Occupational Therapy’s Role in Improving the Quality of Life for Persons With Cerebral Palsy

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Key Words: handicapped • independent living

 Adults with cerebral palsy need assistance to maximize their capabilities, interact with others, and achieve independence. They experience difficulty communicating their needs to successfully obtain medical/rehabilitation and independent living services, which are necessary to achieve independent living. Knowledge of the experience of such clients can help occupational therapists to better serve them. This study, which used a case study design, presents data collected during more than 80 hours of guided interviews with 5 study participants. A data analysis of the participants’ experiences showed recurring themes of the disability as the enemy, the importance of attitude, dependence versus independence, and the significance of purposeful activity. The participants’ experiences with therapists and independent living skills agencies are presented, as is an examination of the medical/rehabilitation and independent living models.

This paper suggests an expanded view of the roles for occupational therapy in improving the quality of life and independent living outcome for persons with cerebral palsy and other significantly limiting physical disabilities.

Adults who are significantly limited by cerebral palsy need assistance to maximize their health and their capabilities, master the physical world, interact with other people, strive for normalization, and take charge of their own lives. Both the medical/rehabilitation and the independent living systems offer services that are designed to help such persons meet some of those goals. However, gaining access to services is often difficult. Adults with physical disabilities who achieve independent living with attendant care continue to have significant unmet needs. When severe communication disorders accompany their disabilities, such persons are unable to articulate their needs. Without client input, decisions made by professionals may reflect inaccurate thinking and therefore contribute to failure to meet goals.

Therapists accustomed to the medical/rehabilitation model often find that their recommendations are rejected by adults with significantly limiting cerebral palsy. Perhaps therapists accustomed to medical or rehabilitation settings who now interact with community independent living programs feel a lack of professional connection or consistency with occupational therapy peers who serve other populations.

Literature Review

Studies and descriptive papers that have sought feedback from adults with significantly limiting disabilities including cerebral palsy cited a low degree of life satisfaction, exemplified by difficulty obtaining regular medical care, coping with sexuality, and achieving independence (Burnett & Yerxa, 1980; Mowatt, 1965; Richardson, 1972).

There is considerable occupational therapy literature concerning children with cerebral palsy (Barrera & Vella, 1987; Johnson & Deitz, 1985; Magill & Hurbut, 1986), but none specifically for adults with cerebral palsy.

Sabari, Wasserman, White, Williamson, and Hinojosa (1983) identified the need for consideration of the impact of biological, psychosocial, and environmental factors on the functional performance of persons with severe disabilities but did not acknowledge the role of occupational therapy in facilitating the transition to independent living. In a recent survey of occupational therapy evaluations for developmentally disabled adults, Neistadt (1986) found that therapists favored remedial goals over those focused on adaptation toward functional independence.

A role for occupational therapists who work with
adults with cerebral palsy can be better understood within the framework of the often contradictory medical/rehabilitation and independent living models.

Within the medical/rehabilitation model, intervention has historically been physician directed, time limited, restorative, and reductionistic (Dejong, 1979; Wolf, 1969; Yerxa, 1983). The patient's deficits are addressed through surgery, drug therapy, or hands-on care, which includes nursing, physical therapy, and occupational therapy. In a function-oriented approach, patients and families are included in the decision-making process (Bleck & Nagel, 1982; Watson, 1980).

The medical/rehabilitation model is most often directed at patients with illnesses or disabilities that are most receptive to intervention; it fails to address the needs of difficult-to-serve groups, including adults with chronic, severe disabilities such as cerebral palsy (American Academy for Cerebral Palsy and Developmental Medicine, 1985; Dembo, 1970).

The independent living model is a product of a number of contemporary social movements, including the rise of consumerism, civil rights consciousness, and the self-help focus (Vash, 1981; Zukas, 1975). Within this model, the person who receives service is defined as a consumer. Services are generally offered by disabled peers, although some professionals are involved. Problems are defined in terms of barriers in economic, architectural, or support systems, rather than in terms of the consumer's physical or mental disabilities. Services include peer counseling, advocacy, and help with the removal of barriers (Dejong, 1979).

Independent living is defined by the following: (a) living without supervision, (b) living outside of a residential facility, (c) living in an apartment or home of one's own choosing, and (d) using attendant care as needed to assure safety and completion of all self-care tasks. The definition implies the freedom of decision making, the power of self-determination, and the dignity of risk.

