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## ABSTRACT

This collection of papers on vocational rehabilitation of persons impaired as a result of traumatic brain injury is designed to provide a resource for individuals concerned with community-based employment. The 11 papers include: "Training Persons with Traumatic Brain Injury for Complex Computer Jobs: The Domain-Specific Learning Approach" (Elizabeth L. Glisky); "Selection and Outcome Criteria for Community-Based Employment: Perspectives, Methodological Problems and Options" (Thomas Kay); "Neuropsychological Evaluation of Persons with Traumatic Brain Injury" (Lance E. Trexler); "Brain Injury Rehabilitation in Small Towns and Rural Communities" (James Malec and Dale F. Thomas); "Development of a Model of Community-Based Employment for Persons with Traumatic Brain Injury" (Dale F. Thomas and Fredrick E. Menz); "Behavior Management of Persons with Head Injuries in Community-Based Vocational Settings: New Challenges for Professionals" (Gary R. Ulicny); "Maintaining Work after Traumatic Brain Injury: Experiences from Two Neuropsychological Rehabilitation Programs" (George P. Prigatano); "Long-Term Case Management: A Rehabilitation System and Community Provider Perspective on Handling Crisis and Non-Crisis Problems" (Robin Ray and Nancy D. Schmidt); "Return to Work: Supported Employment for Persons with Traumatic Brain Injury" (Paul Wehman and others); "Developing Funding Policy in the Public Sector When Resources Are Uncertain and Where Competition Is Keen" (John H. Noble, Jr. and others); and "Public Policy for Persons with Traumatic Brain Injury" (Faith S. Kirk and George Zitnay, summarized by Fredrick E. Menz and others). (References accompany each paper.) (JDD)

# Community-Based Employment Following Traumatic Brain Injury

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# **Community-Based Employment Following Traumatic Brain Injury**

Edited by

**Dale F. Thomas, Ph.D.,  
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and Daniel C. McAlees, Ph.D.**

*Research and Training Center  
University of Wisconsin-Stout*

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# Contents

Contributors and Reviewers . . . . .	v
Acknowledgements . . . . .	vii
Preface . . . . .	xi
Introduction . . . . .	xiii
<b>SECTION I - ASSESSMENT AND CLINICAL APPLICATIONS IN COMMUNITY-BASED EMPLOYMENT</b>	
Chapter 1 <b>Training Persons With Traumatic Brain Injury for Complex Computer Jobs: The Domain-Specific Learning Approach</b> <i>Elizabeth L. Glisky, Ph.D.</i> . . . . .	3
Chapter 2 <b>Selection and Outcome Criteria for Community-Based Employment: Perspectives, Methodological Problems and Options</b> <i>Thomas Kay, Ph.D.</i> . . . . .	29
Chapter 3 <b>Neuropsychological Evaluation of Persons With Traumatic Brain Injury</b> <i>Lance E. Trexler, Ph.D.</i> . . . . .	57
<b>SECTION II - MODELS AND APPROACHES IN COMMUNITY-BASED EMPLOYMENT</b>	
Chapter 4 <b>Brain Injury Rehabilitation in Small Towns and Rural Communities</b> <i>James Malec, Ph.D. and Dale F. Thomas, Ph.D.</i> . . . .	83
Chapter 5 <b>Development of a Model of Community-Based Employment for Persons With Traumatic Brain Injury</b>  <i>Dale F. Thomas, Ph.D. and Fredrick E. Menz, Ph.D.</i> . .	113

# Contents

Chapter 6	<b>Behavior Management of Persons With Head Injuries in Community-Based Vocational Settings: New Challenges for Professionals</b> <i>Gary R. Ulicny, Ph.D.</i> . . . . .	161
Chapter 7	<b>Maintaining Work After Traumatic Brain Injury: Experiences From Two Neuropsychological Rehabilitation Programs</b> <i>George P. Prigatano, Ph.D.</i> . . . . .	179
Chapter 8	<b>Long-Term Case Management: A Rehabilitation System and Community Provider Perspective on Handling Crisis and Non-Crisis Problems</b> <i>Robin Ray, M.S. and Nancy D. Schmidt, M.S.</i> . . . . .	197
<b>SECTION III - PUBLIC POLICY DEVELOPMENT</b>		
Chapter 9	<b>Return to Work: Supported Employment for Persons With Traumatic Brain Injury</b> <i>Paul Wehman, Ph.D., Michael West, M.Ed., Pam Sherron, M.Ed., Christine Groah, M.Ed., and Jeffrey Kreutzer, Ph.D.</i> . . . . .	227
Chapter 10	<b>Developing Funding Policy in the Public Sector When Resources are Uncertain and Where Competition is Keen</b> <i>John H. Noble, Jr., Ph.D., Ronald W. Conley, Ph.D., and Mary Anne Noble, D.N.Sc.</i> . . . . .	251
Chapter 11	<b>Public Policy for Persons With Traumatic Brain Injury</b> . . . . .	275

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Throughout these activities, Richard Melia, the former Project Officer for the UW-Stout RRTC and for Project HIRe, assisted immeasurably in the process by encouraging collaborative research and dissemination activities and actually participated in issue identification and as an ex post facto reviewer.

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Our heartfelt thanks to our Clinical Advisory Committee members who served many roles during the course of events which led to the completion of this book. These individuals, in alphabetical order, include: Thomas Hammeke, Medical College of Wisconsin; William Johnson, Research and Training Center, University of Wisconsin-Stout;



Daniel Keating, RiverRidge; James Malec, Mayo Clinic; Fredrick E. Menz, Research and Training Center, University of Wisconsin-Stout; Mitchell Rosenthal, Wayne State University and University of Michigan Model Traumatic Brain Injury Program; and Dale F. Thomas, Research and Training Center, University of Wisconsin-Stout.

For this advisory committee, a lengthy process of developmental research began in 1988 when the committee was asked to provide input on an upcoming think tank on issues related to community-based employment for persons with traumatic brain injury. The think tank, under the advisement of the committee, was planned and carried out in conjunction with the Annual Symposium of the National Head Injury Foundation. As a result of the input of the many distinguished think tank participants an agenda for a national conference on the same topic was developed, and consequently held in Clearwater Beach, Florida in 1989. The issues discussed at the think tank, and the keynote addresses, as well as all papers presented at the national conference were peer reviewed by this advisory committee. This group also provided input and direction on a developmental research project funded by the National Institute on Disability and Rehabilitation Research known as Project HIRe. Activities of the think tank, national conference, a subsequent follow-up national conference, and the proceedings of this book were all funded in part under the auspices of Project HIRe and through funds of the Rehabilitation Research and Training Center grant.

The role of the Project HIRe clinical advisory committee was expanded in 1990 to begin refining the information and ideas originally put forth in the think tank and national conference, and to identify primary issues for this book. This effort began with a critical review of the papers presented at the national conference. The advisory committee requested authors with field-based knowledge of practical applications and data based research to develop an outline for a proposed chapter. After peer review of the outlines, those accepted by the review process were returned to the authors with comments and suggestions for developing their manuscript. When final drafts were received, advisory committee members, in conjunction with the editors of this book, began a second peer review by pairs of committee members. Because of this review process, the final version of this book represents not only a collection of related chapters, but rather a text created by each respective author with input and suggestions by a panel of reviewers who sculptured this book to reflect numerous and varied approaches. This process of peer review was followed for all chapters included in this book. Updates

and revisions to this text were made with final revisions completed in 1992 and editorial revisions completed prior to the publication date.

Finally, the editors would also like to acknowledge all contributors for their input, direction, and chapters which involved countless hours over a three-year time span to make this publication ready for dissemination. The authors and editors hope that the following pages will provide additional information over and above the standard books already available in the topic of rehabilitation of persons with traumatic brain injury, by providing alternative approaches to the provision of vocational rehabilitation services, and helpful and practical hints which may be used in serving this most interesting population of citizens.

The book, and its activities leading to its publication, were supported in part by a grant from the National Institute on Disability and Rehabilitation Research, U.S. Department of Education, #6008720130. All conclusions and ideas presented in this document do not necessarily reflect either official opinion or policy of the U.S. Department of Education.

The Editors  
1993

## *Preface*

The University of Wisconsin-Stout Research and Training Center is pleased to be able to present this book to those seeking new understandings of the important issues in the vocational rehabilitation of persons impaired as a result of traumatic brain injury. The major authorities in the field have come together to write the most thorough book possible. Their resolve to advance the knowledge base in providing services to persons with traumatic brain injury is apparent throughout the text.

The complexity of modern community-based rehabilitation for persons with traumatic brain injury demands the maximum utilization of current knowledge, experience, and rehabilitation resources. The manuscripts, which comprise this book, are a topical resource for the education and training of persons concerned with community-based employment of persons vocationally impaired by a traumatic brain injury. They represent advances developed and tested through research, demonstration, and clinical application.

The contents of this book warrant the utmost attention of rehabilitation service providers, administrators, researchers, educators, and policy analysts. Deficiencies in the quality of existing evidence regarding the effectiveness and efficiency of community-based services to persons with traumatic brain injury have emerged as a problem in rehabilitation. Common complaints include failure to employ research designs permitting causal inference, under specification of the services provided, expedient study samples, unjustifiably brief follow-up intervals, and, above all, a paucity of formal studies of any kind.

In view of this current state-of-the-art, it is important to highlight, as this book does, occasional advances that occur in the conceptualization and investigation of community-based rehabilitation services to persons with traumatic brain injury. This book has not been designed as a "how to guide." Instead, the goal of the book is to provide a resource to rehabilitation professionals and graduate students preparing for careers

in rehabilitation practice, administration, or research.

The book is truly a joint venture between advocates, researchers, practitioners, and government. It is with deep appreciation that we recognize the roles played by the following groups and individuals in the evolution of this book:

The National Head Injury Foundation for co-sponsoring the Think Tank and the Conference.

The National Institute on Disability and Rehabilitation Research and the Rehabilitation Services Administration for direct support of the research and demonstration efforts being carried out at the several institutions involved in the Conference and for active involvement and participation in the Conference.

The more than 50 clinicians, researchers, advocates, and public servants who willingly gave of their time and personal resources to contribute to the Think Tank, serve on the Steering Committee and present at the Conference, and serve as manuscript reviewers for this book.

We sincerely hope this book will make a difference in the lives of individuals with a brain injury and their families who have supported the Research and Training Center over the years.

Dan McAlees  
Director  
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# *Introduction*

The employment of persons who acquired a brain trauma injury has drawn much attention in the rehabilitation literature in recent years. The reasons for the increase in this population within the rehabilitation community is documented in many sources, and is based primarily on the premise that more persons have survived an injury due to increased skills of medical practitioners, and increased awareness of the resulting psychosocial and cognitive disabilities by families, survivors, and rehabilitation practitioners, which may have previously been overlooked a decade or two ago.

The focus upon the use of supported employment, transitional employment, and other types of community-based employment with varying degrees of support and service arrangements began to capture the attention of rehabilitation leaders with the funding of research projects in this area which began in the late 1980s. A host of government sponsored research and dissemination projects in this area were initiated. The execution and completion of these numerous projects raised the awareness of practitioners and the general public as to the potential difficulties which may belie the apparent physical, psychosocial, and cognitive rehabilitation of persons who acquired a brain injury.

This book was originally proposed as an outcome of a demonstration project initiated in 1988, by the National Institute on Disability and Rehabilitation Research. The project proposed a series of activities that lead to not only a model demonstration, but a collaboration of resources on a national level which identified the primary barriers to community-based employment for this population.

The identification of possible solutions dealing with employment barriers, and the review of relevant research and demonstration projects which appeared most fruitful to enhancing employment options for persons with brain trauma injuries, were also targeted as process objectives. It was proposed that a national think tank and subsequent national conference could be used to identify the primary areas of interest

and concern among vocational rehabilitation practitioners in conjunction with medical specialties, neuropsychological and rehabilitation psychology, and university based programs. The National Head Injury Foundation including brain trauma survivors, their families, and significant others were centrally involved in the planning and execution of this process. This process has spawned a number of additional projects, some of which are described in the following chapters. Although the majority of the authors contributing to this book were not involved directly with service projects of the University of Wisconsin-Stout Rehabilitation Research and Training Center, the majority of all authors contributed to the process of the think tank, national conferences, and coalitions formed by these cooperative efforts. The authors, thereby affected many aspects of research and demonstration projects conducted in the past several years which grew from the initial series of meetings, conferences, and reaction papers.

This book does not intend to provide a thorough review of the nature of head injury and demographic data regarding the onset and disability caused by such an injury, since this has been adequately covered in books already available to the field (Corthell & Tooman, 1985; Corthell, 1990; Rosenthal, Griffith, Bond & Miller, 1990; Lezak, 1987). Rather, the following chapters will identify issues of primary concern in the development of community-based programs and various aspects of assessment, case management, and employment related issues.

Chapter 1, prepared by Elizabeth Glisky, describes an approach to training individuals with a history of an acquired brain injury in complex jobs including applications of personal computers. The domain specific learning approach is overviewed, with case examples of uses of this type of approach in vocational rehabilitation and work settings. The use of this practical application is discussed in detail with implications for the inclusion of the domain specific learning approach in teaching specific work related skills.

In Chapter 2, Thomas Kay discusses the issue of what constitutes employment for persons with histories of a brain trauma injury. A discussion of successful outcome criteria orients the reader to a variety of typical employment outcomes as well as transitional processes which may lead to higher levels of vocational independence. A three-step approach to the critical evaluation of vocational rehabilitation processes is detailed. The concept of "what works for whom" is discussed in detail and case examples are provided as a means of further illustrating this

approach to employment outcome planning.

Chapter 3 examines the philosophy, history, and various types of approaches to neuropsychological assessment and applications to vocational rehabilitation programming. In this chapter, Lance Trexler details some of the common neuropsychological difficulties and cognitive related problems which persons who have sustained traumatic brain injury must face. It is the only chapter in the book that focuses on medical and neuropsychological aspects of traumatic brain injury. Various approaches to conducting neuropsychological assessments, new developments in practice of assessment, and the role of various factors such as differential diagnosis, identification of patterns of strengths and compensatory strategies, and their relationship to work related services are detailed.

Chapter 4 focuses on the similarities between two community-based employment programs for persons with brain trauma injuries serving rural communities in the midwest. The issues identified by James Malec and Dale Thomas not only describe the problems faced in small towns and rural areas, but also the problems well known to programs serving this population in urban areas. The argument that even the most urban brain injury program deals with persons from small towns and rural areas is discussed, with the emphasis on the importance of building linkages back to small towns where many consumers of urban rehabilitation programs eventually return. Barriers to community-based employment for individuals are discussed, as well as the importance of capitalizing on the assets of small towns which are often available not in our urban environment. Suggestions for public policies and planning of rural community-based rehabilitation programs for traumatic brain injury survivors are summarized as well.

In Chapter 5, Dale Thomas and Fredrick Menz present an overview of a field initiated research project conducted by the University of Wisconsin-Stout Rehabilitation Research and Training Center which was instrumental in developing the collaborative networks and liaisons to produce this book. An overview of the history regarding the development of a national research agenda, as well as specific outcomes of the model demonstration project are discussed. As a result of the many aspects of this model demonstration project, a heuristic summary of salient findings are presented for the reader's consideration. Not only are suggestions for evolving programs presented, but implications for national strategies are also provided.

The sixth chapter addresses behavior management strategies for use with persons with head injuries in community-based work settings. Practical approaches to dealing with daily problems are offered. The use of applied behavioral analysis in the management and shaping of vocational related behaviors is reviewed. A five-point approach to dealing with obstacles to employment is detailed. A number of practical considerations to employ in planning services for persons with traumatic brain injury are used to illustrate the impact of this approach in community-based settings.

The topic of maintaining work after a head injury is the focus of Chapter 7. George Prigatano relates experiences from two neuropsychological rehabilitation programs, several important propositions to keep in mind in dealing with persons with histories of traumatic brain injury who are entering or re-entering the employment arena. Seven important factors which can affect a person's recovery from traumatic brain injury to the point of community integration are the focus of the discussion.

Robin Ray and Nancy Schmidt review the application of case management philosophies and approaches in assisting persons with traumatic brain injury into community integrated settings in Chapter 8. Recent trends in service delivery in this area including common pitfalls which are encountered and strategies for dealing with common crises are discussed, and the philosophy of long-term case management approaches are elaborated upon in relationship to the overriding goal of community-based employment and community integrated living.

Chapter 9 examines practical considerations in assessment of potential for community-based employment among survivors of brain trauma injuries. The findings of a three-year model demonstration project are reviewed, with demographic and outcome data being presented in detail. Discussions regarding assessment processes and procedures, community-based support mechanisms, and the findings of a national study on the topic of community integration and traumatic brain injury are discussed at length. Issues for public policy consideration and planning purposes are also summarized. Supported employment approaches for assisting individuals with severe traumatic brain injury to locate appropriate community-based employment is also discussed. A specific approach used by Paul Wehman, Michael West, Pam Sherron, Christine Groah, and Jeffrey Kreutzer to place 41 persons in competitive employment over a 30-month time period is reviewed.



Demographic data regarding the nature of injuries, the types of supports and services provided, and outcome data regarding impact of the services on the individual participants are discussed. Various other factors regarding the provision of services including methods of determining job stabilization, funding coordination, and the provision of job placement and job site training services are also provided.

John Noble, Ronald Conley, and Mary Anne Noble discuss the issue of developing a funding policy in the public sector in light of limited resources and keen competition in Chapter 10. Review of methods to obtain funding for persons with traumatic brain injury in several states are summarized. Mechanisms for financing services and helpful hints in developing individualized service plans are elaborated upon. The benefits relative to costs of services are provided with implications for national policy in this area.

In the final chapter of this book, the editors summarize issues relevant to public policy development and formulation. A framework for action in consideration of local, state, and national policies is introduced, along with a procedure and blueprint for developing such action within the rehabilitation community. This chapter summarizes the findings of a research committee convened by the President's Council on Employment of the Handicapped and the National Head Injury Foundation regarding the subject matter.

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*Section I*

**ASSESSMENT AND  
CLINICAL APPLICATIONS  
IN COMMUNITY-BASED  
EMPLOYMENT**

# *Chapter 1*

## **TRAINING PERSONS WITH TRAUMATIC BRAIN INJURY FOR COMPLEX COMPUTER JOBS: THE DOMAIN-SPECIFIC LEARNING APPROACH**

**Elizabeth L. Glisky, Ph.D.**

One of the most frequently identified consequences of traumatic brain injury (TBI), often cited as a major obstacle to employment, is memory impairment (Bond, 1975; Bruckner & Randle, 1972; Glisky & Schacter, 1990; Levin, Grossman, Rose, & Teasdale, 1979; Prigatano, 1990; Prigatano & Fordyce, 1986; Schacter, Glisky, & McGlynn, 1990; Weddell, Oddy, & Jenkins, 1980). Many persons who suffer a brain injury are left with a permanent memory deficit that manifests itself in an inability to remember recent experiences or to acquire new information. Such a disability makes it difficult to learn the knowledge and skills that may be needed to perform a job. Even when knowledge of a prior employment situation is retained post-trauma, the day-to-day memory demands of the workplace often require on-line monitoring of activities, continual updating of informational and situational variables, and an anticipation of future events--precisely the kinds of memory behaviors that many brain-injured persons cannot manage. For these reasons, training or re-training of persons with a traumatic brain injury for real-world jobs has often been unsuccessful.

In recent years the number of survivors of traumatic brain injury has increased, and knowledge of the nature and characteristics of traumatic brain injury has expanded (Bigler, 1990; Brooks, 1984; Levin, Benton, & Grossman, 1982; Levin, Grafman, & Eisenberg, 1987). There has also been a surge of empirical and clinical activity directed towards rehabilitation of persons with traumatic brain injury (Meier, Benton, & Diller, 1987; Sohlberg & Mateer, 1989; Uzzell & Gross, 1986; Wilson, 1987). Most recently, these rehabilitation efforts have focused on returning people to work. A particularly intractable problem in this area has been the frequent findings of failure of generalization: although persons severely disabled by a traumatic brain injury can often be taught limited skills and information in controlled training environments, they often seem unable to make use of this knowledge in real-world settings (Glisky & Schacter, 1989b; Gordon, 1987; Mayer, Keating, & Rapp, 1986; Miller, 1980). One reason for these failures may be that many of the training programs have relied on the teaching of general rather than specific work skills (cf., Mayer et al., 1986). Considerable evidence exists that knowledge and skills acquired by memory-impaired persons are often content and/or context-specific and do not readily generalize across situations or materials (Cermak, 1976; Crovitz, 1979; Dolan & Norton, 1977; Glisky, Schacter, & Tulving, 1986a, b; Wilson, 1982). These findings suggest that to maximize transfer to the workplace, training programs should be as specific as possible and should simulate the work environment as closely as possible.

## 6 / Training Persons

The present chapter will detail an approach to job training for memory-impaired people that depends on the *acquisition of domain-specific knowledge* (Glisky & Schacter, 1986; Schacter & Glisky, 1986; for a similar approach, see Mayer et al., 1986). This approach focuses on teaching persons with a traumatic brain injury the specific knowledge and skills necessary to perform a variety of relevant everyday tasks, including those associated with real-world jobs. Because all components of the task are taught directly, problems of generalization or transfer are reduced or avoided. To the extent that tasks require flexible application of learned skills, problems of generalization have to be considered.

### THE DOMAIN-SPECIFIC LEARNING APPROACH

The seven steps of the domain-specific learning approach can be summarized as follows:

1. Identify a *specific domain* or problem area in which intervention can significantly reduce the impact of memory disorder (e.g., work).
2. Specify the goal of the intervention, e.g., to teach people the information and skills required for a *specific* real-world job.
3. Analyze the *specific* task or job and break it down into *individual components*, i.e., perform a task analysis.
4. Identify an appropriate teaching or training technique such as the *method of vanishing cues* (see below).
5. Teach each task component *explicitly* and *directly*.
6. Provide extensive repetition and overlearning.
7. Consider *generalization* problems within the task domain.

Before describing some vocational training studies that have evolved within this framework, let me first illustrate the domain-specific learning approach with reference to two early experiments (Glisky, Schacter, & Tulving, 1986a; b) in which the domain of knowledge selected for intervention was that concerned with the understanding and operation of a microcomputer. Possibilities for the beneficial use of microcomputers by memory-impaired people have intrigued rehabilitation professionals in recent years (Ager, 1985; Furst, 1984; Harris, 1984; Jones & Adam,

1979; Skilbeck, 1984) but few successful interventions have been achieved (see Kirsch, Levine, Fallon-Krueger, & Jaros, 1987, for an exception). In many clinical contexts, computers have been used simply to present repetitive exercises and drills that require patients to learn meaningless materials such as random digits, shapes, or unrelated words. Not surprisingly, these drill therapies, lacking theoretical and empirical rationale, have failed to produce any *general* improvements in memory. Although repetitive presentation is necessary to promote long-term learning, the benefits of such practice accrue only to the material practiced. The studies described below illustrate an alternative use of the microcomputer in cognitive rehabilitation--as a means for teaching people with traumatic brain injury domain-specific knowledge with important applications in everyday life.

### Computer Learning

Two early studies (Glisky et al., 1986a; 1986b) explored whether persons with severe disability as the result of a traumatic brain injury could learn some of the basic vocabulary and commands required to operate an Apple IIe microcomputer. The first experiment investigated the effectiveness of a new teaching technique, *the method of vanishing cues*, for facilitating the learning of a computer vocabulary by persons with memory-impairments. In the vanishing cues procedure, sufficient cue information is provided to ensure a correct response on every learning trial and then is gradually withdrawn across trials. Cues are in the form of initial letters of the target words. For example, when instructed to "clear the computer screen," subjects were given the cues H\_\_, HO\_\_, HOM\_\_, until they correctly responded with the command HOME. On subsequent trials, cues were "vanished" one at a time (i.e., HO\_\_, H\_\_, \_\_\_\_ ) until the correct response in the absence of letter cues was produced. This technique was designed to make use of preserved abilities to produce previously-studied information in response to partial or fragmented cues. The preservation of this ability to remember with partial cuing has been empirically demonstrated in persons with memory-impairments many times (Cermak, Talbot, Chandler, & Wolbarst, 1985; Diamond & Rozin, 1984; Graf & Schacter, 1985; Graf, Squire, & Mandler, 1984; Schacter & Graf, 1986; Warrington & Weiskrantz, 1968, 1974).

