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# After Rehabilitation: Meeting the Long-Term Needs of Persons With Traumatic Brain Injury

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*Many survivors of traumatic brain injury have significant needs for long-term support. The rehabilitation professions, including occupational therapy, have begun to recognize these needs more fully during the last decade. The literature describes various models of supported living that provide housing, support services, and vocational assistance; however, these programs are not widely available due to limitations in public funding and inadequate insurance coverage for long-term care. Occupational therapists can contribute a broad expertise to the provision of supported living services, and the profession is encouraged to provide leadership and advocacy with respect to the long-term care needs of survivors of traumatic brain injury.*

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Occupational therapists play a key role in the rehabilitation of survivors of traumatic brain injury. The profession's emphasis on work, functional skills, and quality of life is invaluable to persons recovering from catastrophic injury. Long-term care of such persons is receiving more attention within the medical community due to the increasing population that requires this type of assistance. The 1990 Representative Assembly of the American Occupational Therapy Association (AOTA) passed a resolution stating that "long-term care is a viable health care issue as society tries to assure quality of life while containing health costs at a time when extended longevity and the ability to preserve lives of persons with increasingly more complex degrees of impairment is being realized" (AOTA, 1992, p. 24). This article addresses the issues associated with long-term services for adults with brain injury and explores occupational therapy's contribution to this rapidly expanding field.

## Background

In the last decade, the focus of services for persons with traumatic brain injury has shifted dramatically. Before 1987, long-term care of survivors of brain injury was not significantly addressed in the literature. In past decades, those who survived brain injury were institutionalized, and little was understood about their unique disabilities. However, the 1980s witnessed tremendous growth in the field of brain injury rehabilitation (Jones, Patrick, Evans, & Wulff, 1991). Community re-entry services, a novel concept in the early 1980s, became available across the nation by the end of the decade. These services were initially regarded by the rehabilitation profession as the final stage in the continuum of care for survivors of brain injury. However, continued medical advances now enable recovery for persons with the most severe types of injury. These advances have created a new population of survivors who require lifelong support and cannot graduate to their home communities, even after completion of community re-entry rehabilitation (Jackson, 1992). Supported living programs have evolved that offer housing and support services to those with brain injury who are unable to return to their preinjury home after rehabilitation.

## Scope of the Problem

The alarming incidence and prevalence of traumatic brain injury in our society continues to increase. The National Head Injury Foundation (NHIF) has reported (1992) that every year more than 2 million Americans sustain a traumatic brain injury. What is often not appreciated is the mounting toll on the human service provision system required to serve many of these brain injury survivors on a lifelong basis. It is estimated that between 9 and 11 million Americans with disability are dependent on some form of long-term care. National figures specific to long-

term care for brain injury are unknown, but a comprehensive study of survivors at the time of graduation from postacute rehabilitation programs indicated that one in seven required a supported living option at the time of discharge (Evans, 1991). Additional studies focusing on the components of outcome most crucial to customers in the rehabilitation triad (patient, family, and financial provider) revealed that living setting and level of need with respect to activities of daily living ranked consistently among the top priorities for all three groups (Condeluci, Ferris, & Bogdan, 1992; Hosack, Malkmus, & Evans, 1991; Jones & Evans, 1991).

Data from survivors about their current and desired life circumstances further illustrate the problem. In a recent study of 39 survivors who were at least 2 years post trauma (Condeluci et al., 1992), 48% of survivors reported being in residential settings that they perceived to be unsatisfactory, 79% felt dissatisfied with their vocational pursuits (or lack thereof), and 85% wanted more social involvement.

The Community Programs for Individuals with Acquired Brain Injury [CPIABI] directory (1992) indicates that, nationwide, only 77 programs identify themselves as providing supported living services for survivors of traumatic brain injury. These programs seem to be clustered in certain geographical regions, such as the Northeast and Midwest, whereas many states are completely lacking services. Most of these programs are relatively new, with 89% being established since 1980 (CPIABI, 1992). In addition, only 20% are affordable for those with public assistance funding (CPIABI, 1992).

