

SEQUELAE OF TRAUMATIC HEAD INJURY - REHABILITATION NEEDS/PERSONAL,
ECONOMIC, AND SOCIAL LOSSES: THE WISCONSIN STUDYTHOMAS CZERLINSKY, PH.D.
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Abstract

This paper presents the results of a research project which studied the rehabilitation needs and outcome characteristics of a traumatically brain injured (TBI) population. The study, which was conducted by the University of Wisconsin-Stout Research and Training Center and the State of Wisconsin Division of Developmental Disabilities, was conducted between January and March of 1987. Data describing the rehabilitation needs of persons who had suffered TBI was obtained from 764 friends, relatives, and significant others. The results therefore represent opinions of these "significant others" regarding the residual impairments, common need for care, and other estimations of disability of the person who had sustained the TBI. This paper will delineate the rehabilitation services which were felt to be needed but were not received, including an analysis of the reasons why the services were not received. The nature and extent of the disabilities that follow a moderate to severe TBI will thereby be presented, in order to inform evaluators of the service needs frequently associated with residual deficits following TBI.

Categories of General Needs

The classes of needed services in this study were collapsed and categorized to include those of the State Vocational Rehabilitation (VR) agency, services offered by the local County Department of Social Services (DSS), community options programs focussed upon community living and community support services necessary for independent living, local rehabilitation facility services (sheltered workshops), and services provided by the County Developmental Disabilities Boards in each respective county.

Results suggested that the state VR agency had the highest percentage for "Services Applied For But Not Received." Approximately 14% of the clients applying for state VR services did not receive the services for which they applied. County DSS services, community options programs, and independent living skills programs provided greater percentages of all services applied for. These agencies, on the average, provided nearly 95% of all services requested via direct application.

When asked the reasons why services were not received, 28.3% responded that the services were not received due to lack of information regarding the availability of the services, and 27.6% reported that the services simply were not available. Twenty percent reported being unable to receive the services because they lacked the money needed for transportation or attendant care. Nine percent cited lack of transportation, and 7.1% cited health problems as reasons for not receiving services.

Of all rehabilitation/habilitation services which were needed and received, vocational evaluation was provided to approximately 45% of the individuals. This was followed by daily living skills (43%), and day services, sheltered workshops, and adaptive devices and equipment (28% each). Sheltered employment (22%), employment (job placement) services (11%), and supported employment (8%) were provided less frequently. Additional medical services following emergency care were needed and received by 65% of the individuals, with 30% receiving attendant care services, 19% receiving epilepsy services, and 19% receiving nursing services at home.

Support services including physical, occupational, and speech therapy were received by the majority of all TBI individuals (70%, 73%, and 61% respectively). Family and peer support was provided to 59%, with 40% receiving counseling/mental health services. Case management, education, cognitive rehabilitation services, behavior management services, and social skills training were less often reported as a needed service and therefore were received less frequently. Approximately 11% of the sample received needed alcohol and drug counseling.

The categories for diagnostic service needs

included neuropsychological evaluations, speech and language evaluations, and sensory evaluations (visual, hearing, other). Neuropsychological evaluations were received by 67% of the sample, speech and language evaluations were received by 66%, and slightly over 50% received some type of sensory diagnostic services, such as visual services or hearing evaluation.

Supervised living services were received by only 18% of the sample. Ten percent received respite care services for caregivers, and approximately 8% received services for a group home, live-in attendant, or similar such service.

Of the other services needed and received, financial assistance was necessary for approximately half of the individuals, with accessible community transportation available to approximately one-fourth of those in the survey.

Sources of Financial Support

The survey also explored the financial independence/dependence needs of the individuals who had suffered a traumatic brain injury, during the first year following the injury, more than one year after the injury, or currently (in cases where the injury occurred less than one year ago). After the injury (either within the first year or later), a substantial dependence on public assistance, Social Security Disability, and similar sources was found. Since the majority of the sample was young (approximately 50% of the sample was 18 years of age or younger), many individuals were dependent on family income. Nearly 60% of the sample reported spending money from self income for support, and approximately 17% used savings. The latter were thought to represent college and technical students, since nearly 40% of those in the survey were within the post high school age range of most college and technical schools (i.e., 18 to 23 years of age).