Several occupational therapy frames of reference and theories provide an underlying foundation for practice with adults with cerebral palsy. Among the biomedical frames of reference are studies by Bobath (1971) and Ayres (1972), which focus on specific neural function and associated motor behaviors. Like the medical/rehabilitation model, they are reductionistic and identify the therapist as the expert who seeks to facilitate change in the patient.

The facilitating growth and development theoretical conceptualization developed by Llorens (1976) incorporates a developmental continuum that extends into adulthood and focuses on mastery of skills. Although the view of the client is more comprehensive than that offered by the biomedical theories, this model does not address the client's role as equal participant in decision making or the dynamic factors of motivation and environment involved in the development of adaptive behaviors and skills necessary for independent living. Llorens presented components consistent with both the medical/rehabilitation and the independent living model, but aligned more closely with the former.

The model of human occupation, based on occupational behavior theory first advanced by Reilly (1962) and elaborated on by Kielhofner (1983, 1985) and Yerxa (1983), aligns more closely with the independent living model. It does not fully account for the development of adults affected from birth by significant disability such as cerebral palsy, in which there is an apparent absence of typical self-care, work, and play behaviors.

General systems theory played a role in the development of the independent living model, was incorporated in the model of human occupation, and contributed to the development of occupational behavior theory. Kielhofner (1978, 1983) and Reilly (1974) suggested that the use of general systems theory allows a discovery of commonalities and bonds among bodies of knowledge, including the diverse frames of reference in occupational therapy. They believed that, on a more fundamental level, the general systems theory presents a view of the person as a biological system interacting with other biological and environmental systems.

The purposes of this study were to (a) identify frames of reference and models for the practice of occupational therapy for adults with significantly limiting cerebral palsy and (b) describe a role for occupational therapists who work with this population on the basis of the literature and data provided by adults who have significantly limiting cerebral palsy. The study used a descriptive case study design.

Method

Participants in the study were 5 adults—3 men and 2 women between the ages of 35 and 47—who lived independently with attendant care in urban and suburban areas of Alameda County, California. Participants had been served by providers of medical/rehabilitation and independent living services during childhood and adulthood. All participants were significantly limited in at least two of the following areas: mobility, communication, and use of the upper extremities for functional tasks. All of the participants relied on moderate to maximum assistance by attendants to maintain their independence in the community. They were free of significant mental retardation or other limiting disabilities. The participants' level of education varied, from noncompletion of high school...
to having a master's degree from a major university. Two were currently employed, two had never been employed, and one was temporarily unemployed. All had worked as volunteers.

Working from an outline, I gathered data by means of extended, guided interviews with each participant. A phenomenological approach encouraged participants to share all information they deemed relevant. Participants were not informed of the identity or responses of other participants.

The interviews, which resulted in over 80 hours of audiotape, were transcribed to typewritten form for analysis. The data included information regarding living situations, medical/rehabilitation and independent living services received, childhood experiences, family and other relationships, life tasks, and self-description. A data analysis revealed recurring themes, which were examined for their relevance to occupational therapy theory and practice. (For further discussion of the study's methodology and its implications for occupational therapy, see Kibele & Llorens, in press.)

Findings

For purposes of this paper, data presented and discussed are those relevant to the participants' experiences with independent living services and medical/rehabilitation services, including therapies.

Medical/Rehabilitation Services

All of the participants discussed some experience with occupational, physical, and speech therapy during childhood, although they were unable to remember duration or frequency. One participant had received no therapy services as an adult; the others had received only short-term services and cited lack of funding as a limiting factor. All therapy described was provided in a traditional medical/rehabilitation or social services setting, rather than at an independent living skills agency.

Four participants remembered specific therapists; all had strong opinions about therapy. Occupational therapists had provided traditional activities such as practice of hand skills through crafts and typing and practice in activities of daily living. All participants sensed that, as children, walking was the most important goal for them and their parents and that physical therapy seemed most valued, because it was there that attempts were made to walk with crutches and heavy braces.

Four of the participants recalled that their parents viewed therapists and physicians as experts and supported therapy with home exercise programs which, when combined with homework, occupied most leisure hours. They stated that home therapy follow-up negatively affected their relationships with their mothers. Three of the participants, who now rely on attendants to feed them, cited hours of tiring and unsuccessful practice at self-feeding, well into adolescence. One participant said of his self-feeding efforts that his therapist's expectations were unrealistic and that his parents "bought into" those expectations.

