone? Please tell me your thoughts about your current experiences with such "alone "time.

PARTICIPANT OBSERVATION GUIDELINES
(For study #3)

In this study, in each of two separate participant observation sessions per subject, the researcher will observe each subject in daily activities of his or her choice as they collaborate with one or more "collaborees" in their environment. The researcher will be observing the nature of the collaboration between the subject and the collaboree, particularly for the following elements:

1. What is the task, or set of tasks, central to the collaboration? Do the different tasks change? Do some change in importance or emphasis during the collaboration?

2. In what type of environment is the collaboration taking place? What are the details of the environment- physical, structural, psycho-social, political, economic and/or cultural (for example)?

3. Who are the people collaborating? What are their roles in the environment? What are their roles relative to the task? What are their roles relative to each other? What different task roles do they take on in the collaboration? Do these roles change or switch during the collaboration, and how or why?

4. What is the nature of the power relationship between the subject and collaboree? Who initiates and who follows? What dynamics are observable between them throughout the collaboration process? When, why and how do the dynamics change?

5. What is the nature of the collaboration process? Is there a process and what is it? Does it have a describable trajectory, or series of steps? If you drew a picture or a model of the process, what would it look like?

6. What appear to be the positive aspects or rewards of their collaboration? What appear to be the negative aspects or problems?

7. Is the collaboration successful? What does the collaboration accomplish? What is unsuccessful about it?

8. What is the subject doing when he or she is not collaborating? What do you observe that is different about these times as opposed to times they are collaborating?

APPENDIX C

Correspondence with Journals

Attachment A: Letter of Receipt from Canadian Journal of Occupational Therapy for First Article

Canadian Association of Occupational Therapists
Association canadienne des ergothérapeutes

CANADIAN JOURNAL OF OCCUPATIONAL THERAPY
tel. (204) 453-2835 ◆ fax. (204) 475-3417
E Mail: fswedlove@shaw.ca

225 Yale Avenue
Winnipeg, MB, R3M 0L3
August 8, 2002

Ref: 02-07-03
Celia H. Schulz, MA, OTR/L
Texas Woman's University
1130 John Freeman Blvd.
Houston, Texas

Dear Ms. Schulz,

Thank you for the submission of your manuscript to the *Canadian Journal of Occupational Therapy* entitled:

Collaboration by Persons with Disabilities

Your submission will be sent for peer review. You will be notified as soon as possible concerning the results of the review process.

Would you please sign and return the two enclosed assignment forms. If your submission is accepted for publication, they will be co-signed and one of them returned to you.

Thank you for your interest in the Canadian Journal of Occupational Therapy.

Sincerely,

Fswedlove
Fern Swedlove
Editor, Canadian Journal of Occupational Therapy

CTTC Building, 3400-1125 Colonel By Drive, Ottawa, ON K1S 5R1 Canada
Tel. (613) 523-2268 ▫ 1(800) 434-2268 ▫ Fax (613) 523-2552 ▫ www.caot.ca ▫ www.otworks.ca

Attachment B: Letter of Submission of Second Article to the Editor of the Special Issue of the American Journal of Occupational Therapy (AJOT) Entitled *Disability Studies and Its Implications for Occupational Therapy*

Gary Kielhofner, DrPH, OTR
Department of Occupational Therapy
College of Applied Health Sciences (MC 811)
University of Illinois at Chicago
1919 W Taylor
Chicago, Illinois 60612

Dear Dr. Kielhofner,

Enclosed please find my submission to the special AJOT issue on Disability Studies and Their Implications for Occupational Therapy. My submission is entitled *The Breakdown of Collaboration: Interviews with Persons with Disabilities.*

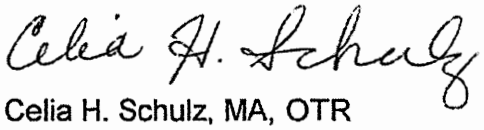
The manuscript is a bit long but I wanted to include all the pertinent quotes I had from research participants for the reviewers as so many of them are very good. This is a work in progress and I heartily welcome any feedback, suggestions, or comments you may have.