Using the method of vanishing cues, four persons (three of which had suffered a traumatic brain injury and one of which contracted encephalitis) were able to acquire 10-15 items of computer vocabulary

## 8 / Training Persons

and retain them over a 6-week delay (Glisky et al., 1986a). A second study (Glisky et al., 1986b) then explored the ability to learn to use various commands to interact with a microcomputer. Four persons who had experienced a closed-head injury and four with memory disorders of other etiologies participated in the study. All were able to learn and use several commands and functions associated with the operation of a microcomputer: a) to display and erase information from the computer screen, b) to store and retrieve information from a disk, and c) to write and edit simple computer programs. Furthermore, their acquired knowledge was extremely durable, surviving across retention intervals of as long as seven to nine months (Glisky & Schacter, 1988). However, although they were able to acquire considerable amounts of complex knowledge, their learning was not normal. Persons with histories of traumatic brain injury needed many more trials than control subjects to achieve acceptable levels of performance. Furthermore, what they learned seemed to be "hyperspecific" (Schacter, 1985); that is, learning was tightly bound to the stimulus conditions that existed during learning and was difficult to access in unconstrained contexts. For example, although persons with traumatic brain injury correctly typed the word "HOME" when instructed to "clear the screen," they never spontaneously used the command and had difficulty generating it to a changed cue. Such inflexibility suggested that transfer from the laboratory to the real-world might be problematic for the domain-specific learning approach and seriously limit its benefits. Our next studies, therefore, were designed to test whether learning acquired in the laboratory could be applied in an important domain of everyday life--the workplace.

Recent attempts to circumvent transfer problems with respect to vocational training have generally taken two forms. The relatively recent strategy of using an on-the-job coach represents one way of overcoming transfer problems. Our alternative approach has been to set up careful laboratory simulations of actual jobs and attempt to teach all aspects of the tasks directly and explicitly. The studies that will be described below demonstrate the use of this approach with respect to three real-world computer tasks--data-entry, database management, and word-processing. These jobs were chosen as potentially good vocational options for persons with traumatic brain injury because they consist of a set of fixed rules and procedures that remain relatively invariant over time and materials. Because of the apparent inflexibility of learning acquired by persons with memory-impairment, it seemed important to select jobs that, even though complex, could be performed in a straightforward manner without reliance on inferences or on-line problem-solving.

### **Vocational Training: Computer Data-Entry**

**Case study.** The first vocational study (Glisky & Schacter, 1987) involved training a severely amnesic person in the laboratory for a real-world computer data-entry job. H.D., a 32-year old woman, had become severely amnesic as a result of herpes encephalitis. Her Wechsler Memory Scale Quotient was only 65. In addition, she had a low-average IQ (WAIS-R = 84) and a slight problem moving objects but no other cognitive deficits. She retained excellent attentional skills achieving normal performance on neuropsychological measures of concentration and reasoning (e.g., six categories on the Wisconsin Card Sorting Test).

The actual data-entry job was carefully analyzed and simulated in the laboratory as closely as possible. The job required H.D. to learn how to extract information from company documents called "meter cards" and enter it into a coded computer display. All cards were similar in appearance and relevant information appeared in the same location across cards. To perform the task successfully, H.D. had to learn general terminology, meanings of various codes, location of critical information on the cards, and mappings between the cards and the display.

In the first phase of training--the knowledge acquisition phase--28 incomplete sentences were presented on the computer screen. H.D.'s task was to type the correct completion for each sentence on the keyboard. The missing words comprised the key facts needed to understand and perform the data-entry task. The training technique was the method of vanishing cues.

On the first trial, H.D. needed 60 letter hints and took 56 minutes to complete the twenty-eight sentences. However, by the end of 27 trials over six sessions, she was performing perfectly without hints and needed only 10 minutes to complete a trial. She then entered the skill acquisition phase of training in which she received extensive practice in the actual data-entry procedures. Steady improvement occurred over a period of five weeks increasing her data-entry speed from 63 seconds per card to 13 seconds, a time that was comparable to that of experienced data-entry clerks.

During the final phase of training, H.D. was accompanied to the workplace where her performance was monitored over several days. She rapidly adjusted to the work environment, making few errors, and by the



## 10 / Training Persons

second day she was performing as quickly as in the laboratory. Because the meter-card job provided only part-time employment, a further training study was undertaken (Glisky & Schacter, 1989a) that, if successful, would enable H.D. to return to work full-time.

The second job in question was an extension of the data-entry task that was several times more complex than the one just described. The expanded task required the entry of information from 11 different document types with varied exemplars, the learning of approximately 250 discrete items of new information concerning rules and procedures for the job, and the transfer of learning to documents never encountered before. The teaching technique was again the method of vanishing cues. Two hundred and forty actual company documents, representing multiple versions of the 11 document types, were used during training in an attempt to facilitate flexible application of learned rules. Training continued in the laboratory daily for approximately five months before H.D. achieved acceptable levels of performance. She then entered the workplace accompanied by a laboratory assistant, who ensured that the job was executed correctly. Although H.D.'s performance initially slowed considerably, she nevertheless managed to accomplish the task with minimal help, and within four to five weeks on the job, she had exceeded laboratory levels of performance. From that time, she has continued to work independently as a full-time employee. Interestingly, however, although H.D. was able to perform the job at a very high level, she could describe the task only very generally (e.g., "I work on a computer") and could not recount specific details of the procedure.

The results of these two experiments demonstrate that a person who is severely amnesic is able to acquire, in the laboratory, the knowledge and skills needed for a complex real-world job and to apply them successfully in the workplace. Although these experiments were successful, they nevertheless represented the training of only one person with a memory-impairment. Furthermore, training required the combined efforts of a researcher, a programmer, and a research assistant for a period of approximately 14 months. Two important questions are raised by these observations: First, are such programs appropriate for other persons with memory-impairments, particularly persons with traumatic brain injury who may have additional cognitive deficits, and second, do the high costs in time and labor for such individualized programs outweigh the benefits? The first of these questions, we have addressed experimentally and the answer is "yes."

The second question pertaining to high costs in time and labor for individualized programs outweighing the benefits can be answered only speculatively at this time. Several points are relevant: First, the programs outlined here are, in some sense, prototypes and have required lengthy development time; later programs will take much less time. Second, although these original training programs were highly individualized, recent versions are more general and can be readily adapted for individual use by caregivers or training assistants; furthermore, patients work at the computer independently, at their own pace, and require minimal assistance (e.g., starting the program). Third, possibilities for training many patients in the same task at one time await only the availability of facilities and vocational placement opportunities. For example, in the data-entry task described below, eight patients have been trained in the past year, despite the availability of only limited laboratory facilities. Finally, according to statistics provided by the National Head Injury Foundation, putting one young head-injured person back to work will result in a lifetime savings of \$4 million--to say nothing of the savings in emotional terms. Benefits, therefore, may already have exceeded costs. Nevertheless, continued research in this area, along with rapid technological development, will almost certainly lead to improved cost-effectiveness of the domain-specific learning approach.

**Group study.** The case study, described above, demonstrated that a person with a memory-impairment, H.D., was able to learn a computer data-entry job and thereby secure full-time employment. An important issue concerned whether similar outcomes could be obtained with other persons with brain injuries. Although H.D.'s memory impairment was severe and her I.Q. was relatively low, she nevertheless possessed excellent attentional capabilities that may have contributed to her success. Many persons with a traumatic brain injury, as a result of frontal lobe damage, have attentional deficits that may contribute to difficulties in lengthy learning tasks. To test the generality of our findings with other brain-injured people, we constructed an analog of the laboratory training segment of the meter card task to be administered to persons with a range of cognitive deficits. The exact procedures of the prior study were replicated; the only difference was that the documents used were laboratory imitations rather than real meter cards.

Eight persons with memory disorders of varying severity and of various etiologies along with five control subjects participated in the study. The study group consisted of five head-injured subjects, two

persons who suffered ruptured aneurysms of the anterior communicating artery, and one person with encephalitic symptoms. All people were at least one-year post-trauma and had memory deficits disproportional to any intellectual impairments. The mean difference between IQ (WAIS-R) and Wechsler Memory Scale Quotient (WMS-R) was 21.3. In addition, five of the people had motor deficits, and all except one showed signs of frontal lobe pathology and in that respect differed from H.D. Control subjects were approximately matched with respect to age and IQ but scored significantly higher on the Wechsler Memory Scale.

The results of the knowledge acquisition phase of training, which required the learning of 28 facts, are shown in Table 1. (H.D.'s results are also included for comparison purposes.) All persons with brain injury, even those with the most severe cognitive deficits (i.e., M.R., M.C., J.L.), were able to acquire the information needed for the data-entry job. Seven out of eight reached the criterion of two consecutive perfect trials, and one continued to need a single letter hint for one response. At the start of training, there were no differences in the mean numbers of hints that brain-injured persons (89) and control subjects (88.4) needed to produce correct responses. This finding suggests that the two groups were equivalent in prior knowledge and comprehension abilities. The brain injured group, however, learned the task more slowly than the control group (58.5 trials compared to 19 trials) and required more time to complete a perfect trial (10.9 minutes compared to 6.6 minutes). Note, however, that people with mild memory impairments (C.C., V.R., D.L.) performed as well or better than normal subjects on all measures.

In the subsequent skill acquisition phase of training, where persons with brain injury actually performed the data-entry task, results indicated steady improvement over trials, with speed of performance increasing from an initial mean of 133 seconds per card to 50 seconds per card after 45 trials. Although there was considerable variability in speed of data-entry across subjects and persons with brain injury were generally slower than control subjects, the pattern of skill learning was similar in all cases.

The final part of this experiment differed from the case study in that transfer to the workplace could not be assessed. Instead, we explored the extent to which learning would transfer across relatively minor changes in materials--the kinds of changes that might reasonably be expected in a real-world job. Two different transfer tasks were devised:

In Task A, two of the descriptive headings were omitted from the meter cards; in Task B, in addition to the omitted headings, the location of two pieces of information was reversed on the cards. Subjects were informed of the nature of the changes and were instructed to proceed with the data-entry task as before. Persons with brain injuries showed no significant increases in errors on either of the transfer tasks although performance slowed significantly in both cases. More importantly, after one trial, speeds returned to baseline levels. These observations indicated that some changes in the data-entry task could be handled by memory-impaired patients without serious disruption to job performance.

**Table 1**  
**Results of the Knowledge Acquisition Phase**  
**of the Computer Data-Entry Task**

Persons With Brain Injuries <sup>1</sup>	Diagnosis <sup>2</sup>	Trials To Criterion	Range of Hints	Range of Times (min)
H.D.	ENCEPH	27	60-0	55.5- 9.9
C.C.	CHI	15	42-0	41.4-11.6
V.R.	CHI	9	41-0	18.6- 6.4
M.R.	CHI	50	106-0	114.4-25.7
M.C.	CHI	61	167-0	50.0- 9.3
J.L.	CHI	114	101-0	70.3-10.6
W.D.	ACAA	79	107-1	79.0-10.1
B.R.	ACAA	125	92-0	62.0- 7.2
D.L.	ENCEPH	15	56-0	19.9- 5.9
Means	(N=8)	58.5	89-0	56.9-10.9
CONTROLS				
J.N.	--	20	79-0	50.4- 7.8
J.U.	--	15	66-0	23.8- 5.3
J.S.	--	17	97-0	19.8- 7.4
D.C.	--	19	106-0	20.3- 6.3
B.Y.	--	24	94-0	32.4- 6.0
Means	(N=5)	19	88.4-0	29.3- 6.6

<sup>1</sup> C.C., V.R., and D.L. had mild memory impairments.

<sup>2</sup> CHI = closed head injury, ACAA = anterior communicating artery aneurysm, ENCEPH = encephalitis

On the basis of these findings, we concluded that a computer data-entry task would be an excellent job choice for individuals who have suffered traumatic brain injury. Although the task is complex and requires the acquisition of considerable amounts of new information, even persons with severe cognitive deficits were able to master it. Furthermore, the demonstrations of successful transfer, to the workplace in the case of H.D. and across minor variations in materials in the group study, suggest that laboratory training for real-world jobs is feasible.

There are a number of reasons why laboratory training of job skills may be preferred over on-the-job training. First, many jobs, such as the data-entry task just described, do not lend themselves easily to on-the-job training because they are too complex. Persons with brain injuries are often not capable of assimilating many complex steps of a procedure at one time. Each task must therefore be broken down into manageable components, which have to be individually and painstakingly learned and then re-assembled into an integrated and smooth sequence of operations. Even for simpler jobs there are advantages to laboratory training. Extensive repetition in the laboratory, under controlled conditions, ensures quality of work for the employer from the outset. Problems can be anticipated and handled without disruption to a regular work environment. In addition, by the time trainees enter the workplace, they are able to present a positive image and inspire confidence in fellow workers and employers. If the laboratory trainer, who knows the job thoroughly, accompanies the client on the job for the first few days, a smooth transition into the workplace can be accomplished.

### **Vocational Training: Database Management**

Database management is another computer task that requires knowledge of a set of fixed rules and procedures that, once learned, remain invariant across applications. However, unlike the data-entry task in which rules are applied to similar materials under identical conditions, the database management procedures are applicable to a wide range of materials and an infinite number of problems. The task thus presents an opportunity to explore transfer situations that are much more complex than those studied in the data-entry task.

The subject for this investigation was patient V.R., who, prior to a closed-head injury, had been employed as a financial planner for a major corporation, a job that he was unable to perform after his accident. At the time of this study, V.R. was three years post-trauma, had a mild-to-

moderate verbal memory deficit, complained of sequencing problems, and lacked initiative. A database management job, which existed within his company, provided the model for the laboratory training program that we devised.

The task required the acquisition of a small number of computer commands in a language known as SQL, Structured Query Language, which could be used to retrieve information from a database. A large number of rules governing the use of these commands also had to be learned, but once learned, they could be applied to any database that was organized in table form (i.e., in rows and columns). The real-world job required retrieval of information from the company's financial database, but because of the confidentiality of this information, training with the actual database was not possible. The training strategy, therefore, was to teach the rules and procedures using an experimentally-created database and later to assess transfer to the real world. Because of the possibility of serious generalization problems, however, we decided to address transfer issues experimentally in the laboratory by using two different databases during training.

The job was broken down into simple components, and a series of study and test programs of gradually increasing complexity was constructed. The study programs were designed to teach concepts, language, and syntax concerning the writing of queries--relatively short programs designed to access and retrieve information from a database. Learning was by the method of vanishing cues and training continued to a criterion of two consecutive trials in which no hints were needed. Each study program was followed by a corresponding test program, which measured retention and transfer of learning to new problems and a new database. Two databases were used: one containing information about presidents of the United States and one concerning the organizational structure of a corporation. The study programs were comprised of incomplete sentences that introduced the basic SQL commands and the rules and procedures for using them, along with example problems to be solved. All explanations and examples in the study program referenced just one database. The test programs were made up of a series of problems that could be solved using the knowledge and procedures acquired during study. Half of the problems accessed the same database used during study and half of the problems concerned the other database. Problems were either identical to, similar to, or different from the example problems presented during the study phase. Similar problems were of the same form as the study problems

and rules were applied in a straightforward manner. Different problems required integration of two or more concepts and flexible application of rules.

V.R. was able to acquire the information in each of nine study programs, but he experienced difficulty with problems in the test programs that he had not encountered previously. Furthermore, as problems became more difficult and increasingly dissimilar to those used during training, V.R.'s performance declined and transfer became increasingly poor. In addition, transfer across databases, although reasonably good for the easier problems, began to break down as problems became more complex.

Examples of some of the Test 1 problems and their correct solutions, along with the experimental results, are illustrated in Table 2. The performance measures were the number of times the solution was tested or "run" against the database before it was correct and the time taken to achieve the correct solution. Incorrect runs were followed by a cue indicating the line(s) of the query in which the error(s) occurred. The subject was then given an opportunity to correct the errors and re-run the query.

Problems from Test 1 were relatively easy, consisting of two- or three-line queries. Results indicate that the person had no difficulty remembering the solution to a problem learned during study (i.e., same database, identical problem). However, when the problem was changed slightly (i.e., same database, similar problem), requiring the selection of a different column from the database, V.R. experienced some difficulty, needing six runs to solve the problem, whereas a control subject had no such trouble. Furthermore, with a greatly changed problem (i.e., same database, different problem), which required an integration of two concepts taught during study, V.R. was considerably disadvantaged relative to the normal subject, making 17 runs before achieving the correct solution. However, there was very good transfer across databases. Performance was perfect on the first attempt for identical and similar problems, and even for different problems, having learned the integrative solution in one database, V.R. was able to make use of that learning to solve the same kind of problem in the other database.

As training progressed and problems became increasingly complex, transfer across databases became less reliable. Some sample results from Test 4 are shown in Table 3.

**Table 2**  
**Sample Problems and Results From Test 1 of the Database Management Task**

	Same Database	Different Database
Identical	<p>Write a query that lists the party names with duplication.</p> <p>SELECT DISTINCT PARTY FROM PRESIDENT</p> <p>V.R.: Runs = 1 Time = .60 min</p> <p>Cont: Runs = 1 Time = .63 min</p>	<p>Write a query that lists employee jobs without duplication.</p> <p>SELECT DISTINCT JOB FROM STAFF</p> <p>V.R.: Runs = 1 Time = .8 min</p> <p>Cont: Runs = 1 Time = .5 min</p>
Similar	<p>Write a query to produce a list of unique states where presidents have been born.</p> <p>SELECT DISTINCT STATE BORN FROM PRESIDENT</p> <p>V.R.: Runs = 6 Time = 5.9 min</p> <p>Cont: Runs = 1 Time = 2.4 min</p>	<p>Write a query to produce a list of unique departments where employees work.</p> <p>SELECT DISTINCT DEPARTMENT FROM STAFF</p> <p>V.R.: Runs = 1 Time = .9 min</p> <p>Cont: Runs = 1 Time = .7 min</p>
Different	<p>Write a query to show for each party an alphabetical listing of states where presidents have been born.</p> <p>Order by party.</p> <p>SELECT DISTINCT PARTY, STATE BORN FROM PRESIDENT, ORDER BY PARTY, STATE BORN</p> <p>V.R.: Runs = 17 Time = 27.6 min</p> <p>Cont: Runs = 3 Time = 5.7 min</p>	<p>Write a query to show for each department an alphabetical listing of jobs within that department.</p> <p>Order by department.</p> <p>SELECT DISTINCT DEPARTMENT, JOB FROM STAFF, ORDER BY DEPARTMENT, JOB</p> <p>V.R.: Runs = 2 Time = 2.1 min</p> <p>Cont: Runs = 2 Time = 2.3 min</p>



**Table 3**  
**Sample Problems and Results From Test 4 of the Database Management Task**

	Same Database	Different Database
Identical	<p>List employees, their total yearly earnings, their commissions, and the percentage that their commission is of their total earnings.</p> <p>SELECT NAME, SALARY + COMM            COMM, 100*COMM/(SALARY + COMM) FROM STAFF            WHERE 100*COMM/(SALARY + COMM) &gt; = 5</p> <p>V.R.: Runs = 1 Time = 2.6 min</p>	<p>List presidents, their years of service, their age at death, and the percentage of their lives that they served in the White House. Include only those presidents who served as president for at least 10% of their lives.</p> <p>SELECT PRES NAME, YRS SERV, DEATH, AGE, 100*            YRS SERV/DEATH_AGE FROM PRESIDENT            WHERE 100* YRS_SERV/DEATH_AGE &gt; = 4</p> <p>V.R.: Runs = 5 Time = 8.9 min</p>
Similar	<p>List employees whose commission is less than 2% of their total earnings</p> <p>SELECT NAME, COMM, SALARY + COMM,            100* COMM/(SALARY + COMM) FROM STAFF            WHERE 100*COMM/(SALARY + COMM) &lt; 2</p> <p>V.R.: Runs = 2 Time = 6.4 min</p>	<p>List presidents whose years served in the White House were less than 5% of their lives.</p> <p>SELECT PRES NAME, YRS SERV, 100* YRS            SERV/DEATH_AGE FROM PRESIDENT WHERE 100*            YRS_SERV/DEATH_AGE &lt; 5</p> <p>V.R. Runs = 5 Time = 14.9 min</p>
Different	<p>List employees, their yearly commissions and weekly salaries, whose weekly salaries are no more than 75% of their yearly commissions.</p> <p>SELECT NAME, COMM, SALARY/52, 100*            SALARY/52/COMM FROM STAFF            WHERE 100*SALARY/52/COMM &lt; = 75</p> <p>V.R.: Runs = 8 Time = 56.7 min</p>	<p>Which presidents were more than 50% older than their spouses? Include ages of both spouses.</p> <p>SELECT PRES NAME, PR AGE, SP AGE, 100* PR            AGE/SP AGE FROM PRES MARRIAGE            WHERE 100* PR AGE/SP AGE &gt; 150</p> <p>V.R.: Runs = 11 Time = 55.2 min</p>

As in Test 1, performance became poorer as problems became less similar to those used during training; however, in this test there was no evidence of transfer across databases. V.R. seemed unable to access the rules or the solution to problems from the first database to facilitate his performance in the untrained database. These results, along with observations from the solution protocols, suggested that V.R. may have been relying heavily on memory for specific solutions rather than on memory for rules. When problems were few and simple, this strategy worked reasonably well. But as increasing numbers of complex problems were presented, the memory load may have become too great. In addition, it was noted that when V.R. made an error, attempts to correct it seemed random, rather than rule-based; there was no indication that he was attempting to apply any rules whatsoever to achieve the solutions. The control subject, on the other hand, when cued for an error, had little difficulty recognizing and correcting it, and corrections appeared to be rule-driven.

Reasons for the specific transfer difficulties experienced by V.R. are unclear. Rules were taught explicitly during study programs, and results indicated that he had, in fact, learned them. However, their application seemed strongly tied to the specific problems used during training, and V.R. seemed unable to access and/or apply the rules to new problems. V.R.'s learning thus had the same "hyperspecific" quality that we had noted in our earlier computer learning studies. These observations suggested that transfer to the workplace would be difficult. In the actual job, all problems would be novel, requiring creative solutions and flexible application of acquired rules. Unfortunately, because of V.R.'s voluntary termination of employment for reasons unrelated to this project, we were unable to assess adequately the extent to which laboratory training generalized to the workplace. The results that we were able to obtain suggested that, as expected, when switching to the company's financial database, V.R. experienced considerable difficulty with all but the simplest problems.

The database management task employed in this study was extremely complex. Nevertheless, V.R. was able to acquire a large amount of information concerning the task, and he learned to solve a considerable number of problems. Many database management jobs are less complex and consist of a more limited set of problems. In these cases, it is possible that subjects could be trained with enough sample problems to guarantee successful performance. We are currently designing simpler database management tasks to investigate these issues in the laboratory.

### **Vocational Training: Word-Processing**

Another computer task that has the potential to provide employment for people with brain injury is word-processing. Like the computer tasks already described, word-processing comprises a domain of knowledge that consists of a circumscribed set of rules and procedures that applies in a relatively straightforward manner across situations and materials. However, unlike the database management task, the problem-solving and inference-making requirements of word-processing are few and are likely to be simpler. All word-processing functions can, in principle, be taught and should apply in the same way in all cases. All that varies is the content of the processed or typed material. For these reasons, word-processing might be expected to transfer more easily from the laboratory to the real world. The memory demands of the word-processing task, however, are substantial. A large number of functions have to be learned, each requiring a unique combination of key presses. Although we have yet to observe any limit on the amount of information that can be acquired by persons with a memory-impairment, the word-processing task will clearly challenge these limits.