The participants, all of whom now use power wheelchairs, received their first manual wheelchairs between the ages of 5 and 9 years. All recalled experiences of mobility in wheelchairs and on go-carts and tricycles as among their best memories of childhood therapy. Their worst memories of therapy included pain from stretching and braces, fear of falling, and therapists who communicated a businesslike, uncaring, or condescending attitude. They recalled repeated feelings of failure as a consequence of being unable to meet goals such as walking or feeding without help. In addition, the participants said that time spent in therapy had negatively affected the continuity of their academic experience.

Three participants noted that occupational therapists with whom they have worked as adults have helped them with goals related to some aspects of independent living. However, all 5 participants stated that neither their parents nor any professional with whom they had worked as children had focused with them on adult independent living with attendant care as an attainable goal.

One participant said that therapy she has received as an adult has worked for her when she has been treated as an equal partner in the evaluation of her needs and in the mutual discovery of workable solutions toward independent living.

All participants cited difficulty as adults in finding appropriate, physically accessible medical care. They expressed difficulty with office receptionists unable to understand their speech and examination chairs, tables and other equipment unsuited to their special positioning needs. Three participants cited experiences with physicians and hospital staff who viewed cerebral palsy as an illness and viewed the participants as incapable of experiences typical of those without limiting physical disabilities.

Independent Living Services

All 5 participants have had contact with a major independent living skills agency in the San Francisco Bay area. In addition, 1 participant helped with the founding of the agency; another had been employed there. Two participants have received services from more than one independent living skills agency.

All of the participants expressed agreement with the philosophical basis of the independent living model, but expressed less support for specific ser-
services they had received. Services included group and individual peer counseling regarding money management, meal planning, and recruitment and hiring of attendants. According to 1 participant, training comprised more theoretical discussion than actual practice of skills in a controlled learning environment.

Three participants said that initiation into the independent living model, with its emphasis on individual responsibility and autonomy, was difficult for them, since professionals and parents had always assumed responsibility for decision making. Two participants acknowledged that staff and peers at independent living skills agencies displayed a lack of understanding of the functional limitations imposed by cerebral palsy, which are not necessarily experienced by persons with other disabilities.

Another participant summarized his comments with the expression that the services of an independent living skills agency are appropriate for people with cerebral palsy, but would be more easily accepted and more smoothly implemented if disabled children and their families were exposed to the philosophy and services at an earlier age. Speaking about independent living, that participant concluded:

The attitude of the medical system is that you have to earn your way out; the burden of proof is on the individual to prove [he or she has] what it takes. With the independent living model, the [individual's] right to make that decision is assumed.

Discussion

A number of themes recurred during the interviews. Four are discussed here in terms of their significance for occupational therapy theory and practice.

First, the study participants indicated that they and their parents had developed the perception, on the basis of their early interaction with physicians and therapists, that the disability was the enemy; it was something to be overcome, as has been alluded to by authors such as Vash (1981).

A major source of the perception of the disability as the enemy, according to participants, was the narrow focus of goal orientation. Medical and therapy goals such as ambulation, correction of joint deformity, and maximum self-reliance in activities of daily living implied the need to correct imperfections within the child. Participants expressed that such goal orientation had a number of consequences. It contributed to the sense of dependence on professionals as experts that was experienced by participants and families. It also led to the experience of repeated failure from an early age, as participants were unable to walk functionally or to feed themselves, despite hours of therapists' and families' encouragement and assistance.

With each failure to meet a goal of therapy, participants expressed a sense of having been betrayed by their therapists, whose role was to correct their physical and functional deficits. This early loss of faith in rehabilitation professionals may have contributed to the participants' distrust as adults of the medical/rehabilitation model and its services.

In addition, the participants described the ways in which therapy's narrow goal orientation eroded the relationship between themselves and their parents, as parents sought effective cures and enforced therapy home programs. The participants felt isolated from the mainstream of childhood and family experience. They said there were few occasions when they felt encouraged to enjoy their environments or to be a part of family celebrations. This finding is consistent with that of Richardson, Hastorf, and Dornbusch (1964), who noted impoverished social interaction among disabled adolescents.