This manuscript is original, has not been previously published, and is not under consideration by any other publication. A related article based on the literature review for my dissertation research (titled *Collaboration by Persons with Disabilities: A Literature Review*) has been submitted to and reviewed by The Canadian Journal of Occupational Therapy and suggestions have been provided by the CJOT reviewers for revision. I have enclosed the completed and signed AJOT Authorship Responsibility and Financial Disclosure Form.

You may use either my work or home e-mail address to contact me. If you need to fax me, I only have a fax number at work, so please indicate on the fax "attention Celia Schulz" to make sure I get it. If you need to contact me via regular mail regarding this manuscript, please use my work address (below). The mail to my home address is unreliable and important items have been lost in the past.

Thank you very much for your consideration of this manuscript for the special AJOT issue, or another issue of the special issue is not possible.

Sincerely yours,



Celia H. Schulz, MA, OTR

WORK CONTACT INFORMATION:

Mailing address:
Celia H. Schulz, MA, OTR
Recruiter for the CAReS Project,
The University of Texas Health Science Center,
School of Nursing, Center on Aging,
6901 Bertner Avenue, Suite 635,
Houston, TX 77030-3901
Telephone number: (713) 500-9945
Fax number: (713) 500-0266
E-mail address: Celia.H.Schulz@uth.tmc.edu

HOME CONTACT INFORMATION:

Celia H. Schulz
7600 Kirby Drive #614
Houston, TX 77030-4327
Telephone number: (713) 839-1701
E-mail address: heliotrp@flash.net

Attachment C: E-mail after First Review of Second Article Submitted to AJOT from the Editor of the Special Issue of AJOT Entitled *Disability Studies and Its Implications for Occupational Therapy*

Schulz, Celia

From: Gary Kielhofner [kielhfnr@uic.edu] **Sent:** Wed 12/1/2004 2:57 PM
To: Schulz, Celia
Cc: Felicia Walters
Subject: MS#AJOTDS-16
Attachments:

RE: MS#AJOTDS-16

Hello Celia,
I just received the second review of your paper, The breakdown of Collaboration: interviews with Persons with Disabilities. I thought it would be more expeditious to send you an e-mail in place of a formal letter. Both reviewers have recommended that your paper be substantially revised and resubmitted for consideration. This reflects their judgment that the findings of your study have potential, while the current version of the manuscript would need substantial revision before consideration for publication. I have carefully examined their feedback and looked over your paper several times. I agree with them on both accounts. that is, the paper has real potential, but it needs substantial rewriting.
At this point I will leave it to you whether you wish to pursue a rewrite for this special issue as I would need to have the rewrite by the end of January, which I think is a tight timeline for the amount of revision we are going to ask for. But, if you wish to attempt a revision, I will resubmit the paper to the two reviewers for a second review. If at that time, the paper is deemed suitable for publication, I will recommend it to Mary Corcoran who makes the final decision. Keep in mind it is likely that additional revisions would be required following a next submission. Please let me know as soon as possible if you wish to attempt another revision. In either event I will summarize the reviewers feedback and mine in hopes it will be helpful for a revision of your manuscript whether or not you decide to resubmit for this special issue.

Both reviewers and I made comments on the manuscript so I will send them to you under separate cover as well.

Both reviewers commented that the topic of collaboration seemed to come out of nowhere. In your literature review, you do not make a thorough case for why it is an important topic and in your discussion of the research, you don't give a sense of how this topic emerged. So, for instance, you might begin with a more thorough treatment of the topic of collaboration in the lit review and point out that you looked for data on collaboration in response, or you might argue that the topic emerged as one of importance from a broader research question.