The combination of these factors has produced a national crisis for brain injury survivors and their families seeking a suitable living option with adequate supports. As a result, far too many survivors remain at home in isolation or are inappropriately placed in nursing homes or state hospitals. These placements result in inactivity, loneliness, frustration, and depression, which only compound the problems faced by the survivor and his or her family. Fortunately, many rehabilitation providers are beginning to recognize this situation, and services are being developed to address this critical need (CPIABI, 1992).

### Theoretical Framework for Supported Living

A theoretical framework for supported living is the interdependent paradigm (A. Condeluci, August 1991, personal communication). The interdependent concept suggests that supportive services should be consumer driven, focus on the person's capabilities, and be directed toward increasing the number of relationships the survivor has with his or her community. The interdependent paradigm defines the problem of disability not from what is wrong with the person, but from the context of limited supports to allow the person with a disability the opportunity to participate (Condeluci, 1990). Community inte-

gration is therefore achieved by securing a viable place to live, meaningful day activities, viable supportive relationships, and opportunities for recreation and leisure. Service providers encourage the survivor to develop the roles of friend, neighbor, consumer, and citizen, and offer environmental adjustments and support staff members acting in partnership with the survivor (Condeluci, 1990). In addition, supported living providers must embrace the principles of empowerment to provide effective services. They must serve as community guides to facilitate associations for the consumer with his or her community based on trust, friendship, and capabilities (McKnight, 1988).

Although supported living programs are striving to embrace concepts such as empowerment, many have been developed as adjuncts to more traditional, medically based rehabilitation programs. As such, they are typically burdened by the dilemma of providing risk-oriented services within the confines of a system steeped in paternalism, regulation, and fear of litigation. Despite this situation, there are a number of existing models that promote success and facilitate interdependence for those being supported.

### Living Setting Models

The essential elements of supported living services are the least restrictive environment and some form of professional intervention to assist the survivor in maximizing his or her potential for a full community life. Varying models have been described in the literature, differing in both the location of services and the types of support provided (Condeluci, 1990; Condeluci, Cooperman, & Seif, 1987; Jackson, 1992; Jones et al., 1991; Vander Schaaf, 1990). Funding constraints play a major role in determining service provision. Models have been developed to accommodate both private and public funding and to serve survivors along a broad continuum of needs. These models can be organized into the categories of *supervised housing*, *shared services*, and *foster care*.

The majority of supported living programs offer supervised housing in either apartments or shared homes. Disagreement exists within the consumer movement as to which of these options is preferable. The empowerment school of thought suggests that survivors are best served in apartments or single person dwellings, as these most resemble a normal living arrangement. However, the economics of serving persons with 24-hr care needs has made shared residences an attractive alternative for survivors who would otherwise be restricted to life in a nursing home or other institution.

Dwellings for supported housing are architecturally accessible and resemble the surrounding dwellings so that the survivor's home fits in with the community. If shared residences are provided, these are small, serving four to six adults. Most states require specific licensure for operating such homes, generally under regulations devel-

oped to serve persons with other disabilities.

Supervision and assistance is generally provided by direct care staff members with professional staff members acting as managers. Supervision may be continuous for 24 hr per day or may be scheduled with staff members who arrive during peak need times (such as during self-care). Care staff members are typically those possessing some background in the human service field (e.g., bachelor's degree in psychology) or special training (e.g., nurse's aides). Many are trained in first aid, cardiopulmonary resuscitation (CPR), protective intervention techniques, seizure management, behavioral intervention, and management of brain injury sequelae. Some programs additionally require staff members to have special training in recreation, counseling, or vocational interventions. Advocates suggest hiring persons with broad backgrounds, who are not necessarily burdened with the baggage of human service training in which the consumer is the identified problem (A. Condeluci, 1991, personal communication). Persons who are well connected in their own community and able to act as bridgebuilders to help the survivor connect with others are desirable as staff members.