We have begun attempts to teach persons with a memory-impairment to use a commercially available word-processing package, WordPerfect. We chose this particular software because it is extensively employed in business and industry as well as in home environments, and thus has potential for use in both contexts. Although simplified versions of word-processing programs could be customized for persons with brain injuries to use at home, such programs would likely not be suitable in vocational contexts. Furthermore, given prior problems of transfer, it seemed important to use software that would be most readily available in a real-world job situation.

Our approach to teaching word-processing is similar to that used in our earlier studies. A series of lessons of gradually increasing complexity was constructed for purposes of introducing and explaining the word processing functions. Each lesson focuses specifically on two or three basic operations. Information is presented to the subjects in the form of incomplete sentences with key words or phrases omitted. The task of persons with brain injuries is to type the correct completions on the keyboard. Within each lesson, subjects are also required to execute the actual word processing functions in the WordPerfect environment. The training technique is the method of vanishing cues, and subjects repeat each lesson until they complete two consecutive perfect trials.

Corresponding test programs then assess the extent to which persons with brain injuries can apply what they have learned in novel contexts.

Data for this study were not yet available at the time of this writing. Based on preliminary findings, however, we expect that persons with brain injuries will be able to learn the task although training time may be considerable. The more critical questions concern the extent to which the laboratory-acquired skills will transfer to the real world. In the past, we have waited for job openings to become available before designing training programs. In this way, all aspects of a job could be incorporated into a training regimen and taught explicitly, so that generalization problems could be minimized. In the case of WordPerfect, because of its widespread use in a great many business environments, it seems likely that a single laboratory training program could prepare clients for a range of word-processing jobs. Training could thus proceed before appropriate job placements have been identified. Despite this apparent generality of the word-processing task, specific jobs requiring the use of WordPerfect still need to be identified. For example, jobs such as transcribing, which are quite constrained, will likely be more suited to persons with brain injuries than jobs that require more flexible application of word-processing skills such as secretarial positions.

The word-processing study will provide some information with respect to these issues, but more placement opportunities in the community need to be found. Vocational agencies have often been unsuccessful or uncooperative in finding suitable job opportunities for brain-injured persons in the community because many persons with brain injuries have been considered untrainable. Demonstrations of successful laboratory training of complex skills, such as word-processing, data-entry, and database management, increase the likelihood of securing community assistance and involvement in finding appropriate jobs for persons with brain injuries.

### **CONCLUDING REMARKS**

Persons with brain injuries, who may have diminished learning and memory abilities, can nevertheless acquire considerable amounts of complex domain-specific knowledge that is relevant to their everyday lives. Specifically, they are capable of learning, in the laboratory, complex job skills that can subsequently be applied in community-based employment situations. In this chapter, three tasks that appear to offer

good job possibilities for persons with brain injuries have been described including data-entry, database management, and word-processing. All are computer tasks. Although our job training programs are not all computer-related (see Glisky & Schacter, 1990, for description of a microfilming job), computer jobs may be particularly good choices for persons with brain injuries. They frequently consist of a set of invariant procedures that once learned can be executed repetitively with few demands on memory or other high-level cognitive processes. Under many circumstances, they do not require problem-solving, hypothesis testing, or adaptive use of acquired knowledge. In general, computers are inflexible. They present information and programs in the same way on all occasions. They do not change their minds or ask novel questions, and they do not interact on a social level.

These are characteristics that seem important for rehabilitation practitioners to consider when suggesting jobs for persons with brain injuries. Additionally computer jobs have a "high-tech" image that makes them acceptable to people who may be unwilling to accept jobs in reduced capacities, particularly clerical and professional people, who have been reported as having a much lower rate of return-to-work than blue collar workers (Stuss, Ely, Huzenholtz, Richard, LaRochelle, Pairer, & Bell, 1985). This population, in the past, appears not to have been especially well served by vocational rehabilitation services. Computer-related jobs, because of their implied status, may have been overlooked as possibilities for persons with brain injuries because they seem too difficult or too cognitively demanding. However, it does not appear that the computer tasks that we have studied require exceptional cognitive abilities. H.D., for example, has an I.Q. of only 84 along with a severe memory impairment, and many people with head injuries have attentional problems, motor deficits, and perceptual difficulties as well as memory deficits. Yet all of these people have been able to learn the data-entry task. Learning, however, is slow and is often characterized by a hyperspecificity that may affect transfer from the laboratory to the workplace. For this reason, actual jobs should be simulated in the laboratory as closely as possible.

Issues of transfer and generalization still need to be explored systematically, and new vocational domains need to be identified. There may be many vocational tasks that, although complex, remain relatively unchanging over time and are thereby appropriate for individuals who have suffered brain trauma. We have only begun to tap the potential of technology for persons with brain injuries and to explore the interface

between them. Continued research efforts in this direction should improve the cost effectiveness and efficiency of training programs and increase our understanding of the extent of the capabilities of persons with brain injuries. It is becoming increasingly evident that many of these people need not remain dependent on others for their care and well-being. They are capable, when given the opportunity, of participating in community-based employment and of living productive lives. We need to continue to try to provide that opportunity.

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24 / *Training Persons*

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## *Chapter 2*

### **SELECTION AND OUTCOME CRITERIA FOR COMMUNITY-BASED EMPLOYMENT: PERSPECTIVES, METHODOLOGICAL PROBLEMS AND OPTIONS**

**Thomas Kay, Ph.D.**

## INTRODUCTION: THE NEED FOR AN ANALYTIC APPROACH

In approaching the concept "Selection and Outcome Criteria for Community-Based Employment," one is led to ask a series of common sense and very practical questions: how do we decide what legitimately constitutes "employment," what criteria do we choose for making vocational placement decisions, how do we define "successful outcome," and how do we select clients who qualify for the vocational rehabilitation process? These are questions we tend to gloss over--we assume we know the answers to them, and tend not to think too deeply about them. Forcing ourselves to formulate answers to them requires us to systematically evaluate the process and efficacy of selecting, intervening with, and vocationally placing clients with head injuries. This critical evaluation is long overdue. The upsurge of interest in traumatic brain injury within the past few years has spawned a wide variety of clinical attempts to return cognitively impaired but often physically able young men and women to work, these attempts have led to considerable soul-searching on the part of state VR systems. There is no lack of creative ideas, new ideas, training workshops, and conferences, but there is a distressing lack of systematic efforts to critically evaluate the effectiveness of what works with whom and under what conditions.

This chapter will approach this critical evaluation of the vocational rehabilitation process through a series of three steps. First, to set the stage, consideration of what research can tell us about return to work after head injury, both from the perspective of the natural course of recovery and following specialized intervention, will be explored. Second, this research-drawn picture will be complicated by introducing a clinical perspective in order to examine more closely the complexities of defining outcome, to examine the myriad elusive variables that we know influence outcome, and to tackle the difficult question of just what is *successful* outcome for each individual client. Finally, this chapter will attempt to link selection criteria to outcome criteria: very basically, "what works for whom?" (Persons wishing a comprehensive set of annotated abstracts of published research citing return-to-work data after traumatic brain injury should consult Kay, Cavallo, Ezrachi and Newman, 1988.)

## WHAT DOES RESEARCH TELL US ABOUT RETURN TO WORK AFTER TRAUMATIC BRAIN INJURY?

### The Natural Course of Recovery

The answer to the question of how successfully people *spontaneously* return to work after head injury in the natural course of recovery (i.e., without any specialized rehabilitation efforts) is not as straightforward as it may appear. At its simplest level, this can be appreciated by comparing the outcomes of two studies. In 1970, Steadman and Graham reported the amazing finding that in a study of 415 persons with head injuries, 413 of them, or 99.5 percent, had successfully returned to work five years after their injury. In contrast, Thomsen reported in 1984 that only five of the 40 persons with head injuries she followed, or 13 percent, had returned to work five to ten years after their injury. The differences in outcomes can be attributed to a number of factors. Most obviously, Steadman and Graham were studying consecutive admissions to an acute care hospital where many of the cases would have been neurologically minor. Thomsen's sample consisted of severely injured patients seen in a rehabilitation hospital--two groups that are hardly comparable. Less tangible factors that can contribute to wildly different outcomes include social factors (the studies were conducted in Great Britain and Denmark, respectively) and unspecified differences in criteria for successfully returning to work.

More carefully designed studies have attempted to establish return-to-work rates as a function of severity of injury. Gilchrist and Wilkinson in 1979, for example, reported results of a study of 72 persons with head injuries who were followed up one to 15 years after their injury (this variability of follow-up is itself a methodological problem). Overall, at the time of follow-up, 39 percent of the sample had returned to some kind of work. This figure was shown to be misleading, however, when vocational outcome was broken down by severity of injury, as measured by length of "unconsciousness." It can be seen that when meaningful response to the environment occurred within one week, 82 percent of the subjects returned to work. At the other extreme, when response to the environment took more than eight weeks, only 11 percent returned to work. Intermediate levels of severity had intermediate rates of return to work.

**Table 1**  
**Gilchrist and Wilkinson (1979)**

Sample Characteristics

Sample Size	72
Rehabilitation Hospital	
Loss of Consciousness	> 24 hours
Percent "Unconscious" > 1 Week	85
Follow-up	1-15 years

Percentages (N=72)

<u>Length of "Unconsciousness"</u>	<u>Return to Any Work</u>	<u>Unemployed</u>
< 1 Week	82	18
2-4 Weeks	47	53
5-7 Weeks	18	82
> 8 Weeks	11	89

Deficits

No/Mild Mental Impairments	62	38
Mild/Severe Mental Impairments	23	77

Overall Return to Work

Same Level	24
Lower Level	15
Unemployed	61

Two things are important to note from these findings: First, the more severe the injury, the lower the likelihood of spontaneously returning to work. Second, this relationship is merely one of probability: regardless of level of severity, a certain proportion of persons with brain injuries spontaneously returned to work, and others did not. Other factors besides severity of injury determined the ability to spontaneously return to work.

Another important factor that has been shown to be related to vocational outcome after traumatic brain injury is age. Heiskanen and Sipponen in 1970 followed up, three to five years after injury, 102 head injured subjects all of whom had been unconscious for at least 24 hours. Overall, 53 percent had been able to return to work or school. This overall rate, however, was shown to be strongly influenced by the age of the subject. For example, 70 percent of those under the age of 20 had returned to work or school, as compared to only 30 percent for those over 50. To complicate the picture even more, the authors demonstrated a further interaction between age and severity of injury in return to work. In this sample, *no* subject unconscious for more than four weeks spontaneously returned to work within the follow-up period. More importantly, how long a person could be unconscious and still return to work depended on the age of the subject. No subject under the age of 20 returned to work if unconscious more than four weeks; no subject between 21 and 40 returned to work if unconscious more than three weeks, no subject between 41 and 60 returned to work if unconscious more than one week; and no subject over 60 returned to work if unconscious for more than one day.

These results suggest an interaction between age and severity: the probability of spontaneously returning to work after coma of a given duration depended on how old the person was. Younger persons were able to return to work after longer periods of coma than older persons.

A number of cautions should be made in generalizing from these data. First, as persons get older, baseline rates of employment (which are not reported in the article) may decline, as may the incentive to return to work; thus other factors beside mere capacity come into play. Second, this study had a relatively brief follow-up period; one does not know how many persons *ultimately* returned to work. Third, return to work was not carefully defined; persons engaged in some kind of productive activity, especially older persons, may have been counted as unemployed. Fourth, these subjects received no specialized vocational rehabilitation; many of them who did not spontaneously return to work may have had the capacity, given the proper circumstances. Finally and most important, this is one small sample: 102 persons out of half a million injured each year, taken from one particular hospital in one particular social and geographical region. It is *extremely* dangerous to generalize from results of one study, to all people -- especially in as complex an area as return to work, where multiple factors affect outcome.

**Table 2**  
**Heiskanen and Sipponen (1970)**

Sample Characteristics

Sample Size	102
Loss of Consciousness	≥24 hours
Follow-up	3-5 years

Percentages

Overall Return to Work

To Any Work or School (54/102)	53
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Effect of Age

Under Age 20 Returned	70
Over Age 50 Returned	30

Effect of Coma

No Subject in Coma >4 Weeks Returned to Work

Interaction of Age and Coma:

Return to Work Did NOT Occur for Patients:

- < 20 years old with Loss of Consciousness > 4 weeks
- 21-40 years old with Loss of Consciousness > 3 weeks
- 41-60 years old with Loss of Consciousness > 1 week
- > 60 years old with Loss of Consciousness > 1 day

Nevertheless, given all these limitations, the data for this sample are striking and do suggest that, all other things being equal, age and severity of injury have both main and interacting effects on spontaneous return to work after head injury. The error is in generalizing from these results to rigid laws for *all* persons with head injuries or for any given *individual*. Most professionals with any significant work history in rehabilitation of persons with brain injury can argue that they are now aware of at least one exception to the length of coma and age interaction paradigm as reported by Heiskanen and Sipponen (1970).



Studies have demonstrated that both physical and neuropsychological deficits are related to the ability to spontaneously return to work. As early as 1945, Denny-Brown reported that "mental symptoms" were the chief correlate of extended unemployment after head injury. Bond (1975) found that persons who returned to work after head injury had fewer symptoms, both physical and mental, than those who remained unemployed. Weddel, Oddy, and Jenkins (1980) found that what distinguished those returning to *some* type of work from the totally unemployed was a lower incidence of memory, personality, and neurophysical disturbances.

Other studies have refined these results, demonstrating how physical and mental symptoms interact with the nature of the job to influence return to work. For example, Lewin (1976) reported a long term (10 to 24 years) follow-up of persons with head injuries who had suffered unconsciousness or post-traumatic amnesia for at least one week. They found that failure to return to work, or decline in occupational status, was associated more with mental than with physical disability, except in manual laborers where physical symptoms were more important.

Some of these factors were brought together in the work of researchers in Glasgow, who summarized their work in (Brooks, McKinlay, Symington, Beattie, & Campsie, 1987). Their subjects had been unconscious for at least six hours, had post-traumatic amnesia for at least two days, or had received brain surgery for hematoma. When followed up two to seven years post injury, 39 percent were employed at some level, compared to 86 percent pre-injury. A number of factors were found to predict the ability to return to work, among them age; being described as "energetic" by a significant other; the absence of behavioral, emotional, and communication deficits; and a cluster of cognitive variables, including higher performance on tests of verbal learning, memory, and attention.

The work of fellow associates and mine at New York University (NYU) has taken a somewhat different approach to studying spontaneous return to work after traumatic brain injury. We have been intensively studying small groups of persons with head injuries using repeated neuropsychological evaluations, in order to determine, early on, what cognitive skills are best correlated with different levels of return to work years later.

**Table 3**  
**Brooks, McKinlay, Symington, Beattie, and Campsie (1987)**

Sample Characteristics

Sample Size	134
Loss of Consciousness	≥ 6 hours
Post Traumatic Amnesia	≥ 2 days
Follow-up of Post-Injury	2-7 years

Percentages Unemployed

Percentages (N=134)

Pre-injury	14
Post-injury	71

Predictors of Return to Work

- Age
- Described as "Energetic" by S/C
- Verbal Learning
- Memory and Attention
- Communication Deficits
- Behavioral/Emotional Deficits

One unexpected result of this research was to expose the methodological flaws of extrapolating from group data to individual recovery. This occurred when we adopted the approach of looking at statistically significant changes in each individual subject's performance over time. We found that the commonly accepted idea that widespread neuropsychological recovery occurs within the first year, followed by a plateau -- or at least significant slowdown in improvement -- after that, was an artifact of collapsing data down from separate studies. Within the first year the extent of an individual's making major changes was overstated. The group's significant improvement resulted not from modest gains from almost all subjects, but major gains by some and no significant change by others (Kay, Ezrachi, & Cavallo, 1987). Conversely, the amount of change that occurred between one and three years post trauma was underestimated by the failure of the group to change statistically. This is because four distinct subpatterns were being averaged and cancelled each other out: Some subjects continued to improve steadily, some declined, others showed random improvements

and declines, and some actually made no change. Interestingly, there was some evidence that it was the group that showed most stability in test performance over time that was most likely to be employed.

In the NYU studies of return to work after traumatic brain injury, researchers followed one sample of subjects intensively for a five-year period, testing them on an extensive neuropsychological battery 3-, 6-, and 12-months post injury (Kay, Ezrachi, Cavallo, & Newman, 1988). Subjects were traumatically brain-injured adults with no previous history of central nervous system disorder, psychiatric history of psychotic proportions, or severe drug or alcoholic abuse. About three-fourths were male, the mean age was 27, and more than half had only a high school education. Neurologically, they fell into the mild-to-moderate range of brain injury.

**Table 4**  
**Demographic Description of Study Sample**

Demographic	Percentages/Mean (N=25)
<u>Sex</u>	
Male	72
Female	28
<u>Age</u>	
Average	27.2
Range	18-56
<u>Education</u>	
High School Diploma	56
Technical Certificate	20
Some College	16
<u>Loss of Consciousness</u>	
Less Than 1 Day	40
1 Day to 6 Weeks	60

The sample was divided into four vocational outcome groups at five years: 1) persons returning to work at levels comparable to their pre-injury status and reporting no difficulties, 2) persons returning to work at comparable levels but reporting injury-related difficulties on the job, 3) persons working in a reduced capacity, and 4) persons not working at all. Students and homemakers were considered "employed" along the same dimensions.

**Table 5**  
**Work Status at Five Years Post Trauma (N = 25)**

Return To Work Status	N	Total Sample (N=25)	Employed Sample (N=16)
Comparable Level, No Problems	5	20	31
Comparable Level, Residual Problems	6	24	38
Reduced Capacity	5	20	31
Unable to Return to Work	9	36	--

A number of interesting findings emerged relevant to return to work. First, while 64 percent were able to return to some level of productivity five years after injury, only 20 percent had returned to work at a comparable level and reported no residual problems. A quarter of the sample returned to work at comparable levels but reported residual problems, cognitive or physical, that interfered with functioning. One fifth of the sample had returned to work but only on a part-time basis or at greatly compromised levels. The largest subgroup, one third of the total sample, was unemployed.

Second, subjects who by five years were working at comparable levels returned to work earlier than subjects who wound up working at reduced levels. Table 6 shows that 100 percent of the group working at comparable levels at five years had returned to work within two years of

their injury, while the majority of persons who ultimately returned at reduced levels returned between two and five years post injury.

**Table 6**  
**Timing of Return to Work By Level of Work Among Subjects**  
**Employed at Five Years Post Trauma (N = 16)**

Level of Work	N	By 1 Year	Frequencies (Percentages) Returned to Work	
			Between 1 and 2 Years	Between 2 and 5 Years
Comparable	11	73	27	0
Reduced	5	20	20	60
Total	16	56	25	19

Third, through one-way analyses of variance, we identified six tests that consistently, (i.e., at evaluations 3-, 6-, and 12-months post trauma) differentiated subjects in the four levels of return to work as identified in Table 5, at five years. We conducted a discriminant function analysis, entering demographic and neurological data first, and then the six neuropsychological variables, in an attempt to retrospectively "predict" five year vocational outcome from data collected within the first year.

As can be seen in Table 7, sex and education were consistent predictors of outcome - although in a complex way. Males with less education were least likely to return to work; however, at increasing levels of education, males were more likely to return to work than were females.

Neuropsychologically, the six test variables combined with sex and education to predict which of four vocational outcome levels subjects would achieve five years post trauma. The exact level of vocational outcome at five years was predicted with 76 percent accuracy from 3-month data, 80 percent accuracy from 6-month data, and 72 percent accuracy from 12-month data. Tests of visual memory, visual attention

and reasoning, and speeded inferential reading were the most consistent predictors. Different variables were better discriminators at different times within the first year.

**Table 7**  
**Discriminant Analysis Classifying Subjects**  
**Into Four Vocational Outcome Groups**

Test Point	Variables Entered	Percents Classified Accurately
3 Months	Sex, Education  WAIS Picture Completion LAVA Memory Ravens CPM Gates-McGinitie Accuracy	76
6 Months	Sex, Education  LAVA Memory Gates-McGinitie Speed Gates-McGinitie Accuracy	80
12 Months	Sex, Education  Benton Memory Errors Gates-McGinitie Accuracy Gates-McGinitie Speed WAIS Picture Completion	72

At least in this small sample, neuropsychological test performance within the first year, when combined with demographic factors, accounted for a significant portion, though not all, of the variance associated with vocational outcome five years post injury. This, of course, is a small sample, and the replicability of these conclusions is needed to more confidently accept these outcomes. Nevertheless, two inferences can be made: persons who spontaneously return to higher levels of productivity after head injury have fewer neuropsychological deficits and there may be a cause and effect relationship among

improving cognitive abilities within the first year. Both inferences seem to be related to the ultimate level of work which can be expected.

### **Rehabilitation Outcomes**

There have been relatively few studies of return to work after vocationally oriented rehabilitation programs. Prigatano, Fordyce, Zeimer, Roueche, Pepping, & Wood (1984) have reported results from their original program at Presbyterian Hospital in Oklahoma City. They compared 18 head injured clients who went through their six-month rehabilitation program with 17 similar subjects who were recommended for but did not participate in the program. Following the program, people who successfully completed the program outperformed controls on certain cognitive and memory measures and showed less deviance on personality measures. Nevertheless, the percentage of treated clients attending work or school six months later was only slightly higher (9 out of 18, or 50%) than that of the control group (5 out of 13, or 36%). Comparing those of the treated group who did and did not return to productivity, no demographic or post-program neuropsychological differences were found, although the work group showed greater improvement on a speeded copying task and on both visual and verbal memory measures.

These results highlight a number of important issues. First is the importance of including a control group when measuring the efficacy of outcome, especially in programs where subjects are referred relatively soon post hospital discharge, since a significant number of persons with head injuries will return to work even if nothing special is done. Second, persons who benefited from rehabilitation showed more improvements on neuropsychological measures than those who did not, but overall there were no statistical differences between the work and non-work groups on neuropsychological measures. Third, personality and emotional factors may have played a role in determining which persons benefited from training by returning to work. This is an important theme which will be discussed in a following section.

Burke, Wesalowski, and Guth (1988) have reported the results of an intensive program for difficult clients, most with frontal lobe damage and severe psychiatric histories. The 39 subjects were all at least four years post injury, almost all had a high school education, and almost all were described as having emotional and behavioral problems that interfered with community living. One-half also had a history of past psychiatric

hospitalizations, and more than a third were transferred directly from psychiatric facilities into the program.

**Table 8**  
**Prigatano, Fordyce, Zeimer, Roueche, Pepping, and Wood (1984)**  
**(Journal of Neurology, Neurosurgery, and Psychiatry)**

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Sample Characteristics

Program Length	6 Months	
Presbyterian Hospital		
Sample - Traumatic Brain Injury	18	
Control	17	

Post-tests Traumatic Brain Injury Scored Higher Than Controls

- WAIS PIQ
- WAIS BD
- WMS-Q
- Personality Measures

Six Month Follow-up	<u>N</u>	<u>Percentage Work/School</u>
Traumatic Brain Injury	18	50
Control	13	36

Traumatic Brain Injury Work Vs. Non-work

- No demographic or post-program Neuropsych differences
- Non-work more deviant on Katz Adjustment Scale at Post-Test
- Work Group improved more on:
  - WAIS Digit Symbol
  - WMS-Q
  - WMS Visual Reproductions
  - WMS PAL (hard)

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The community re-entry results, as reported, were impressive. No clients returned to psychiatric or rehabilitation facilities (although three-quarters were referred from such facilities). In addition, 87 percent were able to live in the community with either family, in group homes, or independently. From a vocational point of view, two-thirds were able to return to some level of productivity in the community. These people were about equally divided among subjects in competitive employment, supported employment, and sheltered



employment or vocational training.

**Table 9**  
**Burke, Wesalowski, and Guth (1988)**

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<u>Sample Characteristics</u>	
Sample Size	39
Follow-up Post-injury	4 years
<u>Demographics</u>	<u>Percentages</u>
Primary	74
High School Education	94
Emotional/Behavioral Problems	90
Psychiatric Hospitalization	50
Direct Psychiatric Transfer	36
<u>Vocational Status</u>	
Competitive Employment	26
Supported Employment	21
Sheltered Employment	3
Vocational Training	15
Unemployed	35

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The most extensive vocational outcome data have been provided by Ben-Yishay, Silver, Piasetsky, and Kattak (1987). Ninety-four subjects who had been through the Head Trauma Program at NYU Medical Center were followed for a three-year-period. All subjects were at least two years post injury, had completed formal rehabilitation, and entered the NYU program because they had been unable to return to work. (In this sense the subjects acted as their own controls, with a baseline employment rate of 0%.)