Related to this the reviewers and I felt that collaboration was not well defined. At first it seemed as though you were going to report on collaboration within therapy, but then as the paper proceeds one realizes the topic is more broad and addresses collaboration as an adaptive strategy. So you would need to do quite a bit of work to more clearly frame your tropic and justify it.

Both reviewers felt the methods were weak. I made notes on the manuscript to guide you a bit. I would recommend reading other qualitative papers to see how methods are usually reported and follow that format. You also need to tie what you did to concepts and standards of qualitative methodology so that the reader can understand clearly what you did to assure the trustworthiness and dependability of your findings.

In terms of the results, we all questioned whether your real finding was a breakdown of collaboration. It seemed instead that the data pointed toward the importance of collaboration with some information about its challenges. Along with this, it also appeared that the various evidence you gave under collaboration only loosely hung together as a coherent theme. That is, you used the idea of collaboration in a very broad and sometimes changing way. In part this is related to the need to define it more clearly at the outset of the paper. However a larger problem which the reviewers and I noted is that examining the data your provided led us to wonder about the validity of the findings. The quotes your provided did not always seem to fit with your interpretation/presentation. So as a reader one wonders where the idea of collaboration came from? Did clients identify it as a theme? Or is this your take? Also, as I noted the emphasis on breakdown of collaboration did not seem warranted by the data your presented. Thus, the findings need to be woven together more tightly and argued more clearly and your interpretations need to fit the data better than they appear to now. Not seeing all the data you had, it is hard for me to say exactly how you should proceed.

The reviewers also noted that a lot of your presentation of findings, lacked context so it was hard for the reader to follow.

On reviewer also noted that the way you presented findings was not always consistent with the concepts of disability studies. Given that this special issues focuses on this topic, it is important to reflect their concepts. I'm wondering if you could link the paper to the idea in disability studies that "interdependence" should replace the idea of dependence and link the idea of collaboration more clearly to achieving interdependence.

I hope you find this feedback helpful in making a decision about whether to

revise in the necessary timeframe and useful for eventual revision of the manuscript. I thank you for your submission . I think you have an important topic and would like to see the paper achieve the focus that your study deserves.

these were the main criticisms comments.You will find much more detail in the manuscripts when they arrive.

Attachment D: Letter of Transmittal of Reviewer's Comments on Second Article from Assistant to Editor of the Special Issue of AJOT Entitled *Disability Studies and Its Implications for Occupational Therapy*

UNIVERSITY OF ILLINOIS
AT CHICAGO

Department of Occupational Therapy (MC 811)
College of Applied Health Sciences
1919 West Taylor Street
Chicago, Illinois 60612-7250

December 1, 2004

Celia Schulz
The University of Texas
Health Sciences Center
School of Nursing Center on Aging
6901 Bertner Avenue, Suite 635
Houston TX 77030

Dear Celia,

Enclosed you'll find copies of the reviewer's comments regarding your manuscript, *The Breakdown of Collaboration: Interviews with Persons with Disabilities.*

Should you need any additional information, please don't hesitate to contact me at (312) 996-3051 or waltersf@uic.edu.

Sincerely,

Felicia M. Walters, MBA
Assistant to the Head
Post-Professional Admissions Counselor

UIC

Phone (312) 996-6901 • Fax (312) 413-0256

Attachment E: Letter of Submission of Revision of Second Article to the Editor of the Special Issue of AJOT Entitled *Disability Studies and Its Implications for Occupational Therapy*

February 26, 2005

Gary Kielhofner, DrPH, OTR
Department of Occupational Therapy
College of Applied Health Sciences (MC 811)
University of Illinois at Chicago
1919 W Taylor
Chicago, Illinois 60612

Dear Dr. Kielhofner:

Enclosed please find my revised manuscript for the special AJOT issue on Disability Studies and Their Implications for Occupational Therapy. My submission is now entitled *Supporting Collaborations and Symbiosis: Perspectives of Persons with Disabilities* (it was originally titled *The Breakdown of Collaboration: Interviews with Persons with Disabilities*).