For consumers with limited resources and public funding assistance, supported living may consist of shared personal care and homemaker or chore services. The model of shared services is based on the use of federally funded housing for the persons with disabilities, with supplemental supports organized through personal care attendant networks (Vander Schaaf, 1990).

A third method of supported living provides services to individual survivors through foster care. This option matches a survivor with a family who provides housing and support. One member of the family is identified as the mentor. The mentor is specifically trained to provide primary case management and support to the survivor and receives regular professional supervision (Gironimo & O'Connor, 1992).

Supervised housing, shared services, and foster care offer benefits and drawbacks according to the specific needs of the survivor. Most available programs are fairly traditional and operate cautiously with regard to the amount of risk assumed by the provider relative to consumer safety. For example, placing the survivor in the least restrictive housing setting often raises concerns about liability and suspension needs. The desire for independence may conflict with the family's opinion about the amount of supervision that the survivor requires. Insurance companies may advocate for more institutional settings and restriction of the survivor's community access to minimize their financial liability in the event that the survivor sustains additional injury as a result of cognitive limitations or behavioral disorders. In addition, regardless of how housing and support needs are met, providers are faced with the considerable challenge of meeting the productivity needs of those served.

## Vocational Services

Quality supported living programs provide services outside the home, including vocational, recreational, and social pursuits. In fact, the bricks and mortar of supported living may be the lesser challenge for providers, compared with the need to facilitate community access. The lack of dignified vocational options and the social isolation experienced by brain injury survivors are well documented (Condeluci et al., 1987; Deloch, Wilkins, & Walker, 1983; Jacobs, Blatnick, & Sandhorst, 1990). Supported living providers must overcome these obstacles if quality of life is to be achieved for the survivor. As a result, many supported living programs are now emphasizing vocational and avocational services as critical components of the program.

According to a Louis Harris survey conducted in conjunction with the Americans with Disabilities Act (ADA), two thirds of all persons with disabilities are not employed (Tapper & Egan, 1992). Persons who enlist supported living assistance usually are challenged by severe disabilities that greatly hamper their success in the competitive work force. As a result, many survivors find themselves referred to vocational placements, such as sheltered workshops, which are not community integrated, and do not meet their unique needs. Supported employment programs and vocational enclaves offer a less restrictive work setting, but are often not individualized according to the survivor's interests.

Where funding is available, ongoing job coaching may provide the survivor with the best opportunity for vocational re-entry. A few supported living providers are offering job coaching as an adjunct service to the core program, but more of this approach is needed to facilitate vocational success for the worker with cognitive challenge (Jackson, 1992). Comprehensive vocational services for this population include a balanced approach encompassing both competitive and noncompetitive work options, and volunteer work as a viable productive activity.

## Funding Issues

The single greatest barrier to accessing supported living services is funding. The majority of survivors who would benefit from these services are not adequately insured for long-term care. In fact, more than 250 million Americans lack health insurance to cover them for long-term illness (Roybal, 1992). Traumatic brain injuries commonly strike persons between the ages of 15 and 24 years who are typically underinsured, but may require many years of expensive services. As a result, long-term care is the primary health-related cause of financial ruin among the young, because neither Medicare nor most private insurance provides protection against these costs (Halaman-daris, 1992).

Long-term health care can cost millions of dollars over a lifetime. The mean per diem cost for supported living programs in the United States is \$171, with costs ranging as high as \$550 per day (CPIABI, 1992). These costs can only be expected to increase, as medical costs rose at a faster rate than the consumer prices in every year from 1964 to 1983 (Bush, 1990).

Only those injured on the job have the benefit of worker's compensation insurance, which generally covers the costs of long-term care. For those who are uninsured or underinsured, Medicaid or Medicare becomes the only funding source. However, only 21% of existing providers accept in-state Medicaid, and even fewer (18%) accept out-of-state Medicaid, due to the low reimbursement rates of these entitlement programs (CPIABI, 1992). A small number of survivors succeed in winning personal injury litigation due to the circumstances of their trauma, and are able to use private settlement funds to meet these costs.