Subjects were given an "employability rating" upon completion of the program, and then their actual work status was noted 6 months, 12 months, 24 months, and 36 months later. Partial results will be presented in this chapter.

**Table 10**  
**Ben-Yishay, Silver, Piasetsky, and Kattak (1987)**

Sample Characteristics

Sample Size	94
NYU Head Trauma Program	
Post	2 Years
Month Program	8-15 Months
(Remedial & Vocational)	

<u>Vocational Status</u>	<u>Rating at Discharge</u>	<u>6 Months Post</u>	<u>3 Years Post</u>
Unemployed	16	20	30
Sheltered/Subsidized	21	23	22
Competitive (Unskilled)	23	24	25
Competitive (Skilled)	40	32	25

Reasons For Leaving Employment

- Alcohol/Drugs
- Disinhibited Behavior
- Psychiatric
- Unrealistic Quests
- Financial Disincentives

First, it can be seen that there is a relatively close match between expected work status and actual work status at the initial observation point (6 months). Second, 79 percent of the subjects were able to enter some level of productivity in the community, 56 percent of them at a competitive level. Third, a look at the three-year follow-up reveals both substantial maintenance of gains, and some slippage. A total of 50 percent of those followed remained competitively employed, but the number of unemployed rose from 20 percent to 30 percent. The primary factors responsible for leaving employment were drug and alcohol use, disinhibited behavior on the work site, psychiatric problems, unrealistic expectations of higher level employment, and financial disincentives.

More recently, researchers at the Medical College of Virginia have reported successful applications of the supported work model to persons with traumatic brain injury (Kreutzer, Wehman, Morton, & Stonnington,

1988; Wehman, 1988, 1989, 1990). For example, Wehman et al. (1990) reported on 53 persons with severe brain injury (mean time since injury = 7 years) who were accepted into a supported employment program. They reported that 41 subjects were initially placed and that 29 had retained their employment (although it appears from their data that many of these clients had only been at work 1-3 months at the time data were collected, while others had been at their jobs for a number of years). It is not clear from this report whether the competitive employment rate of the total sample was 55 percent (21/53) or 36 percent (reported in a table but not discussed). While the observations of client work status were not assessed at exactly the same points in time, it is nevertheless clear that a supported employment approach holds promise for at least some clients -- although the individual characteristics of who is most likely to benefit from supported employment have not yet been delineated.

While the data from these studies suggest the efficacy of at least some vocational rehabilitation programs, they do not address the issue of what variables determine who will benefit from the program. Researchers at a similar program conducted by staff at NYU, have recently analyzed such data from which will be reported here in a partial and preliminary form (Kay, Ezrachi, Cavallo, & Newman, 1988).

Researchers attempted to statistically "predict" the 6-month work status of 60 subjects who completed the NYU Head Trauma Program, based on a set of post-program variables including both neuropsychological tests and staff ratings. To reduce the number of predictive variables, factors were derived from the data set and entered into a multiple regression equation against a 10-point rating scale reflecting 6-month work status, with a resulting multiple  $r$  of .78.

Six factors emerged which contributed significantly to the variance. Three of the factors represented variables already identified as significant as in the spontaneous return to work literature: neurological severity (as measured by length of coma), physical ability (as reflected in manual dexterity), and cognitive capacity (verbal aptitude -- largely tied to pre-morbid learning). However, three of the significantly predictive factors reflected personal variables less associated with traditional cognitive performance: staff ratings of 1) self-awareness, 2) capacity for involvement with others, and 3) program acceptance. In fact the primary factor which accounted for most of the variance in predicting work status six months later was a clinical rating of the *extent of the subject's*

*acceptance of program demands.*

These results provocatively suggest that it is not just the client's intellectual capacities or the content of cognitive interventions but awareness and acceptance of one's deficits and the capacity and willingness to "give one's self over" to a prescribed routine that are variables related to successful return to work and the capacity to benefit from a formal program.

### COMPLICATING THE OUTCOME PICTURE: A CLINICAL PERSPECTIVE

#### Defining Outcome

Describing employment as the criterion of outcome is inherently problematic. Traditionally, "employment" or "work" connotes services performed in exchange for wages. There is tremendous variability within this definition, however, which must be taken into account in defining outcome criteria for vocational rehabilitation. At least five dimensions need to be considered.

First, there are *levels* of employment. Whether a former circuit court judge returns to work as a lawyer, legal assistant, clerk, or janitor certainly reflects different outcomes, even though they all constitute "employment". Second, employment varies in its *regularity*. Working two hours every other day is a different type of employment from working four hours every day or all day every day. Third, there are differences in *productivity*, both quantitative and qualitative; the amount of work a person with a head injury produces can vary in comparison to his co-worker, as may quality of work. Fourth, employment can vary in the amount of *structure* required to sustain it. At one extreme is the independent worker who needs neither ongoing nor periodic monitoring; at the other extreme is the worker in supported employment, who requires ongoing coaching and structure in order to perform the job. Intermediate levels of structure is most common, where increased structure and periodic monitoring are required to assure ongoing compliance with job demands. Fifth, employment varies in *temporal* aspects; outcome criteria cannot be limited to obtaining a job -- often it is much more difficult for persons with a head injury to maintain their jobs than for them to get them. These five aspects of employment need to be taken into account when defining outcome criteria for a competitive job placement of any given individual.

There is even a more basic difficulty with the concept of "employment," however. The conventional notion of work, in the sense of receiving wages at a competitive rate, is only a slice -- and a very narrow slice -- of the notion of social productivity. For better or worse, our society bestows social value based on what one does -- hence the most useful starter question with strangers at cocktail parties "What is your line of work?" A broader, and more humanistic, perspective might suggest that social productivity can take many forms, with the basic underlying requisite being that persons take part in an activity that is productive in some tangible or social sense and that gives a sense of self-worth through contributing to some effort larger than one's self.

From this perspective, apart from all the complexities of work for competitive wages, there are various forms of social productivity which should be considered legitimate "employment" outcomes. These would include working for a stipend or reduced wages in a special, non-competitive, but non-institutional setting; working in a sheltered workshop; doing a wide variety of useful volunteer activities without pay; and/or engaging in regular social activities that bring comfort and pleasure to one's self and others. We also tend to forget that learning, whether in the sense of formal school or not, or being the keeper and maker of one's home, whether female or not, are legitimate productive activities.

### **VARIABLES IMPACTING ON OUTCOME**

It is obviously inadequate to think that the only variables that impact on return to work, however we define it, are demographic, neurological, and neuropsychological as we might suspect from reviewing most of the research literature. The reality is that from a clinical point of view we need to consider a wide range of variables that bear on a person's capacity to return to work. Some of these are injury-related variables, and some are not.

#### **Injury-Related Variables**

A good neuropsychological evaluation is capable of providing solid initial guidelines for the process of vocational assessment, rehabilitation, and placement (Kay & Silver, 1988). However, beyond easily testable cognitive performance, a number of injury-related variables are potent contributors to vocational outcome. Four such factors are behavioral control, executive functions, compensatory capacities, and levels of self-

awareness and acceptance.

**Behavioral control.** This refers to the person's capacity to guide and control his or her own behavior in ways that are conducive to good interpersonal relations in the workplace. It does not mean the person is (or was) a nice, easy-going person. Plenty of successful workers do not exhibit these characteristics. It does, however, mean that organically disinhibited behavior, outbursts of anger, social inappropriateness, and catastrophic reactions to failure happen infrequently enough, or can be brought under sufficient control, to not disrupt normal working relationships. Most persons with a head injury lose their jobs not because they can't do the work but because they fail to deal successfully with their bosses and colleagues at an interpersonal level.

**Executive functions.** These are those planning and organizing processes that allow us to set realistic goals, based on an awareness of our own needs and capacities and environmental realities; to plan an efficient strategy for reaching that goal; to monitor ongoing behavior to see if we are on track; to realize when we are making errors, offending others, or otherwise veering off course; and to then adjust our own behavior accordingly. Executive functions allow us to plan and organize our environment, our days, and ourselves and to spontaneously remind ourselves when we are forgetting something important. They are notoriously disrupted after head injury, notoriously difficult to evaluate formally, notoriously ignored by naive rehabilitation specialists, and the bane of the worker with a head injury in the workplace.

**Compensatory capacities.** These refer to the person's willingness and ability to compensate for cognitive and behavioral deficits that cannot be remediated or avoided. In vocational rehabilitation we do much more teaching of compensatory strategies than actual remediation. We frequently engage the client in an ongoing process of assessing functional capacities in a vocationally-relevant situation, trying out compensatory changes in strategy or the environment, re-assessing how these improve functioning, and so on. An individual person's capacity for developing, accepting, and utilizing compensatory strategies is absolutely crucial to any level of re-employment after head injury.

**Self-awareness and acceptance.** These are crucial factors in outcome because they will determine the extent to which the client allows him or herself to be guided by the wisdom and experience of others. People may undergo a psychological transformation to find meaning and

dignity in altered goals. They furthermore must be sufficiently aware of the need for change, and to accept the compensatory strategies described above. This self-awareness refers not just to the deficits themselves, but to an appreciation of their functional implications, which is a much more abstract, and difficult, task. The acceptance is not the "it's-OK-with-me-that-I'm-head-injured" variety that never really occurs, but, in Yehuda Ben-Yishay's words, a "calm resignation" to the realities and necessities of one's new life. In our experience, clients who fail to turn this corner on awareness and acceptance will never be able to achieve the goal of sustained employment. Vocational rehabilitation programs which fail to address this need in a formal and systematic way are doomed to sending their clients through endless cycles of vocational chase and miss.

### **Non-Injury Variables**

A number of important variables that impact on vocational outcome have nothing to do with the injury and its consequences. These variables can be divided into person variables and environmental variables.

**Person variables.** We often fall into the trap of thinking that whatever we see in front of us in our client is the result of the injury. We are tempted to see all inconsistencies, disorganized activities, and botched employment attempts as results of acquired brain damage. This is not necessarily so. There are plenty of people who were inconsistent and disorganized, or persons with horrendous work histories before their accident. We must appreciate and ascertain the prior personalities, styles, successes, and failures of present clients before injury, for this information may tell us something about the raw material we have to work. This does not mean that persons cannot go beyond their pre-injury selves. It simply means that it's hard enough to return persons with head injury to the level of functioning they had prior to their accident, and it's that much harder to go beyond it.

Person variables have to do with more than negative personality traits. Furthermore, these variables also have to do with value systems, self-image, self-confidence, interpersonal capacities, and any other qualities that may influence the process of becoming productive again. Person variables also include special acquired skills, knowledge, or training that may be particularly useful to others in a work setting.

**Environmental variables.** In addition to person variables, there are certain variables in the environment which influence the likelihood of

return to work. These variables can be psychosocial, service-delivery, reimbursement, or employer-related.

Psychosocial variables include the person's family and network of friends. Family systems, when they exist, are extraordinarily influential in shaping the person with a head injury's chances for productivity, in positive or negative ways. At best, they can be powerful supports and allies of rehabilitation professionals. At worst, families can be suspicious, uninvolved, or downright subversive to a good rehabilitation plan, either by failing to reinforce essential messages, by imposing their own vocational value system on the person with a head injury, or by over- or underestimating that person's potential. Friendship networks can be equally influential, either positively by supporting the efforts of the head-injured person and accepting the person for who he or she is or negatively by abandoning the struggling person or, worst of all, by involving him or her in a destructive pattern of drug or alcohol use.

Service-delivery variables include the range and quality of vocational rehabilitation services available in the person's geographic area. This will vary greatly in different parts of the country and even within each state. Residential vocational programs located at great distances from the client's home often lose their effectiveness for lack of follow-up after placement. All other things being equal, the quality and availability of professional services can be major factors in return to work for persons with a head injury.

Even when excellent services are available, reimbursement is a variable that will determine whether persons can avail themselves of such services. The insurance policy one's family happens to have, whether the injury was work-related, and state laws governing insurance company liability can all indirectly influence vocational outcome.

Finally, employer-related variables make a difference. Environmental availability and luck both help determine whether a person with a head injury will be able to find the right niche in the employment world. Families of persons with head injuries who run their own businesses often benefit from special employment situations, as do persons in communities with a strong affirmative program and dedication to hiring persons with disabilities. All of these variables contribute to vocational outcomes and are often outside the control of the rehabilitation professional.



## WHAT IS SUCCESSFUL OUTCOME?

Having considered the complexities of defining employment and identified some of the variables contributing to outcome, let us turn our attention to considering what constitutes a successful vocational outcome.

In setting goals for our clients with head injuries, the greatest trap we can fall into is predefining success. Certainly we can aim high, and competitive employment can be an ideal we start with for all clients. If this goal is always our standard of success, however, we will be missing the boat. Each person with a head injury comes to us with a certain potential for employment, which is a combination of injury-imposed limitations, pre-existing personality capacities, and environmental realities. Our challenge is to help the person actualize and reach that potential, but we cannot exceed or change each individual's potential. All of our efforts at cognitive remediation, behavioral change, awareness and acceptance, and job skill training are attempts to actualize pre-existing vocational potential by removing post-injury interference and barriers and to provide the client with tools to utilize his or her inherent capacities.

From this point of view, we need to define success individually for each client, but the definition of a successful outcome can emerge only through the *process* of vocational assessment and intervention. The medical model of "diagnose and treat" cannot be adopted wholesale to the vocational rehabilitation of persons with head injuries. Vocational goals cannot be set immediately, and successful outcomes can only be gradually defined within an individual evolutionary process.

For the now dependent young woman, who was an executive secretary, making a daily trip alone to two hours of volunteer work may be as dignifying and as successful an outcome as the former lawyer's finding a part-time job as a legal assistant. Society may value them differently, but from a vocational point of view, each person may be actualizing his or her potential to the fullest, and therefore the outcomes are equally successful. This does not mean that the young woman should stop striving toward something more challenging. It does mean that we must set our criteria for success according to the capacities of each of our clients and make sure that we neither overestimate nor underestimate these nor stop short of providing whatever it takes to help clients reach their potential.

As a final note on successful outcomes, it should be realized that for persons with a traumatic brain injury, successful vocational outcome does not end with placement. Part of the notion of success must include sustained employment regardless of the level of productivity. The person with a head injury who has 12 jobs in 10 years has multiple failures, not multiple successes. Part of the planning in vocational rehabilitation and job placement must include ongoing monitoring, follow-up, and the willingness and capacity to intervene to head off crises which could jeopardize job maintenance.

### **REHABILITATION OUTCOMES AND SELECTION CRITERIA: WHAT WORKS FOR WHOM?**

Let us conclude by asking the most basic of questions: how do we know what works for whom? This question has both the most complex and the most simple of answers. All we can do in any individual case is guide the evolving potential of the person toward the most productive outcome. The challenge from a research point of view is to systematically determine 1) how to identify the potential of each client, 2) what vocational goals are appropriate to varying levels of potential, and 3) given each level of potential and its corresponding desired outcome, what is the best rehabilitation method for reaching that goal?

To adopt this seemingly simplistic approach would require making some basic changes in how we operate and how we think. It would mean, for example, that we stop asking questions like "Does supported employment work for persons who have sustained a head injury?" and replace it with questions like "For which head injured clients, in what situations, and in what form, does supported employment work?" This reframing of the question would force us to develop a taxonomy of vocational rehabilitation techniques linking client selection criteria, intervention techniques, and desired outcomes. It may be that supported employment will work with cognitively higher-level clients who have adequate behavioral control and with cognitively lower-level clients who have learned awareness of their deficits and are willing to cooperate with learning compensatory strategies on a job originally beneath their expectations. On the other hand, supported employment may be an abysmal failure as long as cognitively impaired persons are actively resisting training in compensatory strategies or for any clients with behavioral dyscontrol. In such a scenario, each situation would require a different approach at different times for clients with different needs. The person with severe cognitive limitations may need a period of time

to develop awareness and acceptance before he or she is ready for supported employment. The person with less serious cognitive limitations may need to bring his or her outbursts under control before being introduced to the work site, while others may benefit immediately from on-the-job coaching.

Such an approach would also lead to the desirable situation where vocational rehabilitation programs would become more flexible, offering a wider range of options and approaches, in order to serve a wider range of clients or conversely would maintain a more narrow approach and specialize in serving clients within a particular range of capacities and needs. A corollary of this approach would be that approaches that were successful in one center with a particular type of client would be adopted by other centers in serving clients with similar needs and goals.

In summary, we need to do three things in order to effectively serve persons with severe disabilities resulting from traumatic brain injury: 1) broaden our criteria for successful outcomes to include both a wider range of social productivity and the concept of sustaining, not just obtaining, employment; 2) determine the individual potential of each client and individually define a corresponding criterion of vocational "success" for that person; and 3) develop a taxonomy of flexible approaches that lawfully links criteria for selecting particular clients to the delivery of particular interventions in a particular sequence, in order to meet individually selected vocational goals.

Establishing such a taxonomy would eliminate the fruitless competition between similar programs, as well as eliminate the approach of picking up whatever tool is closest at hand. Hopefully, such a taxonomy would allow us to select interventions to meet the needs of clients, rather than the reverse process of selecting clients to meet the needs of existing programs.

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56 / *Selection and Outcome Criteria*

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## *Chapter 3*

# **NEUROPSYCHOLOGICAL EVALUATION OF PERSONS WITH TRAUMATIC BRAIN INJURY**

**Lance E. Trexler, Ph.D.**

## INTRODUCTION

The application of traditional vocational assessment and rehabilitation strategies designed for persons with developmental disorders has resulted in disappointing outcomes for persons with traumatic brain injury (TBI). The effects of traumatic brain injury are different from, for example, mental retardation or cerebral palsy because (a) the impairments were acquired after a period of normal development and (b) the effects of traumatic brain injury on the brain are unique. Consequently, new approaches to the vocational assessment and rehabilitation for the person with traumatic brain injury are beginning to evolve.

Long-term adaptation has been shown to be determined primarily by the pervasiveness of cognitive and behavioral disorders following traumatic brain injury. McKinley, Brooks, and Bond (1981) demonstrated that cognitive and behavioral disorders following traumatic brain injury resulted in significantly more stress for families than the residual physical disorders. Further, these cognitive and behavioral disorders are more prevalent and disabling than physical disorders caused by traumatic brain injury (Brooks, Campsie, Symington, Beattie, & McKinley, 1987). The latter investigators followed 134 persons with brain trauma injuries for seven years and found that 73 percent evidenced personality change and 67 percent had significant difficulties controlling emotions. Cognitive impairments of attention and concentration were present in 57 percent of the sample, and memory disturbances were present in 67 percent, seven years post-injury. Similarly, Lezak (1987) found pervasive disturbances of psychosocial adjustment in 30-40 percent of persons with traumatic brain injuries in her study, including difficulties in social isolation, depression, impaired initiative, and poor affective control three years following traumatic brain injury. Finally, Thomsen (1984) found that 84 percent of families complained of significant personality change ten to fifteen years post-injury. Although all of the aforementioned studies dealt primarily with persons who sustained a severe brain injury, similar, although less intense, symptoms are noted when examining persons with milder brain injuries (Kay, 1987).

Cognitive and behavioral disorders following moderate to severe traumatic brain injury have been shown to have a substantial effect on vocational outcome. Brooks, McKinley, Symington, Beattie, and Campsie (1987) found that only 29 percent of traumatic brain injury survivors who were employed pre-injury were employed seven years

after injury. Further, these investigators found that 50 percent who had a management level occupation pre-injury had returned to work, 33 percent of skilled workers had returned to work, and only 21 percent of unskilled workers returned to work. Brooks, McKinley, Symington, Beattie, and Campsie (1987) reported that 39 percent of traumatic brain injury victims who were less than 45 years of age returned to work, whereas only 12 percent of those over the age of 45 returned to work. Finally, it was demonstrated that the severity of physical disability did not predict return to work, but the presence of severe disturbances in cognitive functions and behavioral or emotional functioning was almost always associated with a failure to obtain gainful employment.

Almost identical return-to-work rates were found by Jacobs (1988). This investigator conducted a follow-up study on 142 persons with histories of severe traumatic brain injury who were one to six years post-injury. Of the subjects who were employed at the time of their injury, 27 percent were employed post-injury. An additional 13 percent had returned to work but lost their job prior to the follow-up interview. Further, this investigator demonstrated that 37 percent of those working post-injury were employed by the same employer for whom they worked prior to injury.

Another study by Sale, West, Sherron, and Wehman (1991) found that out of 78 supported employment placements of persons with traumatic brain injury, there were 38 job separations. These investigators determined that neuropsychological disturbances were the primary reason for job separation in 32 percent of the 38 job separations and were a contributing factor in up to 45 percent of the job separations.

These findings suggest that (1) return-to-work rates for survivors of traumatic brain injury is approximately 30 percent and (2) the predominant cause for failure to return to work, or maintain employment, is the presence of significant cognitive and emotional/behavioral disorders. The act of conducting a neuropsychological evaluation which includes assessment of these critical variables and their potential impact on work and psycho-social interaction is a critical element in the vocational assessment and rehabilitation of the person with traumatic brain injury.



## **NEUROPSYCHOLOGICAL AND COGNITIVE DISORDERS FOLLOWING TRAUMATIC BRAIN INJURY**

The neuropsychological (also referred to as neurobehavioral) and cognitive effects of traumatic brain injury are extraordinarily heterogeneous and are largely dependent upon pre-injury factors (i.e., education, vocational experience, psychosocial adaptation), injury factors (i.e., length of coma and post-traumatic amnesia, presence of seizure disorder), and post-injury environmental factors (i.e., amount of stimulation, family support, adequacy of medical and rehabilitative care). Further, the type and extent of physical and cognitive disorders following traumatic brain injury are largely determined by how severely the brain is injured. Traumatic brain injury can occur through many different mechanisms including (a) diffuse axonal injury, (b) hypoxic-ischemic injury, and (c) focal cortical contusion and hemorrhage. Whereas other mechanisms of injury also exist, these three types of trauma are the most common and devastating with respect to brain function.

Traumatic brain injury results in relatively diffuse injury to the brain through diffuse axonal injury (DAI), which refers to either the frank shearing of the nerve cell axon or a disruption of the axon's ability to function. Experimental research has shown that particularly the brainstem, corpus callosum, and subcortical white matter are most vulnerable, as these brain regions are largely composed of neurons with long axons. Diffuse axonal injury in these areas of the brain are likely to result in impairments of alertness, attention, speed of cognitive functioning and memory, and may give rise to motor deficits as well.

Diffuse damage to the brain in traumatic brain injury also occurs through hypoxia and ischemia. Hypoxia (decreased oxygen saturation) to the brain affects particularly the cerebral cortex (or gray matter), the hippocampus in the medial aspect of the temporal lobes, and the cerebellum. Ischemia (decreased blood flow) of brain tissue can be widespread but may differentially affect the hippocampi, as well as the basal ganglia (masses of gray matter embedded in the cerebral hemispheres). The consequences of hypoxic-ischemic injury in traumatic brain injury prototypically include significant motor deficits as well as impairments in new learning, memory for recent events, and intellectual functions.

Focal cortical contusion (FCC) and hemorrhage result in more focal damage to the brain, depending upon the exact site or location of the

injury. The most frequent sites for focal cortical contusion are the poles of the frontal and temporal lobes because of their tendency to impact against the rough, uneven surfaces of the skull. Hemorrhages occur because of the distortion or tearing of the artery wall, which results in the formation of a blood clot or hematoma, and can be on the outside of the brain tissue (extracerebral) or within the brain tissue (intracerebral), the latter of which is more destructive. Focal cortical contusions of the temporal lobes can result, as mentioned earlier, in impaired learning and memory functions.