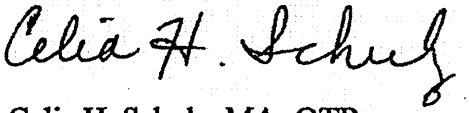
I have tried my best to incorporate comments and suggestions made by you and both reviewers on the original manuscript.

This manuscript is original, has not been previously published, and is not under consideration by any other publication. A related article based on the literature review for my dissertation research (entitled *Collaboration by Persons with Disabilities: A Literature Review*) has been submitted to and reviewed by the Canadian Journal of Occupational Therapy and suggestions have been provided by the CJOT reviewer for revision. I have enclosed the completed and signed AJOT Authorship Responsibility and Financial Disclosure Form.

You may use either my work or home e-mail address to contact me. If you need to fax me, I only have a fax number at work, so please indicate on the fax "attention Celia Schulz" to make sure I get it. If you need to contact me via regular mail regarding this manuscript, please use my work address (below). The mail to my home address is unreliable and important items have been lost in the past.

Thank you very much for your patience and assistance throughout this process.

Sincerely yours,



Celia H. Schulz, MA, OTR

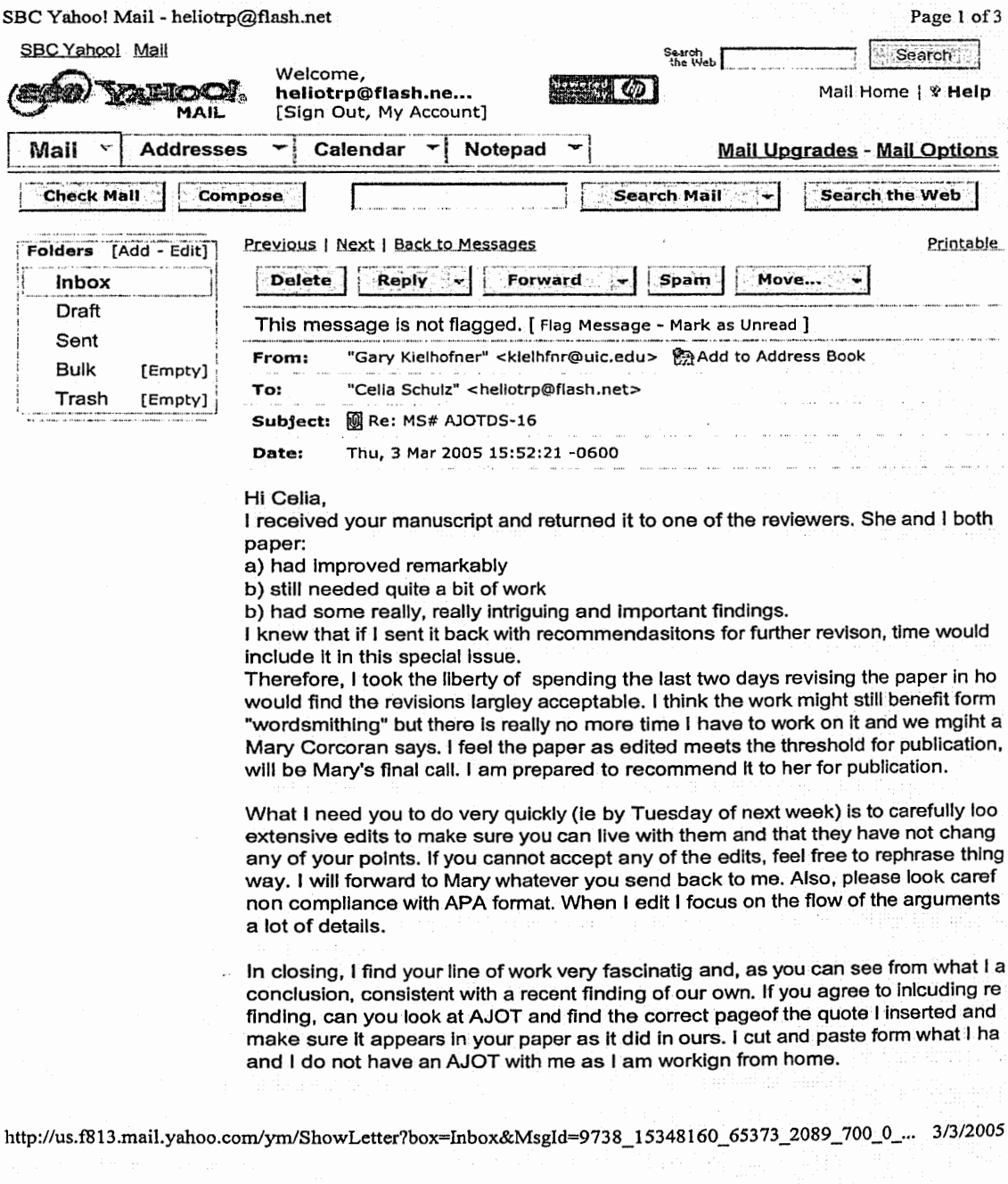
WORK CONTACT INFORMATION:

Mailing address:
Celia H. Schulz, MA, OTR
Recruiter for the CAReS Project
The University of Texas Health Science Center,
School of Nursing, Center on Aging,
6901 Bertner Avenue, Suite 635
Houston, TX 77030-3901
Telephone number: (713) 500-9945
Fax number: (713) 500-0266
E-mail address: Celia.H.Schulz@uth.tmc.edu

HOME CONTACT INFORMATION:

Celia H. Schulz
7600 Kirby Drive #614
Houston, TX 77030-4327
Telephone number: (713) 839-1701
E-mail address: heliotrp@flash.net

Attachment F: E-mail after Submission of Revised Second Article to AJOT from the Editor of the Special Issue of AJOT Entitled *Disability Studies and Its Implications for Occupational Therapy*



SBC Yahoo! Mail - heliotrp@flash.net Page 1 of 3

SBC Yahoo! Mail

Welcome, heliotrp@flash.ne... [Sign Out, My Account]

Search the Web | Search

Mail Home | Help

Mail | Addresses | Calendar | Notepad | Mail Upgrades - Mail Options

Check Mail | Compose | Search Mail | Search the Web

Folders [Add - Edit]
- Inbox
- Draft
- Sent
- Bulk [Empty]
- Trash [Empty]

Previous | Next | Back to Messages Printable

Delete | Reply | Forward | Spam | Move...

This message is not flagged. [Flag Message - Mark as Unread]

From: "Gary Kielhofner" <kielhfnr@uic.edu> Add to Address Book

To: "Celia Schulz" <heliotrp@flash.net>

Subject: Re: MS# AJOTDS-16

Date: Thu, 3 Mar 2005 15:52:21 -0600

Hi Celia,
I received your manuscript and returned it to one of the reviewers. She and I both paper:
a) had improved remarkably
b) still needed quite a bit of work
b) had some really, really intriguing and important findings.
I knew that if I sent it back with recommendasitons for further revison, time would include it in this special issue.
Therefore, I took the liberty of spending the last two days revising the paper in ho would find the revisions largley acceptable. I think the work might still benefit form "wordsmithing" but there is really no more time I have to work on it and we mgiht a Mary Corcoran says. I feel the paper as edited meets the threshold for publication, will be Mary's final call. I am prepared to recommend it to her for publication.

What I need you to do very quickly (ie by Tuesday of next week) is to carefully loo extensive edits to make sure you can live with them and that they have not chang any of your points. If you cannot accept any of the edits, feel free to rephrase thing way. I will forward to Mary whatever you send back to me. Also, please look caref non compliance with APA format. When I edit I focus on the flow of the arguments a lot of details.