Unfortunately, however, most survivors are severely restricted by funding limitations. Supported living models that use public funds are in demand in almost every state (Zitnay, 1992). This situation is not changing rapidly. Few providers are anxious to develop programs because it is so difficult to meet the community standard of appropriate care within the level of reimbursement. In addition, survivors who require a broader array of services, including medical or vocational support, are not optimally served within the current constraints of public funding.

### Occupational Therapy's Role in Supported Living

Philosophically, occupational therapy is centered on the qualities that make relationships meaningful, and on the meaning of occupation in life (Peloquin, 1989). As such, the occupational therapist's approach of assisting the person in relationship building and productive activity is ideally suited to supported living services. Occupational therapists are natural community guides because the profession emphasizes many of the concepts advocated in the empowerment literature. The person with brain injury needs to be recognized for his or her character, rather than for having experienced a catastrophic event (Jacobs et al., 1990). Occupational therapists view the person holistically, and are educated to assess how disability interferes with the survivor's personhood within an interdependent framework.

In the area of long-term care, occupational therapy's role encompasses functions of direct treatment, case management, and consultation (AOTA, 1992). Occupational therapists provide interventions to improve quality of life through their knowledge about the balance of work, play, and activities of daily living (Reed & Sander-son, 1983). Specifically, occupational therapists fulfill a number of roles in existing supported living programs.

More than 70% of supported living programs treating adults with brain injury offer occupational therapy as a specialized service (CPIABI, 1992). Treatment interventions focus on adapting the supported living environment to maximize the survivor's opportunities for success in the setting. Where vocational services are offered, occupational therapists may act as vocational specialists, job coaches, or as consultants regarding the development of a plan for vocational pursuits.

In the area of management, occupational therapists may act as case managers, administrators, or consultants to supported living programs. Particularly in long-term care, case management is critical to managing costs and achieving outcomes. Case management requires that the occupational therapist view the big picture, and become involved in many aspects of the person's livelihood, including family contact, crisis management, and funding negotiation. Occupational therapists may analyze the total support environment and secure services to foster the person's maximum independence and quality of life (AOTA, 1992). Additionally, occupational therapists may bring to the administration position a total understanding of the needs of the person from a physical, psychological and social perspective.

Training for occupational therapists to effectively assume these roles is critical. Direct care experience with persons with traumatic brain injury is a necessity, as well as additional training in such areas as management, the insurance industry, and budgetary administration. In addition to gaining the necessary experience in treatment, entry-level occupational therapists can prepare for management roles by pursuing continuing education through AOTA conferences, as well as those conducted by the National Head Injury Foundation and other advocacy groups.

### Conclusion

The issue of long-term care has become increasingly visible over the last decade. A young population of survivors of traumatic brain injury requires long-term support. Given the youth of these persons, their supported living needs may span decades. The literature offers a variety of models for meeting these needs, each with unique benefits, including various types of living settings as well as vocational and social supports. However, all existing models are limited in the scope of services due to funding constraints. The lack of adequate insurance coverage for long-term care is a national crisis that must be addressed to avoid continued inappropriate institutionalization of this population. Public assistance programs fall short in matching the financial burden assumed by survivors and families in securing long-term supportive services.

Occupational therapy offers special expertise for functionally oriented treatment and long-term service development for this population. The medical community is

beginning to understand the implications of the long-term needs of survivors of traumatic brain injury, and treatment is now understood to continue beyond the acute rehabilitation stage. Taking a leadership role in addressing the issue of access to long-term care (Joe, 1992) will require occupational therapists to actively support legislation to provide catastrophic health care coverage for all Americans. Occupational therapists should involve themselves in health care reform efforts on the local, state, and national level. The number of brain injury survivors who require a supported living program continues to increase, creating a service need that must be met by our society. Occupational therapists can expect opportunities at all levels of long-term care service provision, from direct care to program management. The profession should advocate for society to embrace survivors of brain injury and other catastrophic illnesses and develop adequate support services to meet their needs. ▲

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