Although controversy exists as to whether there is modality-specific lateralization of memory processing in the brain, for sake of simplicity, the following generalizations can be made regarding common injury types. Injury to the left temporal lobe often results in impairments of verbal learning and memory and, depending upon the severity of injury, impairments of auditory attention and discrimination, along with disturbances of language. Right temporal lobe damage most commonly results in impairments of visual learning and memory, but it can also result in visio-spatial perceptual defects. Injury to the surfaces of the frontal lobes can result in a variety of cognitive and neurobehavioral disturbances; cognitive disorders frequently associated with frontal lobe injury include distractibility, loss of abstraction skills and problem-solving abilities, a lack of organizational strategies and a dependence on external structure, impaired initiation of action (despite intact ability to verbalize the need to take action), and impaired mental flexibility. Neurobehavioral disorders often resulting from frontal lobe injuries include impulsivity, dysregulation of affect, a lack of insight or awareness, and inadequate self-monitoring or self-control in a social context.

Because the various mechanisms of trauma to the brain cause somewhat similar damages to the brain, it should be remembered that there is significant heterogeneity among people with traumatic brain injury and that the neuropsychological evaluation is an assessment of individual differences which might be present. Also, it should be noted the more severe the traumatic brain injury, the greater the extent of diffuse axonal injury and the greater likelihood that effects of other injury mechanisms (focal cortical contusion, hemorrhage, hypoxia, ischemia) are present. Therefore, mild traumatic brain injury results in mild to moderate disturbances of primarily cognitive functions, whereas severe traumatic brain injury often results in more complex, multi-faceted disorders of cognition, neurobehavioral status, motor and sensory

functioning, as well as language and perceptual functioning.

Table 1 summarizes common cognitive disorders, and Table 2 summarizes predominant neurobehavioral disorders following traumatic brain injury. Finally, traumatic brain injury can result in a number of more specific emotional and psychosocial disturbances which can occur in isolation from or in association with the previously mentioned disturbances. These specific neuropsychological disturbances are in part summarized on Table 3.

**Table 1**  
**Predominant Disorders of Cognition**  
**Following Traumatic Brain Injury**

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Distractibility

Decreased vigilance, speed, and capacity of cognitive functions

Impaired episodic and prospective memory

Impaired initiation, flexibility, and organization of thought and behavior

Dissociation of intent and action

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**Table 2**  
**Predominant Neurobehavioral Disturbances**  
**Following Traumatic Brain Injury**

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Disregulation of affect and motivation

Lack of awareness

Mood swings

Increased frustration, irritability, and decreased tolerance

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### **Emotional and Psychosocial Disturbances**

The rapidity of occurrence and the extent of disability following traumatic brain injury make psychological adjustment an arduous task. Further, the cognitive functions which enable awareness, judgment, and problem-solving are likely impaired by traumatic brain injury, making the process of psychological adjustment even more formidable. As previously mentioned, Lezak (1987) has demonstrated that 30-40 percent of traumatic brain injury patients demonstrate pervasive disturbances of psychosocial adjustment.

**Table 3**  
**Predominant Emotional and Psychosocial Difficulties**  
**Following Traumatic Brain Injury**

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Lack of awareness of disability and lack of acceptance

Depression and anxiety disorders

Loss of relationships and intimacy

Social detachment and isolation

Loss of meaning

Loneliness and withdrawal

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Reactive emotional changes such as depression and anxiety disorders, particularly when accompanied by physical, cognitive, and neuropsychological disturbances, have a profound impact on interpersonal relationships. Christensen, Pinner, Pederson, Teasdale, and Trexler (in press) demonstrated that many people who were living with significant others returned to live with either parents or siblings after intimate relationships collapsed. Further, these individuals were shown to have significant reductions in leisure activities after brain injury, especially those which were performed outside of the home with other people.

The long-term psychosocial behavior of many traumatic brain injury survivors is characterized by a loss of intimate relationships and social withdrawal. Research demonstrates that the negative coping strategies utilized by persons with a traumatic brain injury to compensate for cognitive defects may interfere with interpersonal communication and psychosocial adaptation. Specifically, Moore, Stambrock, and Peters (1989) demonstrated that persons with a traumatic brain injury who use coping strategies of avoidance and distancing, for example, had poorer psychosocial functioning than those who used positive reappraisal or those who used coping strategies designed to control their environment.

Because of the long-term emotional and psychosocial difficulties that the traumatic brain injury survivor experiences (see Table 4), psychotherapy is often an integral component of neuropsychological evaluation and vocational rehabilitation.

**Table 4**  
**Possible Specific Neuropsychological Disorders**  
**Following Traumatic Brain Injury**

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Reduced attention and concentration	Memory and recall problems
Decreased speed of mental processing	Self regulation problems including difficulties in planning, organizing, and executing activities
Decreased word finding (dysnomia)	Visual field cut (homonymous hemianopsia)
Loss of expressive or receptive language (dysphasia)	Inattention to one half of the visual field (hemispatial neglect)
Impaired sequencing of complex movements (dyspraxia)	Impaired visuoperceptual discrimination, visuoconstructive organization and spatial orientation
Impaired reading (dyslexia), writing (dysgraphia) or calculations (dyscalculia)	Impaired interpretation or expression of emotions (dysprosodial)

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As discussed by Prigatano and Klonoff (1988), the process begins with the neuropsychological assessment. At this juncture, results should be interpreted to the person and family in an educational manner so as to assist their understanding of the cognitive and neurobehavioral effects of the brain injury and the effects on everyday functioning. As both the individual's and the family's awareness of the effects of the injury become more apparent, significant emotional reactions are predictable. Nonetheless, neuropsychological assessment, as applied to vocational rehabilitation, should thoroughly address the issues of awareness and acceptance. Ezrachi, Ben-Yishay, Kay, Diller, and Rattock (1991) have demonstrated that the two most important predictors of vocational outcome for persons with traumatic brain injury were (a) level of awareness of cognitive disturbances and (b) acceptance of their existence.

### **NEUROPSYCHOLOGICAL ASSESSMENT IN TRAUMATIC BRAIN INJURY**

Clinical neuropsychology, stated simply, is the study of brain-behavior relationships in persons with known or suspected impairments of brain function, due to a variety of neurologic disorders or conditions. Neuropsychological assessment may be performed to assist in determining if a person has brain dysfunction (e.g., dementia, mild head injury). In cases of known brain damage (e.g., stroke, severe head trauma), neuropsychological assessment may be utilized to determine:

1. What brain functions may be impaired or spared by the damage;
2. The severity of the impairments;
3. The prognosis for recovery and long-term adaptation;
4. A baseline for the monitoring of recovery;
5. The need for rehabilitation and the approaches to be used in rehabilitation or case management; and
6. The degree of competence present to manage one's own affairs.

The scope of the neuropsychological assessment can vary substantially, depending upon the nature of the referral question. However, in most instances, assessment of a broad scope of different cerebral functions is required to ensure that the assessment does not omit important cerebral functions or miss significant deficits or intact skills and abilities. Some of the major cerebral functions assessed by the neuropsychological examination are provided in Table 5, although this list is not by any means inclusive.

**Table 5**  
**Major Clinical and Cerebral Functions Assessed**  
**in the Neuropsychological Evaluation**

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**MEDICAL HISTORY**

Developmental and adult illness/injuries	Medications
Neurologic and neuroradiologic examinations	Duration of unconsciousness and retrograde and post-traumatic amnesias
Symptom history and onset	

**NEUROBEHAVIORAL AND PSYCHOLOGICAL STATUS**

Awareness and acceptance of deficits	Emotional status
Psychosocial and interpersonal adjustment	Coping skills
	Family adjustment/support

**SENSORY AND MOTOR FUNCTIONS**

Visual sensitivity	Motor speed
Auditory sensitivity	Motor strength
Tactile sensitivity	Coordination and dexterity

**PERCEPTUAL AND LANGUAGE FUNCTIONS**

Visuoperceptual discrimination	Naming abilities
Visuoconstructive organization	Word fluency
Visual scanning and attentiveness	Receptive and expressive language
Visual sequencing	
Reading, writing, and arithmetic skills	

**COGNITIVE FUNCTIONS**

Orientation	Ability to learn new information
Vigilance and concentration	Visual and verbal memory
Mental control and flexibility	"Short" and "long" term memory
Abstraction and problem-solving organizational strategies	

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## **Different Approaches to Neuropsychological Assessment**

The primary impetus for the development of neuropsychological assessment procedures in the 1950s and 1960s was to assist in neurologic diagnosis. As more recent technologies such as computerized axial tomography (CAT) and magnetic resonance imaging (MRI) were not available, the neuropsychological assessment was used to assist in determining if brain damage or dysfunction was present, and if so, what type of damage it was (e.g., stroke, tumor) and where in the brain it was located. Two rather different approaches to neuropsychological assessment simultaneously evolved: the test battery approach and the person-centered approach.

### **The Neuropsychological Test Battery Approach**

The first battery to be developed was the Halstead-Reitan Neuropsychological Test Battery (Reitan & Wolfson, 1985). The tests which comprised this battery of tests were included based upon their statistical contribution to reliably detect the presence of brain damage. In the battery approach to neuropsychological assessment, all the tests in the battery are administered in a uniform, standardized manner to all subjects. The scores on each test are further combined into an overall impairment index, which provides a rating of the presence and severity of brain damage. Neuropsychological assessment with the Halstead-Reitan Test Battery typically includes the administration of the Wechsler Adult Intelligence Scale-Revised (Wechsler, 1981) and the Wechsler Memory Scale (Wechsler, 1945). It was initially advocated that the neuropsychologist should not interview the patient so as to not "bias" the objectivity of test score interpretation.

The interpretation of neuropsychological test data, particularly within a battery approach, relies on different methods of inference, as outlined in Table 6, and relies almost exclusively on the test scores obtained. However, one method of interpreting neuropsychological data, referred to as pathognomic signs, does involve a qualitative judgment on the part of the neuropsychologist as to the adequacy of the examinee's performance. These statistical, quantitative, and standardized methods of obtaining and interpreting neuropsychological data were developed to ensure that reliable results were obtained and that reliable interpretations were made with respect to (a) the presence or absence of brain damage, (b) if present, the type of brain damage, and (c) the location of the brain damage.



**Table 6**  
**Methods of Interpreting Neuropsychological Test Data**

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<b>NORMATIVE COMPARISONS:</b>	Comparison of patient's test scores to normative data for persons with no brain damage
<b>RIGHT-LEFT DIFFERENCES:</b>	Comparison of performance on tests (i.e., motor and sensory) of both sides of the body
<b>PATHOGNOMONIC:</b>	Analysis of particular types of errors that persons with brain damage often exhibit (i.e., difficulties copying the figure of a cross)
<b>PATTERN ANALYSIS:</b>	Determining if the overall pattern of test scores is consistent with the known effects of a neurologic disorder (i.e., stroke, traumatic brain injury)

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### **The Neuropsychological Person-Centered Approach**

While the fixed battery approach to neuropsychological assessment was being developed in the United States, a different approach was simultaneously evolving in the Soviet Union, as pioneered by Alexander Luria (Luria, 1973; Luria, 1980). This approach to the neuropsychological investigation of brain function was later organized and articulated by Christensen (1974). While the overriding purpose of the Luria Neuropsychological Investigation bears resemblance to the battery approach in terms of the diagnosis of the presence, location, and etiology of brain damage, the methods are entirely different. The Luria Neuropsychological Investigation offers a variety of core tests which are systematically administered, but each evaluation proceeds differently according to the individual client and his/her responses. Rather than seeking a quantitative score on the test, the examiner in the Luria approach seeks to discover how the patient goes about performing the task and whether or not the strategy utilized results in a successful

performance. When deficits are discovered, the examiner may manipulate the requirements of the task to determine the underlying reason for failure on the task as well as to determine if by modifying the requirements of the task, the patient is able to perform more successfully.

Observations about how the patient goes about performing the task, the types of errors made, and the use of alternative strategies to complete the task provide information about the qualitative (as opposed to statistical-quantitative) aspects of the person's neuropsychological functioning. Further, in the Luria approach, the examiner must directly examine the person, and each examination is unique and individualized and is guided by the theoretical training and clinical experience of the neuropsychologist. Finally, with the person-centered approach to neuropsychological assessment, the examiner is constantly giving the examinee feedback as to the quality of his/her performance while the examiner is carefully observing the person's emotional reactions, awareness, and behavioral adaptation.

### **New Developments and Practices in Neuropsychological Assessment**

Many contemporary clinical neuropsychologists draw upon both approaches to neuropsychological evaluation and also use their own hybrids of tests and procedures. Further, many neuropsychological tests that are not part of a battery have been developed for the examination of specific cerebral functions. The reader is referred to Lezak (1983) for a comprehensive review of neuropsychological assessment and available tests.

The objectivity of the more statistically based standardized tests allows for quantification and reliable judgments about the severity or level of impairment as compared to similar persons in terms of age or education who do not have brain damage. Moreover, since many individuals with acquired brain lesions, particularly traumatic brain injury, are involved in litigation, objectification and quantification are desirable. On the other hand, the patient-centered approach provides abundant qualitative information which is relevant for rehabilitation. This approach allows for a better understanding of how to modify the person's strategic approach to a task so as to enhance performance or outcome; it also gives an understanding of their emotional reaction, insight, and ability to benefit from or utilize feedback. Within this

approach to neuropsychological assessment, the treatment and vocational rehabilitation processes begin with the assessment.

New neuropsychological tests have been developed by Kaplan and her colleagues (Kaplan, 1983; Milberg, Hebben, & Kaplan, 1986) which have been referred to as the "process-approach" and combine the Test Battery and Person-Centered approaches. For example, Kaplan has modified the Wechsler Adult Intelligence Scale to enhance its utility in neuropsychological assessment (Kaplan, Fine, Morris, & Delis, 1991). Kaplan has developed objective, quantifiable scoring methods to assess important qualitative and strategic aspects of the individual's performance. Cohen and Mapou (1988) have addressed the value of this approach to rehabilitation planning for persons who have sustained a traumatic brain injury. Further, more neuropsychological tests have recently been developed which are designed to assess real-life, functional situations, such as memory for names (Wilson, Cockburn, & Baddeley, 1985). These tests have been developed to more accurately assess how a given impairment may affect the person's ability to function in everyday circumstances.

In addition to utilizing a variety of neuropsychological tests, the contemporary clinical neuropsychologist will review relevant medical and sometimes school records as well as conduct a clinical interview with the person and his/her family to determine present emotional status, the level of adaptation at home, and observations of family members. Formal personality evaluation is also usually included in neuropsychological evaluation.

### **Dynamic Aspects of Cognitive Functioning: Biological, Psychological, and Environmental Conditions**

Investigations have demonstrated, as previously reviewed, that impairments of cognitive functions following traumatic brain injury have a significant impact on vocational outcome. Cognitive functions do not exist, however, in a vacuum. Rather, they operate in context of ever-changing biological, psychological, and environmental conditions, for both brain-damaged and non-brain-damaged individuals. Cognitive functions cannot be viewed as static, invariant properties of an individual as measured in a testing office, no more so than height or weight over a person's life cycle. Table 7 provides some examples of how these biological, psychological, and environmental conditions may influence cognitive functions.

Understanding and describing the dynamics of human cognition represent new challenges to clinical neuropsychology. Some of the neuropsychological tests developed by Kaplan and her colleagues systematically vary certain environmental conditions so as to examine the effect on the client's functioning. For example, when administering the California Verbal Learning Test (Dellis, Kramer, Kaplan, & Ober, 1987), the examiner provides specific types of cues to the patient to determine if this enhances recall of a previously learned word list.

**Table 7**  
**Examples of Biological, Psychological, and Environmental**  
**Conditions Which Influence the Cognitive Functions**  
**of Brain Damage**

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**BIOLOGICAL:**

Fatigue may exacerbate deficits in concentration and memory

Central Nervous System - active medications may slow recovery and exacerbate cognitive deficits

**PSYCHOLOGICAL:**

Depression exacerbates cognitive disorders

Difficulties in emotionally accepting disability may limit response to rehabilitation and long-term adaptation

**ENVIRONMENTAL:**

Support and involvement of the family may result in better long-term adaptation.

Early rehabilitation results in better outcome

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In the Block Design subtest of the WAIS-R as a Neuropsychological Instrument, the examiner may provide a "grid" or structure to a visio-spatial configuration to determine if this environmentally derived

structure assists the examinee in organizing his/her reconstruction of the design. These types of systematic manipulations of the test allow for a determination of the extent to which changes in the environment (test stimuli) enhance or inhibit the person's functioning, which thereby lays a neuropsychological foundation for the rehabilitation process. The manipulation of biological and psychological conditions in clinical neuropsychology represents an untried, yet potentially very important, line of investigation.

### **NEUROPSYCHOLOGICAL ASSESSMENT IN THE VOCATIONAL REHABILITATION OF THE PERSON WITH TRAUMATIC BRAIN INJURY**

The need for a specialized approach to the vocational rehabilitation of persons with traumatic brain injury has brought many new challenges to vocational rehabilitation counselors, neuropsychologists, and rehabilitation therapists. In the rehabilitation setting, the contributions of clinical neuropsychology have expanded beyond neurologic diagnosis and now play a major role in the rehabilitation process. Some authors have now drawn a distinction between diagnostic neuropsychology and interventive neuropsychology (Gross & Schutz, 1986). However, certain aspects of diagnostic neuropsychology continue to be vital for successful rehabilitation planning.

#### **Differential Diagnosis**

The neuropsychological evaluation can address three levels of differential diagnosis, depending upon the nature of the referral question and the clinical situation.

**Neurobehavioral Diagnosis.** The previous discussion detailed how traditional clinical neuropsychology was primarily focused on assisting the neurologist with neurological diagnosis. However, with the advent of new neuroimaging techniques, the neurologist does not need to rely on the neuropsychological examination to determine if some lesions are present, and if present, their location in the brain. However, neuroimaging techniques are not able to image some pathologies affecting the brain (for example, early stage dementia or possible mild head injury) as the effects of these pathologies are microscopic. Therefore, a neurologist may still request neuropsychological examination to differentiate, for example, possible dementia from depression or mild head injury from an anxiety disorder.

**Differentiation of Cognitive Deficits.** Human cognitive functions, such as memory, language or problem-solving abilities, are highly complex and interdependent, and the neuropsychological examination must provide a differential diagnosis with respect to the underlying cognitive difficulty. As an example, if a person has a deficit in language comprehension, he may perform poorly on a task of memory because he did not understand the instructions. Therefore, the neuropsychologist has to differentiate the influence of one deficit on the performance of other tasks which are dependent upon that ability or function.

The other type of differential diagnosis required to clarify cognitive difficulties has to do with the hierarchical level of cognitive functions. Higher-order cognitive functions are dependent upon the functional integrity of lower-order cognitive abilities. For example, if a person has a problem with basic attention and concentration, it can be anticipated that this person will perform poorly on measures of memory functioning, as it is necessary to successfully encode the information before it can be stored and hence remembered. As another example, a deficit in visual perception may impair the ability to read.

In deriving rehabilitation plans, the neuropsychological examination can provide necessary information regarding the underlying cognitive deficits. The neuropsychologist cannot merely list "deficits" but rather must interpret test data in a manner which identifies the reasons for the person's performance on a variety of tests. Poor performance on a test of complex cognitive functions may occur for a variety of reasons. Therefore, stating that a deficit exists is simply not adequate information for the person who must use the neuropsychological evaluation report for rehabilitation planning.

**Differentiation of the Effects of Injury From Non-Injury.** Complex human behavior, (e.g., working) relies on multiple cerebral functions, and vocational disability can be caused by a variety of problems in cognitive functions. A neuropsychological examination should identify the reasons for which the person may be vocationally disabled. However, cognitive functions can be "impaired" because of non-injury factors. For example, the memory functions of a person with traumatic brain injury may be exacerbated secondary to depression or by medications known to affect attention, concentration, and memory. Severe anxiety disorders may prevent the person from effectively concentrating on a particular task. These non-injury factors may mimic cognitive disorders caused by trauma damage. On the other hand, non-

injury factors may mask the effect of the brain injury.

A person with a very high pre-injury vocabulary may have "normal" levels on a test of vocabulary, which still could represent a relative weakness for this person when compared to his/her other abilities. The neuropsychologist, therefore, cannot just compare the scores to the available normative data for that particular test but rather must interpret neuropsychological data in light of knowledge of the individual's history and present environment.

Certainly the derivation of a rehabilitation plan for the survivor of traumatic brain injury is dependent on (a) a clear neurobehavioral diagnosis, (b) a definitive analysis of the underlying or core deficits in cognitive functions (not a listing of poor test performances), and (c) differentiation of injury and non-injury determinants of cognitive functioning.

### **Utilizing Strengths in the Application of Rehabilitation Strategies**

It is not enough to just describe deficits in vocational rehabilitation planning. Successful vocational rehabilitation is more dependent upon a methodology to use preserved or spared abilities. Consequently, a neuropsychological examination must be a dynamic process so as to identify spared abilities or compensatory strategies to use to circumvent or compensate for acquired neurobehavioral problems. In this context, the neuropsychological examination should provide information regarding not only why a vocational disability exists but how it can be treated or managed. Job placement and job site training are dependent upon the utilization of this type of rehabilitation strategy (Kreutzer, Wehman, Morton, & Stonnington, 1988).

Through a patient-centered individual approach to neuropsychological assessment, the examiner observes (a) specific strategies which the person spontaneously uses, (b) the success obtained through the use of spontaneous strategies, and (c) the extent to which improvements in performance can be reached through the use of different strategies. For example, some people may overtly or covertly verbalize or "talk themselves" through a task (particularly those with intact language functions) which can significantly enhance performance. If not spontaneously utilized, the examiner may encourage the person to utilize this strategy to determine to what extent this may influence task

performance. Learning of new information or work tasks may be enhanced by teaching the person to organize the information to be learned according to categories or clusters of information which are related according to the quantity of information the person attempts to learn at any one time. Utilization of these "chunking" strategies may enhance learning and recall with some people, thereby providing a basis for a rehabilitation approach which could be implemented in the vocational setting.

### **Correlation of Neuropsychological Findings With Job Analysis: Identifying Generic and Specific Job Skills**

The neuropsychological assessment can yield not only information applicable to the strategies which might be utilized in vocational rehabilitation but information as to the type of employment which best suits the individual's strengths and weaknesses. The neuropsychological findings can be correlated with the skills necessary to perform a given job. Job development can emphasize the person's strengths and minimize areas where significant difficulties are unlikely to be managed, improved, or modified through the use of compensatory strategies. For example, persons with severe perceptual or visuoconstructive problems are unlikely to work successfully as architects. Conversely, significant impairment of language and communication abilities will likely contraindicate a sales job as a viable vocational goal. Many people have difficulty accepting a job which they feel is beneath their abilities and vocational potential; when the neuropsychologist feels that job goals are grossly out of line with realistic potential, suggestions for addressing these issues in subsequent rehabilitation planning should be addressed in the evaluation report.

Job analysis requires investigation of generic and specific skills. Regardless of the exact nature of the job, certain requirements tend to be universal, such as time orientation, basic appearance and hygiene, and functional ambulation in the work environment. Other generic skills which can be problematic include orientation to the work space, memory for instructions, and learning of basic policies and procedures. Persons with greater experience working prior to their injury are less likely to have impairments of these generic skills, as a traumatic brain injury does not typically result in loss of memory for these types of procedures or learned customs or practices. However, emotional, neurobehavioral, and cognitive disturbances can impair the person's ability to fulfill even these



generic skills required for competitive employment. If such is the case, these issues should be addressed either in the clinical environment or during job site training, depending upon the severity of the problem and flexibility of the work environment.

Any job has specific job skills, which may require minimum motor, perceptual, language, or cognitive functions. If a person exhibited these specific skills pre-injury, the rehabilitation process may be less complicated than if the person is required to learn new job skills. The neuropsychological evaluation is important in determining the extent to which these specific skills exist or in determining the compensatory strategies or methods which can be used to teach specific job skills.