During the first year after the injury, 40% of the sample depended upon family income for financial support, 36% depended upon Social Security Disability benefits, and 20% depended on some type of public assistance. More than one year after the injury, the pattern had changed somewhat. The percentage of individuals depending on Social Security Disability went up to 47%, with 27.5% depending on family income and 20% receiving public assistance. Clearly a shift from independence to dependence was observed following the TBI.

Data was also collected to estimate the short-term and long-term earning potential of the persons who had suffered a TBI. The results suggested that only 3.5% of the respondents felt that the short-term earning potential of the brain injured person was not affected. Also, 5.2% of the respondents stated that there was no effect in terms of long-term earning potential. The majority of the respondents (64%) stated that there was a substantial to severe reduction in short-term earning potential of the person who had suffered a TBI, and 71% reported a substantial/severe reduction in terms of long-term earning potential.

Employment Status

Primarily because of the ages of the subjects in this study, nearly 43% were not employed prior to their injury. Fewer than 1% were reported as being in any type of sheltered employment situation at that time, including day activity work, sheltered employment, or community based or government subsidized programs. Approximately 30% of the TBI sample was independently competitively employed, and nearly 6% were considered to be self-employed or homemakers.

At the time of the follow-up, however, a full 59% were unemployed. An additional 2.9% were engaged in day activity centers, 8.2% in work activity centers, and 6.7% were engaged in sheltered employment at less than minimum wage. One point four percent were involved in community based government subsidized employment (e.g., JTPA), 9.6% were independently competitively employed at minimum wage or better, and 4.3% of the persons with TBI were self-employed or homemakers.

Conclusions

The results of this study suggest that of the wide array of services necessary following a TBI, the majority of those which were requested were being received. The State Vocational Rehabilitation agency had the greatest number of responses in regard to services applied for that had not yet been received (14%), with county social services and community options programs second at approximately 5-6% each. Next were sheltered workshops (5%) and county developmental disability boards (4%). In total, the majority of individuals requesting services have been receiving them or were in the process of waiting for services to be approved.

Of the services not being received, nearly one-third of the advocates of the TBI subjects felt that they did not receive the services because they lacked the information regarding their availability, or that the services were not available in the first place. Twenty percent lacked the money to pursue application of the services, another 9.2% lacked transportation, and 7.1% were unable to pursue such services due to their current health problems.

Of the rehabilitation services needed, vocational evaluation was provided to 45% of the persons, daily living skills training was provided to 43% of the persons, followed by day services (28%), special adaptive equipment (28%), and sheltered employment services (22%). Job placement and follow-along, and supported employment services, were provided to approximately 11% and 8% of the persons, respectively.

For medical services provided, medical care following discharge from the hospital was provided to nearly two-thirds of the persons, with another one-third needing and receiving attendant care services. About 20% of the sample received epilepsy services and 20% received nursing services at home.

In the categories of therapeutic and supportive services, nearly two-thirds were reported as having received physical,

occupational, and speech therapy, as well as family and peer support. Neuropsychological evaluations were the most frequently received diagnostic services (67%), followed by speech and language evaluations (66%).

Living arrangements assistance was the least received service, with supervised living arrangements and respite care to caregivers being provided to 18% and 10.2% of the individuals, respectively. Financial assistance or aid was needed and received by nearly half of the people, and services addressing the problems of community transportation were needed and received by 23% of the individuals.

Results concerning the sources of financial support suggested that a definite shift from independence to dependence occurred as the time after the injury increased. Before the injury, self-income and family income were reported as the major sources of income. During the first year after the injury, family income and Social Security income were the most frequent sources. More than one year after the injury, however, Social Security Disability, family income, and public assistance were the three major sources of income.

Overall, the majority of the respondents felt that there was a substantial to severe reduction in both short-term and long-term earning potential of the individuals. The employment status of these individuals, following the TBI, was also drastically effected (as one might expect). Although a large percentage (43%) of the individuals studied were not employed prior to their injury (presumably largely because of their ages at that time), nearly one-third were independently competitively employed, self employed, or homemakers at that time. At the time of follow up, however, 59% were not employed in any way, and an additional 18% of these persons were being served in sheltered employment of some type, including day activity, work activities, or traditional sheltered employment programs.

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