In closing, I find your line of work very fascinatig and, as you can see from what I a conclusion, consistent with a recent finding of our own. If you agree to inlcuding re finding, can you look at AJOT and find the correct pageof the quote I inserted and make sure it appears in your paper as it did in ours. I cut and paste form what I ha and I do not have an AJOT with me as I am workign from home.

http://us.f813.mail.yahoo.com/ym/ShowLetter?box=Inbox&MsgId=9738_15348160_65373_2089_700_0_... 3/3/2005

Just so you know I'll be away from my e-mail Sunday through Monday evening.
Gary
P.S. I'd be very intrigued to see what else you have found. I really did enjoy readin some on this paper.

----- Original Message -----
From: Celia Schulz
To: Gary Kielhofner DrPH, OTR ; Felicia M. Walters
Cc: Gayle Hersch ; Spencer, Jean ; Jean Spencer ; Jean Spencer
Sent: Saturday, February 26, 2005 1:07 PM
Subject: MS# AJOTDS-16

Dear Dr. Kielhofner,

Attached please find my revised manuscript for submission to the special AJOT i Disability Studies and Their Implications for Occupational Therapy. The manuscr entitled: *Supporting Collaborations and Symbiosis: Perspectives of Persons with* was originally titled *The Breakdown of Collaboration: Interviews with Persons wit*

I am including my cover letter, separate title page, and manuscript text as three s attachments.

Today I sent out by overnight mail the original and three copies of the revision, al page, cover letter, and signed AJOT Authorship Responsibility and Financial Dis packet should reach your office at UIC by 10:30 a.m. on Monday, February 28, 2

Thank you very much for all of your help and your patience in this process.

Sincerely Yours,

Celia Schulz

Attachment

Supporting_Collaborations_and_Symbiosis__1_.doc
.doc file

Attachment scanning provide

Scan and Download A
Scan and Save to my Y
View Attachment

Delete | Reply | Forward | Spam | Move...

Previous | Next | Back to Messages

Check Mail | Compose | Search Mail | Search the Web

Attachment G: E-mail of Receipt from Disability Studies Quarterly for Third Article

Celia Schulz

From: "Stephen Kuusisto " <skuusisto@wideopenwest.com>
To: "'Celia Schulz'" <heliotrp@flash.net>
Cc: <brueggemann.1@osu.edu>; "'SCOT DANFORTH'" <danforth.10@osu.edu>
Sent: Monday, September 25, 2006 8:54 AM
Subject: RE: Here is my submission to DSQ

Dear Celia Schulz:

Theeditors of Disability Studies Quarterly have received your electronic submission and we will be sending your article for peer review shortly. Thank you for submitting your scholarship to Disability Studies Quarterly.

Stephen Kuusisto
Editor
DSQ

From: Celia Schulz [mailto:heliotrp@flash.net]
Sent: Sunday, September 17, 2006 5:30 PM
To: Scot Danforth; Brenda Brueggemann; Stephen Kuusisto
Cc: Celia Schulz
Subject: Here is my submission to DSQ

Dear Stephen Kuusisto, Brenda Brueggemann and Scot Danforth,

Attached please find my submission to Disability Studies Quarterly entitled: "Collaboration in the Marriage Relationship Among Persons with Disabilities". This submission is intended for the peer-reviewed article category.

I will need an official letter from DSQ stating that the editors have received my article for review. It will be a requirement for my graduation that I have a copy of such a letter and I will need to place it in an appendix in my dissertation. If you would please provide me one as soon as possible via e-mail or snail mail, I would greatly appreciate it.

My contact information is as follows:

Celia Schulz, MA, OTR
7600 Kirby Drive #614
Houston, TX 77030-4327

(713) 839-1701

heliotrp@flash.net

I am looking forward to the reviewers' comments on my article. Thank you for considering my article for DSQ.

Sincerely yours,

Celia H. Schulz