### **SUMMARY**

Traumatic brain injury results in a variety of work related problems, but those which have been found to be the greatest impediments to competitive employment are impairments of cognition, neurobehavioral functions, and emotional and psychosocial adaptation. These impairments result from a variety of pathophysiological mechanisms affecting the brain, including diffuse axonal injury, hypoxia and ischemia, and focal cortical contusions. The most predominant neuropsychological disturbances following traumatic brain injury are of attention, memory, dysregulation of affect and intention, slowed mental processing speed, lack of acceptance, and lack of awareness. The neuropsychological evaluation in vocational rehabilitation needs to provide a variety of diagnostic information, including (1) neurobehavioral diagnosis, (2) differentiation of cognitive disorders, and (3) differentiation of the effects of injury from other non-injury influences on cognitive functioning. It is not so important which neuropsychological tests are administered, but rather how they are administered and interpreted and how the information is used. Successful vocational rehabilitation of the person with a traumatic brain injury relies upon the use of present strengths of the individual or the development of compensatory strategies. Job development and job training should rely upon the neuropsychological examination to assist in determining what types of work tasks and work environments are most likely to result in successful job performances and adaptations to work.

The literature associated with vocational outcome demonstrates that without specific intervention, only approximately 30 percent of persons with a traumatic brain injury become competitively employed. However,

with the development of specialized evaluation and rehabilitation services, greater success has been demonstrated. Neuropsychological evaluation and rehabilitation practices have evolved from the point of simply identifying problems and deficits to the point of suggesting prescriptive programming. As the role demanded of the neuropsychologist continues to change, vocational specialists should expect neuropsychological evaluation reports to provide treatment and training strategies that can be applied to the work place.

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*Section II*

**MODELS AND APPROACHES  
IN COMMUNITY-BASED  
EMPLOYMENT**

## *Chapter 4*

### **BRAIN INJURY REHABILITATION IN SMALL TOWNS AND RURAL COMMUNITIES**

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The development of vocational rehabilitation programs for persons with traumatic brain injuries (TBI) residing in rural areas presents a complex set of challenges. Emergency and acute care in rural environments are typically adequate (with the possible notable exception of remote rural areas); however, post-acute rehabilitation services are less available. Community re-entry and employment services for this population are the exception rather than the rule in rural areas. The dilemma of being unable to access adequate employment and appropriate community-based hiring arrangements for a survivor of a traumatic brain injury in rural areas is a major roadblock to their eventual rehabilitation.

This chapter will define the common characteristics of rural areas that make head trauma rehabilitation programs difficult to foster and suggest ways to deal with barriers to community integration. General programmatic issues will be discussed which evolved from experiences with two brain injury rehabilitation service and research programs: the Mayo Clinic Traumatic Brain Injury Care Management Model and the University of Wisconsin-Stout Head Injury Re-entry Project (Project HIRe). More specific details of the latter are discussed in greater detail in Chapter 5.

The Mayo Care Management Model evolved from experience with persons served at the Mayo Medical Center Brain Injury Program located in Rochester, Minnesota, many who live in rural areas in Minnesota and Wisconsin. This model is a comprehensive approach to traumatic brain injury medical care and rehabilitation that combines hospital-based post-acute brain injury rehabilitation with community-based transitional and supported employment programs. Project HIRe piloted an employment and case management model project at three rural supported employment programs serving persons with severe disabilities as a result of a traumatic brain injury. Findings from both of these programs will be discussed in terms of service delivery in non-urban communities and for larger rehabilitation programs serving people in outlying areas.

### **CHARACTERISTICS OF THE RURAL REHABILITATION COMMUNITY**

Many characteristics of small towns and rural communities serve to promote the community re-integration of persons with disabilities. The authors, who have worked in both urban and rural environments, feel that the most important positive element in rural rehabilitation is the family networks which are typically more established than in urban

areas. In agricultural areas, maintenance of a farming economy results in a cross-generational family cohesion that has been reinforced by the economic necessity of using the extended family as a primary workforce. This serves to also fortify emotional ties. These family networks often intertwine through social, fraternal, and church affiliations to provide the person with a disability returning to such a community with a secure network of social support.

In rural areas where mining, tourism, or logging are the principal types of employment, traditions of the entire community are often shaped around the lifestyles of persons in the predominant labor market. This work-focused community identity and lifestyle support strong family traditions and roots to create bonds that can provide invaluable support to a brain injured person's rehabilitation. In addition, this type of social network appears to foster an acceptance of a person with a disability.

### **Barriers in Rural Brain Injury Rehabilitation**

**Geographical Distance Between Consumers and Providers.** Aside from the benefits mentioned above, other characteristics of rural areas result in specific barriers to rehabilitation and re-integration of persons with brain injuries. Even though the overall incidence of traumatic brain injury in rural areas is significant (i.e., age-adjusted annual incidence rate in Olmsted County, Minnesota, per 100,000 = 270 for males and 116 for females [Annegers, Grabow, Kurland, & Laws, 1980], the number of individuals needing specialized brain injury services is low in any given community or area as compared to urban areas with a larger population base. Thus, specialized brain injury rehabilitation services tend to be located in more highly populated areas. This localization of rehabilitation services in metropolitan areas interferes with rehabilitation efforts for the rural dweller with a brain injury in several ways.

The location of services in urban areas requires long distance travel to receive services. Services also tend to be provided in surroundings which are markedly different from the rural environment to which the individual with brain injury plans to return. For instance, as part of a metropolitan-based rehabilitation program, a person with brain injury may, of necessity, learn such urban survival skills as using a bus schedule, making connections on the subway, and meeting new people in his or her apartment complex. However, when this individual returns to work in the grain elevator that his uncle runs in a town with no public



transportation, few of these skills may be needed. Difficulties with abstraction and transfer of learning can be major barriers to "pre-vocational" training and frequently occur with persons with traumatic brain injury. Generalization of skills to the home environment, therefore, may be complicated by training of inapplicable skills.

A final consideration is that the urban environment itself is often not acceptable to the rural dweller. Young adults, the age group with the highest incidence of brain injury in rural areas, are aware that they have the option to move to a city to find employment. Those who declare a preference for rural living by choosing to stay in the rural environment are not likely to change their preference because of a brain injury. Since brain injuries make it more difficult for people to adapt to new situations (Lezak, 1989), it is unlikely that the rural dweller with a brain injury will change his or her preference for rural living. If relocation to a larger city is attempted, difficulty adapting to the unfamiliar urban environment is likely to be made worse by the limitations caused by the brain injury, and additional adjustment problems may occur.

**Lack of Local Experts.** Specialized brain injury services tend to be centralized in metropolitan areas. Therefore, rehabilitation and clinical service providers who are experts in brain injury gravitate to these population centers. Conversely, rural rehabilitation providers tend, of necessity, to be generalists without extensive knowledge of the specific needs of persons with brain injury. Again, because of the dispersed population, individual providers in rural areas see few clients with brain injury each year.

While it is difficult to find individual rehabilitation workers who are experts in brain injury in rural areas, it is almost impossible to locate teams of providers who can furnish comprehensive, coordinated services to address the vocational, social, independent living, and medical needs of the client with brain injury.

While training local providers appears as an obvious solution, large geographical distances separating providers is also a barrier to implementing this process. Centers for research and demonstration service projects in brain injury rehabilitation within a given region that might furnish such training also tend to work in isolation from each other because of geographical distance. A cooperative effort among regional brain trauma rehabilitation programs is a critical first step towards overcoming barriers to effective, coordinated regional programs for

training local providers in brain injury rehabilitation. In addition to geographical distance, lack of funding for long-term case management and supported employment serves as a significant barrier to the development of decentralized, comprehensive rehabilitation programming in rural areas.

**Consumer Needs for Information, Support, and Advocacy.**

Another barrier, characteristic of both rural and urban environments, is the difficulty encountered by consumers and families in locating adequate information regarding brain trauma rehabilitation. Consumers, including persons with head injury, their families, and significant others, lack easy and immediate access to information about traumatic brain injury and may be unaware of the nature of residual difficulties (e.g., changes in behavior and personality) following a traumatic brain injury. Moreover, families may be unable to locate appropriate services or, in many cases, even a person knowledgeable in brain trauma rehabilitation.

The needs of the family for support and education may be particularly difficult to meet in rural areas. Geographical distances again present barriers to people getting together for support and advocacy group meetings. Because of the denser population, support and advocacy groups tend to be most highly represented in urban areas. Unless such urban-based consumer groups make a specific effort to involve rural dwellers, the needs of rural persons and families with brain injury for support, advocacy, and legislative action may go unmet.

**Lack of Funding.** During a meeting of a community advisory committee, one participant proposed to the author that all problems related to community re-entry of persons with traumatic brain injury can be traced to a lack of reasonable and adequate financing for programs and services. This person argued that given unlimited funding, one could receive state-of-the-art programs and services in any location and that nearly any environment could be modified as needed to accommodate the needs of persons with disabilities. The majority of the other participants disagreed and raised the point that rehabilitation programs need to operate in the real world with the realization that other factors, such as the spirit and determination of the persons with disabilities and their supporters (family and significant others) and the availability of an understanding and committed job coach, care manager, or employer, are of utmost importance. Regardless of a person's stand on this issue, the establishment of a funding stream of a sum sufficient to ensure adequate provision of ongoing services is critical to program

development and support.

### **RELATED RESEARCH FINDINGS**

The sparse and scattered populations of rural areas limit rehabilitation in several ways as identified in a study of the range of barriers to effective rehabilitation services that was carried out by the Brain Injury Task Force of the Wisconsin Department of Health and Social Services. This study found a lack of expertise in rural areas to meet the rehabilitation needs of the broad range of disabilities presented by persons with brain injuries (Thomas, Czerlinsky, & Smigielski, 1990). The Wisconsin study found that such expertise was concentrated in a small number of urban locations within large rural areas. In both rural and urban areas, provision of brain injury services often suffered from lack of coordination. An informal needs assessment of persons and families with traumatic brain injury in rural Minnesota conducted through the Minnesota Head Injury Association resulted in findings that were consistent with the Wisconsin study. Thus, the results of the Wisconsin study may apply to most rural areas of the upper Midwest and may be generalizable to many rural areas of the United States. Results of these surveys suggest that an effective program of vocational rehabilitation and personal independence may need to involve a central coordinating office within each state with "hub cities" responsible for coordinating and providing liaison consulting services (Thomas, 1989).

In a survey of 111 rehabilitation facilities providing services to brain injured persons in Wisconsin and Illinois, Wagner (1988) found an average daily census of 111 persons, of which only 5 had experienced a traumatic brain injury. Estimates of persons with brain injuries served on a daily basis varied widely, with a standard deviation of 9.38. Although 70 percent of the facilities used community-based employment options, only about a third of them served persons with traumatic brain injury. Of the community-based work options used, supported employment with job site training was used in 47.7 percent of the sample. Time-limited transitional employment was used in 37.8 percent and industrial-based, supported enclaves were used in a fourth of all cases. Projects with Industry supported employment targeted funds were used to finance supported employment in 16.2 percent of the cases.

Wagner's (1988) study also found metropolitan areas to serve larger numbers of persons with traumatic brain injury, with many providing specialty programs with highly specialized staff. Facilities located in

areas with large university medical hospitals and clinics also tended to have larger vocational rehabilitation programs for persons with traumatic brain injury. Many large hospital-based programs which offer medical and vocational services also provide services to persons who eventually return home to small towns and rural communities (Thomas & Czerlinsky, 1987). In this regard the problems associated with rural brain trauma rehabilitation may be ubiquitous to all medically-oriented rehabilitation programs serving large catchment areas.

A more recent study (Thomas, Menz, & Hanson, 1991) examined the program characteristics of persons whom the state vocational rehabilitation agency designated as brain injury specialists. This six-state New England regional sample consisted of 35 rehabilitation professionals. The average number of persons with histories of brain trauma served per year was seven. The majority of the people providing data for this study were state vocational rehabilitation agency counselors who typically served a general caseload but who were designated by their state agency to become traumatic brain injury specialty counselors. Because of a tendency for survivors of traumatic brain injury to avoid rehabilitation, facilities providing sheltered employment as a principal rehabilitation activity was considered undesirable as an employment outcome.

In the Thomas, Menz, and Hanson study, all participants were provided three days of training in a specific method of analyzing and compiling vocationally relevant information using the Vocational Assessment Protocol (VAP) for persons with traumatic brain injury (Thomas, 1990) in order to obtain a picture of the types of persons served in programs designated as brain trauma programs. The participants each analyzed two referrals and provided demographic and behavioral data as well as opinions of survivors and friends regarding rehabilitation needs and survivor issues. Group discussions with the participants following the profiling of selected clients found the representatives from the various states to share similar concerns for persons in predominately rural areas which revolved around five key issues. These issues, which appeared quite consistent with the experience of the Mayo and UW-Stout groups and the Wisconsin and Minnesota surveys, included the following:

1. Long-term funding of programs is a major impediment to the provision of services.

2. A general lack of trained professionals with a background in brain trauma rehabilitation exists in rural areas.
3. Transportation is unavailable, extremely costly, and schedules of carriers are often inconvenient.
4. Advocacy and support groups are often not as strong and well-organized due to the limited population base. When a group exists to cover a wide region, long distances must be traveled.
5. The limited range of employment opportunities provides further restrictions on employment horizons (Thomas, Menz, & Hanson, 1991, pg. 3).

### **Leveling the Barriers**

**Geographical Distance.** Decentralizing services by providing them locally has been a common practice with other disability groups such as persons who are mentally retarded (Kreutzer & Wehman, 1990) and persons with severe and persistent mental illness (Anthony, 1992). This phenomenon has not occurred on a national scale for brain injury rehabilitation programs, probably due to the previous underestimates of the rural incidence of traumatic brain injury and misclassification of such injuries. As decentralization of services occurs, the barrier of long distances to travel for services will be diminished but not eliminated. In the long run, telecommunication and transportation systems will continue to shrink today's world, and geographical distances will become less of a problem than the low demand for brain injury services in a given provider location. In the more immediate future, the barriers created by geographical distances can be reduced by addressing a related barrier, the lack of local expertise in traumatic brain injury rehabilitation.

**Lack of Local Experts.** Because most rural providers see few persons with brain injury each year, it is not reasonable to expect that all of these local providers can or should become experts in brain injury rehabilitation. The low demand for brain injury services that any specific rural provider experiences is a principal reason why rural providers lack expertise in brain injury rehabilitation.

A solution to the problem of a lack of local expertise is the development of a system in which local providers can access consultation with an expert in their field regarding specific cases of brain injury as the

need arises. Ideally, comprehensive teams of local providers could access centralized expertise in brain injury rehabilitation regarding issues that cross disciplines. This model has been partially actualized during the last six years in catchment areas for medical rehabilitation at Mayo Clinic in Rochester, Minnesota, and for three years in the University of Wisconsin-Stout Rehabilitation Research and Training Center. These model programs are described in greater detail later in this chapter. This approach is similar in many ways to the case-specific model proposed by Prickel and McLean (1989) but is more general in scope and long-term in application.

The first step towards the development of a system of expert consultation specific to the needs of local providers involves both a central effort with the administrations of existing agencies and a local, grassroots effort with concerned individuals in particular locales. At the administrative level, formal and/or informal commitments must be obtained from the management of service agencies to the importance of identifying experts in traumatic brain injury within each agency who can consult with local providers in that agency. Formal agreements and policies are preferable since the effectiveness of agency experts is greatly enhanced if they are officially designated as the people that other agency staff should consult regarding traumatic brain injury. Support for training of these experts is also encouraged by official designation.

Once the concept of an intra-agency system of experts is accepted at an administrative level, the second step involves identification of specific individuals who are willing to become "experts" in brain injury and acceptance of their expert capacity by local providers. This second step is more of a grassroots effort that is facilitated by local organization and pressure from concerned individuals.

One form of grassroots organization for brain injury advocacy is the local brain injury advisory committee. The brain injury advisory committees in rural communities can serve as a catalyst mechanism for action both in terms of encouraging a few providers to become liaisons for their agencies concerning brain trauma rehabilitation, as well as encouraging use of the system of experts by local providers. For any given locale, the brain injury advisory committee includes representatives of consumers of brain injury services (persons with brain injury and their families), those who serve as a link to state and national head injury associations, and representatives of major provider organizations: medical rehabilitation, vocational rehabilitation, independent living,

social service, and education.

Such a brain injury advisory committee was developed five years ago in Rochester, Minnesota, and has been effective in encouraging area identification of agency experts in traumatic brain injury and in area coordination of brain injury services. More recently, the Minnesota Head Injury Association with the help of a federally funded grant has facilitated the development of brain injury advisory committees with similar missions in other Minnesota rural communities and regions.

Similar advisories were studied at the University of Wisconsin-Stout in two separate research and demonstration projects. Both projects used high schools in predominantly rural areas of Wisconsin as the organizing agents to mobilize the local communities into a network of consumers and providers with expertise primarily cognitive or neurological disabilities. The role of these consumer/provider advisory committees was to review the needs of each student and to identify which programs and services available within the community network could assist in optimizing full integration into the community. An important finding of these studies was that, given a core set of program materials, training, and access to disability-specific consultants, programs were able to develop community-based transitional and supported employment sites in rural areas, using local advisory networks for support and direction (Thomas, Coker, & Czerlinsky, 1988).

A brain injury advisory committee can serve as a mechanism for exchange of knowledge and information among professionals in different agencies. Such knowledge exchange enhances the knowledge of designated experts and concomitantly enhances their expert status. Knowledge exchange among experts can also result in forums for dissemination of knowledge to local providers, such as in multi-agency inservices. Knowledge exchange may be general, such as in interagency or intra-agency inservices, or case specific. For instance, through the coordination of the Rochester Brain Injury Advisory Committee, representatives of external agencies (e.g., state rehabilitation services, vocational training workshop, county social service, independent living center, educational system) have participated in biweekly Patient Care Conferences for persons with brain injury who are participating in a hospital-based post-acute rehabilitation program and who are served by community agencies as well. Through such efforts as coordination of services, both duplication and failure to provide needed services are avoided.

In small towns, a brain injury advisory group made up of key players in the rehabilitation process can function in an effective manner. These types of advisory groups tend to get cumbersome and difficult to manage in a time efficient manner when more than 12 people are involved. Larger cities also encounter difficulties when attempting to create this type of structure. For this reason, a community advisory group has tended to be a phenomenon experienced chiefly in smaller communities.

**Consumer Needs.** Establishing stable networks also appears to be a reasonable solution to meeting rural consumer needs. Local committees and state and national head injury associations form a basis for family support, education, and advocacy in rural areas.

The Minnesota Head Injury Association (MHIA), through their Community Support Network and Heads Together program, has shown that an urban-based effort to engage rural dwellers can be successful. MHIA has its home office in Minneapolis. Minneapolis, with its sister city St. Paul and surrounding suburbs, forms an urban area with over one million inhabitants and is the only metropolitan area in Minnesota with a population over 100,000. Thus, MHIA finds itself responsible to serve the large geographical region comprising all of Minnesota from a central urban hub which is as far as a six-hour drive from outlying Minnesota communities. With the help of federal funding, MHIA has developed a system of regional networks that includes brain injury advisory committees and an MHIA representative ("community coordinators") in each of several rural regions throughout the state. The community coordinators serve as liaisons between consumers and professionals both within the region and throughout the state. Besides linking consumers with professionals, the community coordinators assist persons with traumatic brain injury in finding a supportive friend or family member to work with them towards community re-integration in the Heads Together program. With the advisory committees, community coordinators also play an important advocacy role both locally and statewide. The Community Support Network and Heads Together program have been specifically targeted to several underserved rural areas in Minnesota.

**Lack of Funding.** The professional and consumer networks advocated thus far in this chapter form the mechanism for identifying available funding sources for brain injury rehabilitation and for political advocacy to secure additional funding for such services. In some cases, it will be desirable to develop a finance subcommittee of the advisory



committee to examine each case of a person affected by a brain trauma injury in order to insure an appropriate funding stream. By necessity there will need to be a source of third party funding to provide long-term efforts, such as ongoing supported employment services. With persistent advocacy, the services of nontraditional rehabilitation providers, such as employment training specialists or job coaches, may be funded in part or in total through a state vocational rehabilitation agency, an insurance carrier or other third party funding agent, or through fees generated by the services components.

One of the promising ways of developing funding for support services uses a Plan to Achieve Self-Support (PASS). In this application Impairment Related Work Expenses (IWRE) are used to adjust income levels for individuals receiving social security benefits (California Department of Rehabilitation, 1990). Although an explanation of this approach is beyond the scope of this chapter, information on the use of this type of incentive program is available through the Social Security Administration.

Persistence and creativity can result in viable novel solutions to secure funding. A brain trauma rehabilitation program founded at the Threshold Inc., a not-for-profit rehabilitation facility in West Bend, Wisconsin, for example, used an innovative approach for initiating a brain trauma program. Brain injury survivors, family members, and staff members negotiated with the local municipality for funding a vocational rehabilitation program. This facility was provided seed money by the county board equivalent to the cost to maintain one person in a state institution for one year. This program was able to prove that the investment of dollars at the local level more than offset the potential cost of additional days in state funded inpatient rehabilitation and long-term care facilities (Thomas, 1989).

## MODEL PROGRAMS

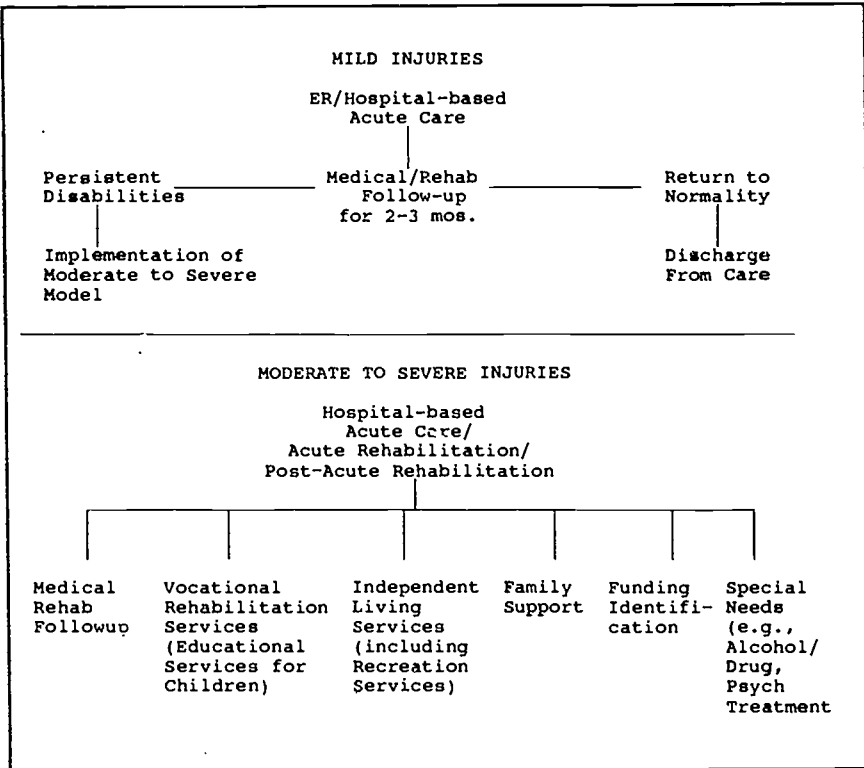
### Mayo Clinic

During the last eight years, rehabilitation professionals at Mayo Clinic have developed a model of long-term care management for persons with brain injuries in conjunction with state and local agencies. The development of the Mayo model found a basis in decades of emergency, acute medical, and rehabilitation services at Mayo for persons with brain injuries. In recent years, post-acute brain injury

rehabilitation programming has been developed to include (a) a hospital-based comprehensive outpatient program; (b) community-based vocational services through the Minnesota Department of Rehabilitation Services (DRS) and the Rochester Ability Building Center (ABC), and educational services through the Rochester school system (RSS) and Rochester Community College (RCC); (c) community-based independent living services through the Southeastern Minnesota Center for Independent Living (SEMCIL); (d) family support services through Mayo and SEMCIL in affiliation with the Minnesota Head Injury Association; (e) funding identification through Mayo and Olmsted County Social Services; and (f) specialty care at Mayo (e.g., behavioral neurology, neuropsychiatry, substance abuse treatment).