Participants expressed that the relatively narrow focus of medical and therapy treatment goals had the effect of protecting them and isolating them from real-world experiences. Within the framework of therapy services, participants were not challenged to consider issues such as independence, dealing with stereotypes and prejudice, and developing the assertiveness necessary to manage their own complex needs. They were not encouraged as children to acknowledge or to deal with external environmental forces that contributed to disability; rather, in their view, dysfunction of the individual was seen by the medical/rehabilitation system and the therapist as the source of disability.

A second theme that recurred during the interviews was the issue of dependence versus independence. All participants said that their upbringing, largely influenced by their educational experience and exposure to services in the medical/rehabilitation model, fostered emotional dependency on others for direction and decision making. Four participants continue as adults to be totally physically dependent on others, and the 5th participant requires some assistance.

The independent living model, which did not exist during the participants' childhoods, demands a level of independence for which participants were ill-prepared and of which several were physically incapable. Participants confirmed the author's observation that nonprofessional staff at independent living skills agencies often lack sufficient expertise to address complex positioning, adaptive, and communication needs of adults with significantly limiting cerebral palsy.

As a result, for those adults, although the philosophy of the independent living model applied, actual services offered did not fully meet their needs, espe-
cially in the areas of evaluating the need for adaptation of devices for activities of daily living and of positioning for function.

Several participants continued to experience some guilt or anger over their dependence on others. Reliance on attendants for assistance with activities of daily living was perceived as a necessary evil. The participants expressed an ongoing struggle to balance the need for privacy and control of life with the need for care adequate to sustain life and to prepare for activities of work and leisure.

It appears that the person with significant physical disability is called upon to compromise self-determination, self-control, and independence in order to minimize risk in an independent living situation. Opting for increased self-autonomy requires acceptance of greater risk than may be comfortable for those who are most disabled or who have minimal previous experience of responsibility for decision making.

A third theme that recurred throughout the interviews was the critical nature of the attitude expressed by the professional toward the consumer of services. Participants noted that some persons with whom they interacted displayed uncaring, aloof, or removed attitudes. Professionals and peers perceived as helpful were those who took time to listen and who sought and respected the participants' viewpoints.

Underlying a caring and respectful attitude is an awareness of the person as a person first, but one who has a physical disability. All participants noted that such ability to see people as people is critical to providing assistance to adults seeking to attain or maintain independent living.

A final recurring theme with meaning for the practice of occupational therapy was the significance of purposeful activity in the lives of the participants. Their experiences confirmed the value of work and play advanced by Friedman and Havinghurst (as cited by Lewis, 1979) as well as occupational therapy theorists like Reilly (1962) and Kielhofner (1978). All of the participants expressed awareness that payment for services confirms a person's value in society and that paid or volunteer employment provides a focus for one's life and opportunities for increased socialization.

All of the participants said they had experienced diminished awareness of the surrounding environment, the passage of time, and the required physical effort during engagement in meaningful tasks. This experience, shared by those without physical disabilities, was defined by Csikszentmihalyi (1975) as "flow." During such engagement, study participants described being less aware of and able to transcend the limitations of their physical bodies. Even while engaged in tasks thought to require motor skill which they lack, such as swimming, dancing, and lovemaking, the participants felt so satisfied with their performance that lack of physical coordination was devalued.

Implications for Occupational Therapy

Theory

Examination of the study data and recurring themes indicates that both the medical/rehabilitation and independent living models offer valuable services to children and adults with cerebral palsy. However, participants have had mixed experiences with both models. A challenge facing occupational therapy theorists is to incorporate the valid criticisms of both models offered by the study participants into a practice theory that continues to allow optimal utilization of the knowledge and skills of occupational therapists.

Occupational therapy practice necessarily draws from frames of reference identified as reductionistic in nature, which are associated with the medical/rehabilitation model. Occupational therapists must have knowledge of neurobiological mechanisms underlying functional performance. Such knowledge is useful in positioning to minimize the effects of dysfunctional movement patterns and in developing assistive devices and environmental modifications.

A workable practice theory encompasses components of more broadly based frames of reference, including facilitating growth and development and occupational behavior. The study data confirm the appropriateness of the focus of occupational therapy theory on the value of purposeful activity, including work and leisure.

Results of this study support a theoretical and practical consideration of the client as a biological system interacting with and influenced by other systems in his or her environment. Focus on norm-referenced skills is meaningful when clients and their families collaborate with therapists to understand and value the role of functional skills in the achievement of attainable goals, including future independent living.