The Mayo model of care management for persons with brain injury, which is diagrammed in Figure 1, emphasizes early identification of and intervention with persons with brain injury. Early identification, ideally on presentation to the emergency room, initiates a system of follow-up based on assessment of injury severity. Persons with mild head injuries and their families are followed by a team including a neurosurgeon, a physiatrist, a neuropsychologist, and a social worker for two to three months. If brain injury sequelae persist, the person with mild injury is directed toward the comprehensive system of hospital-based and community-based services consisting of medical rehabilitation, vocational/educational services, independent living services, family support, funding identification, and any needed special services. Examples of special services are substance abuse treatment or evaluation and neuropharmacologic treatment of cognitive and behavioral disorders by a behavioral neurologist and a psychiatrist at Mayo. Such a comprehensive system is initiated during acute care for individuals with moderate to severe injuries. This comprehensive system remains in place for the person with a head injury and family long term with a goal of vocational re-entry and community re-integration.

Brain injury care is coordinated within Mayo by the institutional Multispecialty Brain Injury Committee which is chaired by a physiatrist and attended by an emergency physician, a neurosurgeon, a behavioral neurologist, a neuropsychologist, a psychiatrist, an anesthesiologist, a nurse supervisor, and an administrator. In the community, the Mayo model of brain injury care management is coordinated by the Rochester Brain Injury Advisory Committee.



**Figure 1**  
**Mayo Model of Care Management for Brain Injury**

Mayo, which opened its comprehensive post-acute brain injury rehabilitation program in December 1988, integrates a range of services (i.e., psychiatric medicine, rehabilitation nursing, occupational therapy, physical therapy, speech, neuropsychology, vocational counseling, recreational therapy) to address the cognitive, behavioral, emotional, social, physical, and vocational barriers created by brain injury for the injured persons and their families. The comprehensive post-acute program at Mayo is an outpatient program accredited by the Commission on Accreditation of Rehabilitation Facilities. It is based on group treatment and modeled after the program developed by Prigatano in Oklahoma City (Prigatano, 1985).

In Rochester (and in the Mayo model of brain injury care management), community-based supported employment and supported living programs are coordinated with hospital-based post-acute

rehabilitation services. An example of this coordination is the attendance of community-based service providers at biweekly patient conferences for appropriate patients in the hospital-based post-acute brain injury rehabilitation program. Thus, the Mayo model emphasizes use and nonduplication of existing services. As participants progress in the program, the focus of interventions shifts from the hospital to the Rochester community and eventually to the program participant's hometown. Throughout this sequence of programming, family issues are addressed individually in a biweekly family group and through local support groups affiliated with the Minnesota Head Injury Association.

To date, results of the comprehensive program have been positive. Methods for program evaluation include use of the Portland Adaptability Inventory (Lezak, 1987), Goal Attainment Scaling, and documentation of independent living and vocational status. These methods of program evaluation are detailed elsewhere (Malec, Smigielski, & DePompolo, 1991), and review of outcomes here will be limited to independent living and vocational status. Of the first 24 graduates, 46 percent entered the program in living situations which required no supervision; 92 percent left the program to unsupervised living situations. Of these 24 graduates, 16 completed the program one year or more prior to this writing. These 16 were contacted by telephone one year after program completion, and at that time, 88 percent remained in unsupervised living situations.

Vocational outcomes for program graduates were graded using the Work Outcome scale described in Table 1. As can be seen in Figure 2, about 60 percent of the first 24 program participants left the program to either transitional or competitive employment situations. Unemployment was reduced from 79 percent to 33 percent following program participation. Of the 16 followed up at one year, most who had graduated to transitional employment progressed to competitive employment with 50 percent of the total sample in competitive placements at one year follow-up. Whether placements in sheltered or long-term supported employment constitutes successful treatment is largely a matter of perspective. On the one hand, those graduating to sheltered or supported employment did not accomplish their program goals which included transitional or competitive employment. On the other hand, a degree of success for the program may be found in the acceptance of such placements by individuals who were unable to function effectively in more independent work settings, but who, prior to program participation, were not satisfied with sheltered or supported work.

**Table 1**  
**Work Outcome Scale**

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**Competitive Employment (5)**

Part- or full-time work outside a sheltered workshop performed without supports or assistance

**Transitional Employment (4)**

Part- or full-time work outside a sheltered workshop performed with temporary supports or assistance (e.g., reduced hours, temporary job coach, training)

**Supported Employment (3)**

Part- or full-time work outside a sheltered workshop performed with temporary supports or assistance (e.g., work enclave, part-time volunteer work)

**Sheltered Employment (2)**

**Unemployed (1)**

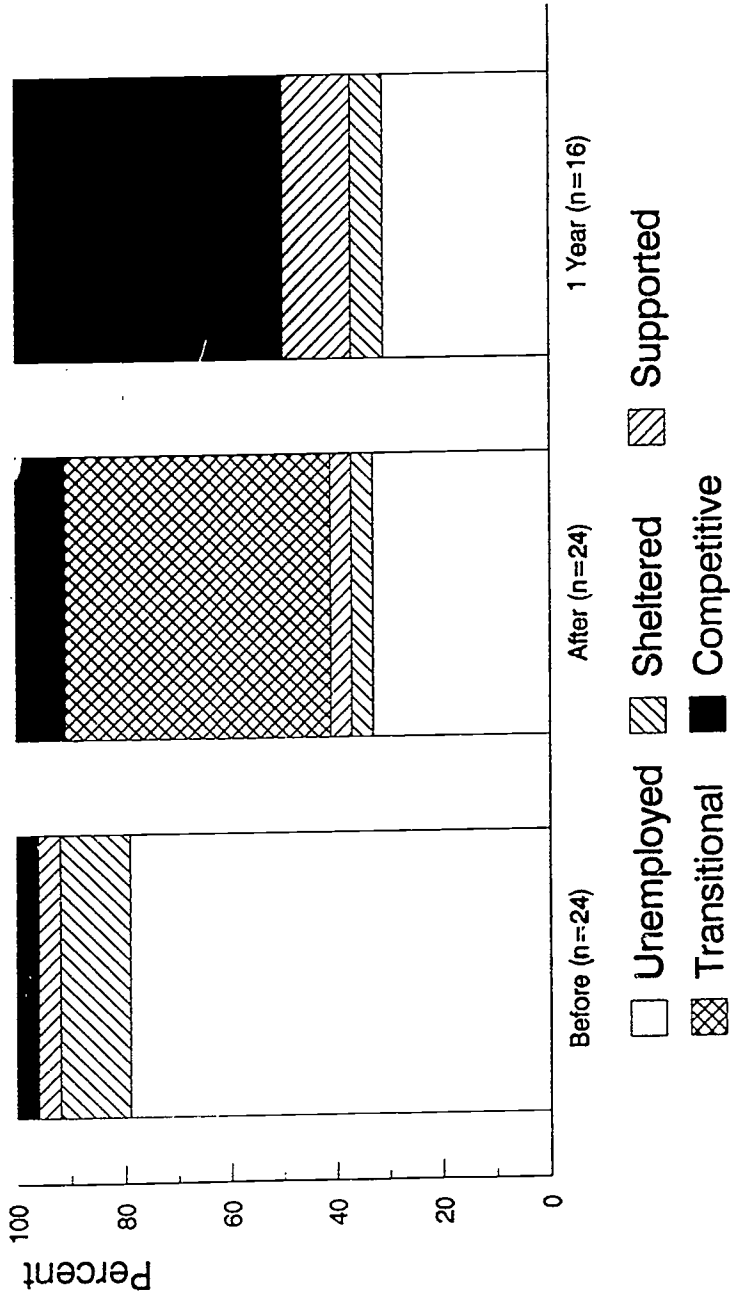
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**The Head Injury Re-entry Project<sup>1</sup>**

The Project HIRe model of community-based employment for persons with traumatic brain injury was designed to serve predominantly rural areas, where extensive resources are limited and staffing limitations preclude the development of complex service arrangements and central service locations in larger cities. The model is based on the assumption that one of the essential elements of success when working with this population is the ability to develop an understanding of the persons, their work and personal history as well as skills, abilities, and functional limitations.

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<sup>1</sup> Data and information in this chapter are taken from the research monograph *The Final Report of the Head Injury Re-entry Project (Project HIRe)*, Thomas and Menz (1993). These excerpts were reprinted with permission of the authors. Please refer to this document for full details of project design and findings.



**Figure 2**  
**Work Status for Graduates of Mayo Brain Injury Outpatient Program**  
**Before, After, and at 1 Year Follow-up**

Information that exists in hospital records, background information, and neuropsychological evaluation reports serves as a vital tool in structuring a preservice assessment and a prescriptive vocational evaluation. This assessment phase, unlike many supported employment models with other disability groups, is a critical point upon which certain future decisions must be made.

The HIRe model suggests the use of a team approach during the assessment phase to identify available community resources and profile neuropsychological, medical, and background information in functional terms understandable to lay workers who have had specific training in the needs and treatment provisions for persons with a traumatic brain injury. Once initial assessment and job site training has been completed, a less intense model of service delivery is typically necessary. This model advocates the use of an employment training specialist who has background in both vocational rehabilitation and traumatic brain injury rehabilitation. The employment training specialist serves as a primary liaison among all other parties and is responsible for a small caseload involved in evaluation and initial supported employment. This person later relinquishes the responsibilities of support to a maintenance job coach who has had less specific training in traumatic brain injury. The maintenance job coach assumes the long-term and ongoing support needed for that person, with consultation of the treatment team if problems arise (see Chapter 5 for greater detail of the HIRe model).

### **Demonstration of the Model**

Figure 3 provides a summary of the alternate paths in the HIRe model<sup>2</sup>. The stages in the model include assessment and planning, community-based employment, and maintenance. During assessment and planning, a multidisciplinary team of rehabilitation professionals provides diagnostic, vocational, and therapeutic services necessary for transition to the community job site. During the community supported employment stages, the initial labor and skill intensive assessment and transitional services are transferred to services designed to maintain the person on a job. A job coach and/or case management rehabilitation team gradually assumes responsibilities for services at this time in the maintenance phase.

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<sup>2</sup> See Chapter 5 for a detailed description of the HIRe model and specific steps that take place in each stage of the process.

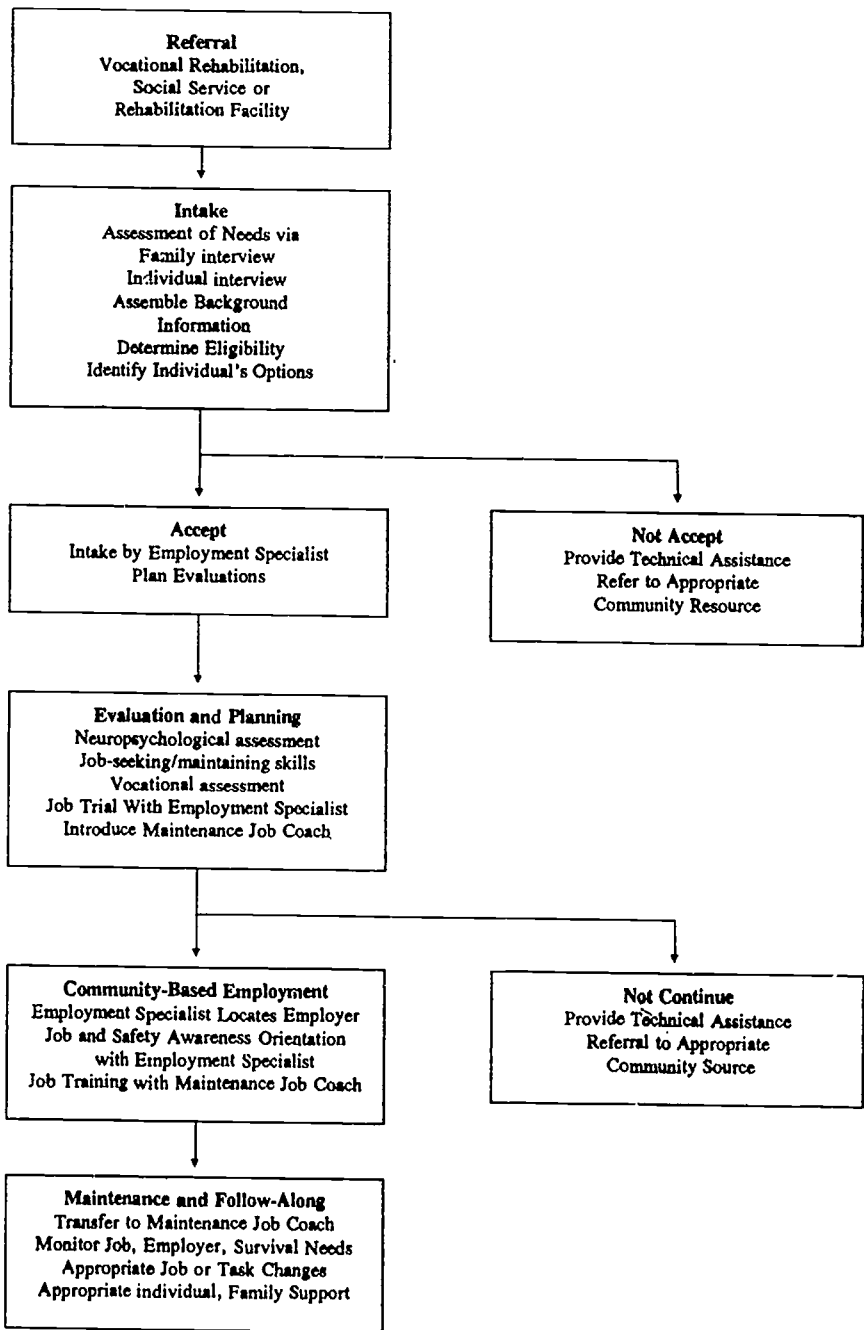


Figure 3  
Alternate Program Paths Under the HIRe Model



## PROJECT FINDINGS

### Subjects

In total, 27 persons were studied in Project HIRe. Of these, 19 were male and 8 were female. The average age at the referral to the program was 25. Considerable variation in age was evident, with the youngest person being 18 and the oldest being 51.

All of the persons in the sample were white, a cultural phenomenon of the Midwest rural area where this research occurred. Marital status for most persons remained approximately the same from before the injury to the time of entry into the project. The majority of persons studied were considered to have a closed head injury. Seven sustained a skull fracture as a result of the injury. The majority of the injuries were sustained in motor vehicle accidents, with one-third of all known cases to be related to alcohol use. The average coma length was approximately 32 days, with wide variation reported among the various subjects.

A review of the information regarding the nature of the initial brain injuries and the types of problems being exhibited found that persons served in this project had significant and severe injuries. Without support of job coaches, case managers, and client advocates, these people would probably not have had the opportunity to access competitive employment in community-based situations. One general finding of the project was that it was not necessarily the degree of physical disablement that precluded people from working as much as factors such as insight into the nature of their problems, interpersonal work problems, and general social adaptive behavior difficulties.

People who were less predictable in their behavior tended to be the ones that had the most problems. For example, two of the more severely disabled persons from both a cognitive skills and physical perspective were very predictable in the manners in which they would interact with other persons. They therefore could be managed at the worksite by developing compensatory strategies and environment modifications for overcoming physical and behavioral barriers. Persons who exhibited wide swings in mood and styles of interactions with persons that seemed to "catch their employers off guard" were more likely to exhibit work-related problems and were subsequently terminated because of these behaviors. Employability, therefore, appears to be based on not only the

severity of the disabilities but the stability of the disability.

### **Employment and Educational Status**

The employment and education history of persons referred to the program varied widely; however, the majority of all persons had completed high school or a general education equivalency diploma (GED) prior to their injury. Of those who did not, the remainder completed their GED or high school diploma after their injury. Although 14.8 percent were noted to have been involved in vocational and technical training since injury, none of the individuals had attended college before referral to this project; however, two people went on to attend a four-year college program after participating in the project.

Prior to the injury, 47.8 percent were not employed in any manner. Some of these individuals were employed at the time of referral but were having problems that required employment support services. Some of those referred were in a supported employment program because of additional needs secondary to the traumatic brain injury. Of the 52.2 percent persons who were reported as being employed at the time of referral, the vast majority (83%) were considered part-time. For those who were employed prior to the injury, the large majority (67%) were considered full-time.

It was hypothesized that a traumatic brain injury would affect the earning potential of the person with a head injury. As reported by family members, it was found that nearly 75 percent of the respondents felt that there was a substantial reduction in short-term earnings, and approximately two-thirds felt there would be deleterious effects on long-term earning potential (Thomas & Menz, 1993).

### **Employment Outcomes and Model Effectiveness**

The effectiveness of the Project HIRe model of supported employment must be considered both in terms of the number of persons who were able to be successfully employed and the ease of adapting this process to existing rehabilitation facility programs. Table 2 displays the employment outcomes and characteristics of the support services that were provided to all participants in Project HIRe. This data reflects only the individuals who were placed at the two replication sites. The outcomes of individuals served at the pilot site were not included in the total. Note that the data listed in Table 2 were obtained at a follow-up

conducted three months after project funds had expired.

As Table 2 illustrates, the number of hours of work per week and the wages earned by the persons studied were limited. The vast majority of all subjects at one time had worked on an individual placement which tended to offer better wages, benefits, and opportunities for integration with nondisabled workers. At the time of the last follow-up, however, the majority were working at an enclave or in a work crew with other persons with disabilities. The reason that this occurred was due to the fact that the extra funds allocated to the replication sites were used to free a job coach from traditional duties to assist in providing support on an individual basis specifically for persons with a traumatic brain injury. Because many of the people were unable to work on an individual site without periodic, time-intensive intervention, these persons were often placed in enclaves or work crews where supervision is less costly when problems at the worksite occurred after supplementary funding provided through grant resources were exhausted.

**Table 2**  
**Employment Benefits for Last Job Placement at Replication Sites, Three Months After Conclusion of Project HIRe<sup>1</sup>**

Employment Variables	Wisconsin Site	Minnesota Site
<b>Number of Workers</b>	3	10
<b>Job /Characteristics</b>		
Total weeks worked	70	269
Total weeks available for work	73	304
Percent Actually Worked	95.9	88.5
<b>Employment Benefits Last Job</b>		
Average hours/week	23	19
Average weeks worked	15	19
<b>Wages Compared to Minimum Wage</b>		
Number Workers Above	2	5
Number at or below	1	4

<sup>1</sup> Figures are based on n's of 3, and 10, respectively, for the two demonstration sites. Persons placed during model development at the pilot site were not included in this table.

### **Summary of Findings**

The following are some general findings in regard to the development of community-based employment programs serving persons with a traumatic brain injury in small towns or rural communities:

1. Methods of providing long-term funding of employment supports must be readily available. One of the greatest problems in providing services to this population was in securing mechanisms of long-term support.
2. A psychodynamic group process which allows persons placed on community-based employment situations to process the successes and failures on at least a weekly basis should be an essential part of any program. Prior to the implementation of a weekly support group, individual concerns needed to be dealt with on an individual basis which required considerably more in the way of staff time and which did not offer the peer support as did group processing of these issues.
3. Community-based programs are likely to be more successful if existing supported programs are in place and if staff are experienced at the process of providing community-based work services.
4. Staff must be trained in the basics of brain behavior relationships and brain injury rehabilitation processes in order for them to understand the constellation of problems encountered by the head injury survivor.
5. Programs serving traumatic brain injured persons in community-based settings must be prepared to deal with a wide range of severity among the client referrals they receive. Clear intake and exit criteria must be established to determine which of these clients will be served as well as mechanisms for making referrals to other programs.
6. Consideration should be given to providing services to individuals with mild residual impairments secondary to traumatic brain injury, since the demand for services and the length of service supervision may make these individuals appropriate referral for such services.

7. Private-not-for-profit community-based rehabilitation programs appear to be in a good position for offering community-based programs for traumatic brain injury survivors. Despite the fact that many persons who survive a traumatic brain injury do not wish to enter sheltered employment, community-based programs are likely to be in the best position for providing other employment options for the following reasons:
  - a. Familiarity with providing vocational related services in community-based settings.
  - b. Capacity for providing replacement workers in the event that a supported employee is not able to show up for work.
  - c. Extensive employment contact networks are often in place and staff trained in vocational counseling, rehabilitation engineering, and the provision of worksite services is generally readily available.
  - d. Job seeking skills training and worksite intervention services are typically available when the need occurs.
8. Linkages need to be established between developing programs and existing programs for traumatic brain injury survivors prior to initiating a community-based program. These linkages include an affiliation with the state vocational rehabilitation agency, county or municipal funding agents for long-term funding, state developmental disabilities or mental health agencies which may co-fund existing programs, mental health clinics and inpatient psychiatric settings which provide services to these individuals, alcohol and chemical dependency programs, public schools which provide transitional employment programs, and vocational technical school training programs which also offer remedial education and skill training alternatives.
9. Parental support groups, client advocacy groups, and survivor groups need to be included in the planning, execution, and program evaluation at all levels of program involvement. Advocates and survivors should include persons from all the organizations mentioned in the earlier point, as well as business and industry and local and state political contacts.

10. Implementation of a community-based employment program for traumatic brain injury survivors in rural areas may continue to be a considerable problem in the future. Despite the evolution of the field in general, when rehabilitation programs are provided in rural areas, "being rural" adds a unique set of barriers which must be dealt with. Some of the problems identified include the following:
  - a. Personnel. Availability of personnel with knowledge of brain injury and of rehabilitation approaches appropriate with brain injury survivors is especially limited and represents one of the greatest barriers to rural rehabilitation.
  - b. Travel time. Persons with traumatic brain injury in community-based employment may still have significant needs for specific rehabilitation services. Rarely are such services convenient to their work and because significant amounts of time are spent in travel to obtain services, the time available for them to work is often quite limited.
  - c. Appropriate jobs. Brain injury often requires considerable flexibility and selectivity in job placement in order to match people with jobs that are appropriate. However, there are both fewer employment opportunities available and a limited variety of job options in rural areas. Many persons may be eliminated from the labor market in a rural area because of such limited opportunities to match individual needs with jobs or they may face extended unemployment when they are between jobs.
  - d. Decentralized arrangements. The relatively low incidence of the disability across sparsely populated geographic areas usually means that qualified medical and vocational resources are of limited availability. The availability of support groups and advocacy organizations to promote increased service opportunities provide an additional disadvantage.

**A COMPREHENSIVE SOLUTION:  
MERGING PROFESSIONAL AND CONSUMER NETWORKS**

As regional networks of service providers who have developed expertise in neurobehavioral rehabilitation develop alongside a network of consumers, the transition of persons with brain injury from centralized acute and post-acute medical rehabilitation services to home community

will be facilitated. The network of providers becomes the mechanism by which referral to local service agents is made. Although the provider network also may become the mechanism to assure quality long-term follow-up in the local community, it is the network of consumers that will support long-term efforts of local providers. The consumer network unavoidably has the responsibility to assure that their locale receives the support and expertise necessary to reintegrate persons with traumatic brain injury who reside in their area. A willingness to share this responsibility by the provider network will result in optimal mechanisms for identification and response to the individual needs of persons and families with traumatic brain injury.

Ideally such a system could form a comprehensive referral network. Many state head injury associations have developed directories of individual rehabilitation providers in their state. The directory concept can be extended to a database that identifies teams of local providers and responsible consumers who have knowledge of brain injury rehabilitation and familiarity with each others' work. These teams of local providers and consumers can be referenced to the regional agency experts and consumer representatives who are available for consultation regarding specific client needs. Ultimately such a system of provider and consumer networks may form the basis for interagency professional organization, for sharing knowledge and information within and between agencies, for formal continuing education of local providers and consumers, and for economic and political advocacy and action.