Practice

The study participants contributed an appreciation of the need to integrate occupational therapy treatment with the developmental timing of each child. During infancy and early childhood, the focus is on attainment of communication skills, maximum independence in developmentally appropriate activities of daily living, and mobility for environmental exploration. During the school years and into adolescence, the focus of therapy shifts toward issues of time-and-life-skills management, adaptation to maximize inde-
Therapists and educators must consider the long-term effects that removal of a disabled child from the classroom for therapy has on that child's academic experience. Therapists should also consider how a focus on getting better and on improving deficient skills affects a child's self-esteem. The study participants had, as children, interpreted that such a focus implied that they were inadequate.

The findings of this study regarding the importance of engagement in purposeful activity lend support to occupational therapy practice. Participants confirmed the power that such engagement had in strengthening their self-esteem and coping skills. For children unable to master even minimal motor tasks typical for their peers, focus on and engagement in enjoyable tasks can provide opportunities for success, self-acceptance, and transcendence over the limitations of the disability.

Occupational therapists can assist in the evaluation and decision making of adults with cerebral palsy who are in a stage of transition to independent living. The therapist can assess the adult's present level of self-care, work, and leisure skills and help the adult determine which areas of need are critical in the independent living situation. Intervention can include recommendation, procurement, or fabrication of adapted environmental control devices. Through clinical observations and conversation with the adult, the therapist can assess the impact of wheelchair positioning on communication and maintenance of critical life functions including digestion, respiration, and mobility.

None of the study participants demonstrated positioning that met criteria typically established as ideal by occupational and physical therapists. All participants indicated that positioning had to incorporate their preferences and needs, which ranged from mobility greater than to lesser than that which might have been advocated by a therapist. Only by communicating with and respecting the preferences of clients can therapists propose an effective compromise.

The study participants affirmed that, as persons born with limiting physical disabilities, they were accustomed to needing assistance with the most personal care needs. Occupational therapists can capitalize on the ease with which such individuals accept help and can use ingenuity to help develop energy-, space-, and time-efficient methods for achieving functional positioning and completing self-care tasks with attendant assistance.

Therapists can assist clients in the development of the assertiveness necessary to manage attendants. In this capacity, therapists can work closely with peer counselors, sharing knowledge about the effect of abnormal movement patterns on positioning, mobility, and handling by attendants.

Finally, those occupational therapists who currently serve adults with cerebral palsy recognize the impact of public health policy on the provision of services. All study participants acknowledged their difficulty obtaining appropriate occupational therapy services, because public and private insurance funding for such service is not easily obtained. Therapists must increase their awareness of the politics of disability and must learn how they can advocate pertinent issues at the federal, state, and local levels.

Summary

This study was conducted to examine the role of occupational therapy with persons who are significantly limited by cerebral palsy. A literature review defined the role from the perspectives of existing occupational therapy theory and practice as well as the medical/rehabilitation and independent living models.

Results of this study indicate that no single occupational therapy model adequately serves as a basis for occupational therapists who serve the study population. Neither the medical/rehabilitation nor the independent living model provides consistently appropriate services in a manner perceived as satisfactory by the study participants. The occupational therapy role can expand on the best of both models to reduce conflict, improve communication between professionals and consumers, and improve the provision of services. The study participants identified critical tasks for occupational therapists who serve them in medical/rehabilitation and independent living services agencies. These tasks included help with the following: (a) identifying and strengthening inner resources, (b) facing the reality of external restraints, and (c) overcoming or compensating for environmental and societal barriers to independent living.

Acknowledgments

I gratefully acknowledge the assistance of Lela A. Llorens, PhD, OTR/L, FAOTA; Gordon Burton, PhD, OTR; Karen Diasio Serrett, PhD, OTR, FAOTA; and Edward V. Roberts, MA, in the preparation of this study. I also thank the 5 study participants, who shared their experiences and invested in the completion of this study.

This paper is based on a study submitted in partial fulfillment of the requirements for the degree of master of sciences from the Department of Occupational Therapy at
San Jose State University, California. The paper was originally presented at the 1988 California Children Services Conference in Newark, California. It was also presented at the April 1988 Annual Conference of the American Occupational Therapy Association in Phoenix.

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