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## *Chapter 5*

### **DEVELOPMENT OF A MODEL OF COMMUNITY-BASED EMPLOYMENT FOR PERSONS WITH TRAUMATIC BRAIN INJURY**

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The Head Injury Re-entry Project (Project HIRe) discussed in Chapter 4 is expanded on in this chapter. This project was a model demonstration grant conducted by the Research and Training Center at the University of Wisconsin-Stout. The HIRe Model of community-based employment was designed to accommodate needs of persons with traumatic brain injury in rural areas. The Model suggests use of a team to identify available community resources, profile background neuropsychological, medical and background information in functional terms, and develop a community rehabilitation plan.

### **WHO THE MODEL IS INTENDED TO WORK WITH**

The Project HIRe Model can be tailored to fit the severity of functional limitations imposed by a person's disability. The following discussion will give examples of how this model can be tailored to fit various levels of severity.

#### **Persons With Mild Functional Limitations**

The person who has sustained a mild to moderate head injury and demonstrates mild residual impairments are often the most appropriate persons to serve in a transitional type of employment program. Persons served in Project HIRe within this category were provided neuropsychological consultation or evaluation, family counseling and at times on-the-job or off-the-job supports depending on needs. In some cases, people referred to the project had sustained a head injury and were returning to a former job.

Oftentimes, other physical problems not directly related to the head injury were also noted, such as back injuries, and injuries to limbs. In such cases, a work hardening program or a gradual return-to-work program with volunteer experiences were appropriate. As physical injuries continued to heal and as the person continued to gain strength and stamina, they were often able to return to work with limited supports. In some cases, a vocational evaluator or one skilled in applied behavioral analysis was used to go to the job site to determine the demands of the job, the behavioral characteristics necessary for success, and any restructuring of the job or the job site which may be necessary before the return. In some cases, this was all that was necessary to return a person to employment. Although this does not represent a true supported employment model, the innovations necessary to rehabilitate any individual were encouraged whenever possible.

### **Persons With Moderate Residual Impairments**

People with moderate residual impairments often exhibited more notable difficulties insofar as speech and language problems, difficulties with balance, cognitive related difficulties, and psychosocial problems. These individuals frequently needed more than time limited transitional employment and required extended periods of supported employment. Some people with a moderate degree of residual impairment required indefinite support services. Depending on the nature of the deficits, rather than the severity of the initial injury, employment programs had to be tailored for each individual.

### **Persons With Severe Residual Impairments**

Persons with severe residual impairments required initial support services, as well as long-term community support both off-the-job and on-the-job. One notable exception occurred in the case of a person with severe physical limitations, behavioral problems and extensive cognitive and language difficulties who was able to be placed on a competitive work site without supports but required off-the-job supports in terms of transportation and independent living services. In most cases, however, persons with severe residual limitations required extended support services if placed on community employment work-sites. The important element was that support services needed to be available upon demand to work through crisis situations or everyday work problems that arose.

## **CRITICAL ELEMENTS OF THE HIRe MODEL**

### **Staffing for the Model**

Descriptions of the staff positions for Project HIRe are presented on Table 1. The HIRe Model used two different levels of job coaching. The first type principally involved an employment training specialist with extensive background and training in traumatic brain injury rehabilitation. A long-term maintenance job coach had primary skills in the nature of the work being performed.

This position did not require advanced training or a college degree, however, all of the employment specialists in Project HIRe had a bachelor's or master's degree. The employment training specialists used in Project HIRe had a bachelor's or master's degree, however, a relatively high turnover rate was experienced because they obtained other

types of employment after a relatively brief experience with this population. The employment training specialist functioned as an interim case manager and worked with the rehabilitation team from intake through the placement and follow-along stage, which is typically provided primarily by the long-term job coach. The employment training specialists in Project HIRe were charged with intake, gathering family background and conducting an interview with the head injured person in addition to the aforementioned support services.

Both the job coach and the employment training specialist were involved in the vocational evaluation to some degree. The employment training specialist encumbered a greater role in assisting the evaluator in tasks which were time demanding or which required specialized attention. The long-term job coach, wherever possible, was introduced to the client referred to the program at the intake interview, and became familiar with them from the onset.

The employment training specialist typically introduced the long-term job coach to the process during on-the-job assessments. In longer term job trials, the employment training specialist would begin to fade their time and to transfer the person to the long-term job coach as the more technical aspects of job training were sorted out. Often, individuals were placed on a transitional worksite in which they continued to learn job skills and develop work habits, with a reduction in time from both the long-term job coach and the employment training specialist. If their first employment following the job trial was on a long-term job site, the employment training specialist would eventually fade involvement to the point where occasional follow-ups were needed. When the person was faded to job maintenance, the employment training specialist would be available only as problems arose.

The long-term job coach in the Project HIRe Model typically worked with a wide range of persons with disabilities in addition to traumatic brain injury. Typically, several long-term job coaches were available for providing job site services to the head injury referral, on the basis of the nature of the work, the job location, and the availability of the job coach. The amount of time necessary for support was individually decided upon and no set minimum hours of weekly or monthly contact were assumed to be necessary. The primary concern of the long-term job coach was to see that the job got done, to train the person on the technical aspects of the job, and to assist with work production activities at the onset if the person was not fast enough.

**Table 1**  
**Staff Positions for Project HIRe**

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**Employment Training Specialist.** The person that fills this position will typically have a bachelor's or preferably a master's degree in a professional discipline such as vocational rehabilitation, applied psychology, occupational therapy or a related field. The essential prerequisite is a solid understanding of brain behavior relationships, and of physical and vocational rehabilitation programs for persons with traumatic brain injury. Good working knowledge of neurobehavioral rehabilitation models and approaches is also important. This person will serve as the main contact with all client services aspects of the case involved in an employment program. If a community appears to have too few referrals to warrant the employment training specialist position, it may be best to have several communities, a county or several counties or districts cooperate to co-fund such a position to be shared among various locales.

**Maintenance Long-Term Job Coach.** This person will be responsible for the day to day supervision and monitoring of persons after they have been placed on a job. Persons in this position typically will have had some industrial or employment related experience but not necessarily a college degree. The most important characteristic of a job coach is a person who sincerely wants to perform that type of job and has an earnest interest in working with persons with disabilities.

**Work Trainer.** The work trainer refers typically to an individual with substantial background, knowledge and experience in the job for which the client is being considered. Entry level jobs such as floor sweeper, small parts assembler, etc. may not require a person who has had specific training in this area and may be able to be learned by the job coach and passed on to the client. However, a person who is going into a job such as a welder, automobile mechanic, or automobile mechanic's assistant or such similar technical occupations may require a person who knows the job very well to assess skills and abilities and teach the specific skills on the job.

**Lead Worker.** This person may be used when a work trainer is not necessary. A person who already knows the job and can oversee various aspects of day to day work functions is needed. A former client who has been thoroughly trained in job demands and demonstrates capability of overseeing the work of others, or a regular employee of a company who has the added responsibility of checking the supported employment worker's production or work quality may be used. This person is not intended to replace a job coach, but to serve as an on-the-job mentor and overseer of daily operations.

**Table 1 (Continued)  
Staff Positions for Project HIRE**

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**Community Support Worker.** This person typically has a bachelor's or master's degree in a human services area, and typically has a caseload of persons with various disabilities whom he/she oversees for both independent living and work related needs. This type of professional may be funded through local funding options and is likely to have a chief responsibility for community support services rather than work. Community support services may include mental health services, alcohol and other drug abuse related issues and necessary crisis intervention services.

**Case Manager.** This person is typically a degreed professional who assumes the responsibility of overseeing all aspects of community integration for a worker with a disability. This person may be a rehabilitation counselor, work adjustment specialist, rehabilitation nurse or may serve in a similar type of position. This person's chief responsibility involves working with the client and family, coordinating aspects essential to community integration of both independent living and employment related issues and determination of rehabilitation needs and potential funding sources.

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Whereas each site had one employment training specialist for training, most sites had several job coaches to transfer cases when longer term support services were necessary.

Other vocational rehabilitation professionals are likely to become involved in the program as well, and may in fact function in one of the above mentioned capacities as a type of community integration specialist. Others include the vocational evaluator, vocational rehabilitation counselor, and employment specialist, sometimes known as a job placement and follow-along person or a employment development specialist. In facilities in rural areas or small towns, it is not unusual for one person to serve in two or more of these capacities, depending on the number of clients served in the immediate service program and availability of other professionals.

### **Staff Development and Preparation**

Inservice training for all levels of service providers was an essential requisite to program success. Most persons working with the program

had limited knowledge of traumatic brain injury, which is not uncommon in most rehabilitation facilities. Education and training programs should be a primary consideration when developing employment programs. This includes both preservice and in-service training for professionals in disciplines relevant to vocational rehabilitation (i.e., medical, psychological, vocational, educational). Programs where job coaches, rehabilitation case managers, counselors, and employment training specialists can acquire basic skills necessary to competently perform their jobs are essential elements to consider in the development of a rehabilitation team. Similar programs were also valuable for parents and advocates, and for employers.

### **Community Advisory Committee**

The Community Advisory Committee was an important element at the onset of implementing programs to serve persons with traumatic brain injury in rural community sites. This committee was used to examine available funding streams, monitor progress in provision of services, and help identify alternate service delivery methods. This advisory committee was based on the capacities of key people to network and served as a means of insuring that programs pursued and accomplished realistic goals and objectives. Its functions were to review new referrals, identify ways to resolve individual funding problems, establish networks for employment and other community supports, and to monitor the process of the program. The committee included representatives from the public sector: consumers, agencies, professionals, and employers as suggested on Table 2.

### **Eligibility and Selection Criteria**

In order to be included in a community-based employment program, individuals were selected based on criteria recommended by the Clinical Advisory Committee. Referrals needed to be willing to work, be a survivor of a traumatic brain injury, and be unable to work in an independent competitive employment situation due to the severity of disability. The selection criteria used in HIRE were as follows:

1. Eighteen years of age or older and no longer actively involved in a high school education program.
2. Verification of eligibility for vocational rehabilitation services through the state vocational rehabilitation agency.



**Table 2**  
**Composition of a Community Advisory Committee**

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**Perspectives and Representatives**

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**Providers and Funding Agencies**

County developmental disability  
County mental health  
Vocational rehabilitation program  
Community-based rehabilitation programs

**Professionals**

Psychiatrist  
Neuropsychologist  
Neurologist  
Rehabilitation counselor  
Placement and employment specialist

**Public**

Consumer(s)  
Advocate(s)

**Employment**

Community employers  
Labor or union representatives  
Job Service representative  
Private industry council liaison

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3. Reasonable likelihood of functioning in supported employment given the resources of job coaches and present family involvement.
  4. Must be at least one year post-injury and not in a medically unstable or rapidly changing state.
  5. Seizures, if present, are under control. It was not necessary to be seizure free as long as there was adequate control (i.e., medication) of seizures.
  6. Responsible for their own eating and toileting or have a person available to assist as necessary.
  7. Able to state that they are willing to become involved in a program and to meet all program requirements.
  8. Have an established long-term funding source for providing ongoing supported employment services if supported employment was necessary and would extend beyond the period of time covered by an initial funding agency (e.g., vocational rehabilitation).

9. Able to identify any specific job delimiters which they are unwilling to accept in a job (e.g., a minimum acceptable wage, a maximum distance that they are willing to travel, and specific working conditions that are intolerable).
10. Recent physical examination which stipulates the person's ability to work at least 20 hours per week must be on file.

### **Adaptation of the Model to Local Conditions**

The HIRe model can be adapted to the service needs of individuals. All phases of this approach need not be conducted with each person referred. It is up to the rehabilitation team to determine the logical steps in the sequence of activities, depending upon the individual needs of each referral.

For example, a person who is brought in through the intake assessment and neuropsychological process may be judged not ready to undertake a vocational evaluation because of severe depression or psychiatric disturbances. In such a case, referral to an outside source to provide these services may be made and the program may be temporarily interrupted. In other cases, when it is apparent that neuropsychological and vocational evaluations have been completed or are not felt to be necessary on the basis of recent treatment or clinical findings, a person may proceed directly to a job trial and perhaps to transitional supported or even competitive employment. The design and flow of the model is intended to provide an overall blueprint of the types of services that are necessary and will be arranged for each referral.

If this model is considered for incorporation into community-based sites, it must be understood that availability of staff and job assignments may demonstrate a wide variability between locations and flexibility in this regard is necessary. The key element in the entire process, however, is that an employment training specialist who has a solid knowledge of brain behavior relationships and traumatic brain injury and who can be trained in the basics of vocational rehabilitation, vocational evaluation, and job placement needs to be available for the program on a full time basis. Persons with split assignments typically get drawn away from the demands associated with the employment training specialist position, therefore a full time person in this capacity is deemed essential. The second inherent quality of this model is that a thorough assessment and review of background information is done prior to

initiating any type of vocational related services. Failure to have a full time employment training specialist and failure to follow the thorough preservice assessment and case review violates the spirit and intent with which this model was developed.

### **Desirable Features of a Neuropsychological Evaluation and Vocational Assessment**

Several factors were found to be desirable in a community-based assessment model which were not necessarily applicable to the provision of supported employment services to other disability groups. Two such factors included the completion of a comprehensive neuropsychological consultation or evaluation and vocational assessment.

1. The neuropsychological evaluation was primarily aimed at observing optimal learning styles, safety awareness, and potential hazards such as visual field deficits, motor and coordination problems, and difficulties in sensations for hot and cold, etc., in addition to the assessment of cognitive and neuropsychological behavioral functions. Neuropsychological data was essential to good planning of vocational assessment tasks. For instance, persons who were found to demonstrate better capacity for learning material presented verbally, as opposed to visually, were assessed primarily using verbal rather than visual methods. Individuals who demonstrated left sided neglect had work stations designed so that the majority of the materials were shifted to the right of the body line, with special attention being paid to objects that may cause serious danger if overlooked. In some cases, special glasses may be used to compensate for visual field deficits.
2. Vocational assessment was also deemed as a critical means of determining patterns of assets and functional limitations prior to placing persons on work sites. This included analysis of behaviors in work situations as well as assessment of activities typically associated with executive functions such as searching for a job, processing supervisory feedback, modifying behavior on the basis of task performance and demonstrating self-regulatory behaviors.

Approaches were found to be useful to consider in the assessment process. These approaches are grouped into the six categories of assessment methods listed below:

1. **Formalized testing.** Formalized testing included neuropsychological testing and specific vocational testing completed as part of the evaluation. Specific vocational tests of achievement or aptitude, vocational interests, and capabilities that are able to be examined through standardized test procedures.
2. **Traits and abilities testing.** Traits and abilities testing included dexterity tests, and work samples which examined a unitary factor or trait such as fine motor skills, gross motor coordination or fine assembly skills.
3. **Safety evaluation.** This included an assessment of one's safety awareness especially involving machinery or moving objects. When a person was being asked to do machine tending or machine operation and there was a suspicion that cognitive or attention difficulties may interfere with safe operation of the machine, a safety evaluation was conducted prior to actual placement on the job.
4. **Behavioral assessment.** Behavioral assessment was often done during the course of the evaluation and continued during the course of a community-based assessment or job trial. This included an assessment of interactions with other workers, and documentation of behaviors which would tend to interfere with social adaptation or on-the-job functioning.
5. **Environment analysis.** This included an assessment of the environment in which the person would be placed. The environment was assessed both prior to placement on the job and after the person was placed on the job. A job analysis and a content task analysis of specific duties as well as evaluation of co-workers and the immediate environment in which the person would be working were essential elements considered in the environmental analysis.
6. **Functional assessment.** This included an assessment of a person's ability to get along socially in the neighborhood, to use public transportation, to interact socially with others, and to be able to perform the functional skills necessary for job survival. This often included an assessment of a person's ability to open doors of access and egress, accessing toilet facilities, and obtaining food and medical help if that was necessary while at work.

### THE MODEL DESCRIBED

The HIRe Model (illustrated on Table 3) of community-based employment used in this program provided community-based employment for persons with traumatic brain injury using a three stage approach: (a) assessment and planning, (b) community-based employment and training and, (c) maintenance. Services were initially provided by an employment training specialist. One employment training specialist worked with six to eight persons in various phases of intake, job site evaluation, initial transitional employment training and eventual fading of time with involvement by the maintenance job coach.

**Table 3**  
**Outline of HIRe Model**

Stages and Steps	Activities
Assessment and Planning	
1. Intake	<ul style="list-style-type: none"><li>A. Screen against established eligibility criteria.</li><li>B. Identify sources for referral, services, and potential long-term funding.</li><li>C. Develop initial assessment plan.</li><li>D. Review purposes of program and alternatives with consumer and significant others.</li><li>E. Obtain working commitment from consumer and significant others.</li><li>F. Identify and examine alternative job goals in order to identify appropriate assessment sites.</li></ul>
2. Neuropsychological Evaluation and Consultancy	<ul style="list-style-type: none"><li>A. Identify work skills and functional limitations to optimal work performance.</li><li>B. Arrange neuropsychological evaluation if one has not been completed, or arrange neuropsychological consultation.</li><li>C. Following neuropsychological evaluation determine whether additional evaluations are required.</li><li>D. Identify preserved skills to be built upon in work and other appropriate settings.</li></ul>

**Table 3 (Continued)  
Outline of HIRe Model**

Stages and Steps	Activities
2. Neuropsychological Evaluation and Consultancy (continued)	<ul style="list-style-type: none"> <li>E. Re-examine functional limitations.</li> <li>F. Identify deficits or limitations that are likely to be problematic to achieving targeted job goals.</li> <li>G. Identify alternative compensatory strategies that should be explored during vocational evaluation and planning.</li> <li>H. Summarize and share information regarding existing skills, in relation to deficits, and devise potential adaptive strategies in a pragmatic and descriptive manner with consumer and significant others.</li> </ul>
3. Vocational Assessment	<ul style="list-style-type: none"> <li>A. Establish tentative assessment plan, including community-based situational assessment and roles for employment specialist and job coach.</li> <li>B. Implement assessment plan and address specific referral questions regarding functioning at supported or transitional employment sites.</li> <li>C. Explore work related aspects of preserved skills, and limitations identified by neuropsychological evaluation in a controlled environment, typically in a vocational evaluation unit.</li> <li>D. Explore utility of compensatory strategies suggested in neuropsychological consultancy or report.</li> <li>E. Assess adaptive psychosocial and vocational behaviors and plan for dealing with potential recurrent problems.</li> <li>F. Arrange a situational assessment in a protected (sheltered) situation and eventually to a community-based site for 1 or 2-1/2 days.</li> <li>G. If appropriate, consider a community-based work trial of 1 to 2 weeks with support.</li> </ul>

**Table 3 (Continued)  
Outline of HIRe Model**

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Stages and Steps	Activities
3. Vocational Assessment (continued)	H. Further develop plans for obtaining necessary on- and off-the-job support services and long-term funding.

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**Community-Based Employment**

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|------------------|--|
| 4. Job Placement | A. Identify and promote community-based employment alternatives available in the least restrictive environment.<br>B. Prepare and implement community-based employment plan based on evaluation prior to any service phase. This plan will (a) be the product of the evaluation staffing; (b) be prepared by the employment training specialist; (c) identify specific targeted job goal and alternatives; (d) identify work delimiters imposed by client (e.g., minimum pay needed, travel distance from home); (e) identify training services that are anticipated (e.g., job coach time, follow along schedule, transportation); and (f) estimate costs and potential sources to pay for required services.<br>C. Match prospective employee needs (e.g., considering client characteristics, job delimiters and supports needed) to potential job opportunities.<br>D. Interview potential employers and/or conduct orientations for employers and co-workers. |
| 5. Training      | A. Instruct client on specific skills and demands of job.<br>B. Prepare method for transferring case to maintenance job coach for long-term support.   |

**Table 3 (Continued)**  
**Outline of HIRe Model**

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Stages and Steps	Activities
5. Training (continued)	<ul style="list-style-type: none"><li>C. Provide needed employer training and job site preparation.</li><li>D. Conduct necessary job modification and restructuring or acquire appropriate rehabilitation engineering services.</li><li>E. Provide further evaluation with individual for potential remediation of needed job skills and adaptive psychosocial behaviors.</li><li>F. Communicate relevant information and plans to consumer and significant others.</li><li>G. Establish work routine and off-job support plans with individual and identified long-term maintenance job coach.</li><li>H. Establish support and intervention network or resources for individual, including long-term funding sources.</li><li>I. Provide on-job and off-job supports as required.</li></ul>
<hr/> <b>Maintenance</b>	
6. Fading and Transfer to Maintenance Job Coach	<ul style="list-style-type: none"><li>A. Implement plan to fade time intensive support and training services to maintenance job coach.</li><li>B. Employment training specialist provides necessary in-service to job coach prior to transfer and technical assistance following transfer of follow-along duties.</li><li>C. Secure long-term funding and alternative services and resources for individual.</li></ul>
7. Long-term Job Coaching and Support	<ul style="list-style-type: none"><li>A. Employment training specialist transfers the person to the maintenance job coach.</li><li>B. Long-term job coaching provided by maintenance job coach.</li></ul>



**Table 3 (Continued)**  
**Outline of HIRe Model**

Stages and Steps	Activities
7. Long-term Job Coaching and Support (ccatinued)	C. Employment training specialist serves as liaison to other members of the care team (e.g., vocational evaluator, neuropsychologist, rehabilitation engineer, rehabilitation counselor and program consultants). D. Employment training specialist and job coach conduct periodic case reviews and employment specialist provides mentorship to job coach.

### **Assessment and Planning Stage (Steps 1-3)**

Evaluation planning starts once the employment training specialist receives a referral. A referral is initiated using a project referral form, which is followed by a brief interview with the person, the family and significant others. A sketch of background information and current vocational needs are established by the conclusion of this interview. The intake criteria identified on Table 3 are strictly adhered to.

Releases of information must be signed as soon as possible. Obtaining background medical and other records can be a costly and time consuming operation, therefore, an expense account for obtaining records is advised. Time needed to obtain the information may require a trip to a hospital, time and expense to make telephone calls, and costs for copying records. No further evaluation or services should be provided until all requested background information is obtained and an application for other subsequent services is completed. This will eliminate the possibility of repeating diagnostics which have already been completed, as was often the case during the early stages of this project.

When all background information is received, the referred person and the family are invited to an intake interview, at which time all

background information is reviewed for accuracy and completeness.

The Project HIRe Model is based on the premise that traumatic brain injury rehabilitation should include a comprehensive pre-employment neuropsychological and a prescriptive vocational assessment with planning recommendations for dealing with work related problems prior to involvement in community-based employment. Once an evaluation of work skills has been completed, professionals with experience and training in brain injury rehabilitation provided transitional support services in community-based worksites. Later, after the initial period of adjustment to the worksite which includes training in specific work duties, the primary responsibility for management of the case is transferred to a maintenance job coach for long-term support.

The type of vocational assessment necessary to assess a person relative to placement into a community-based employment situation will need to be determined by the evaluator. In some cases, a return to a former level of employment is warranted, which may require a visit to the worksite for an environmental and job analysis, and a brief evaluation in a controlled situation to determine if the necessary skills, aptitudes and behaviors that the person exhibited before the head injury are still adequate for managing a return to work. In other cases, the vocational assessment may require a limited assessment in a controlled situation such as a vocational evaluation laboratory to determine (a) safety awareness, (b) ability to follow directions and instructions, (c) compensatory strategies which are needed or have been developed, and (d) alternatives and methods for interacting with people. A situational assessment in a targeted job area, if one has been identified, or a more extended job trial, may be appropriate for determining compatibility with the job match.

A specific treatment and rehabilitation plan must be stipulated. Ongoing medical appointments, physical, or speech therapy appointments may interfere with a job. Likewise, involvement in ongoing therapy or support programs do not necessarily preclude involvement in the program, but are factors which must be taken into consideration when arranging a placement.

A physical examination should identify the ability of the person to tolerate a minimum of 20 hours of work per week and document any special precautions that must be taken. Finally, a neuropsychological examination must be performed, if a recent report is not available.

Whenever possible, this information should be compiled on the Profiling Forms.

On the basis of background information and the results of a neuropsychological evaluation, the vocational rehabilitation services are formalized and initiated (Step 3). A prescriptive vocational assessment is structured which involves components designed to assess the following:

1. Ability to use a telephone to search for jobs, or to call in sick (if appropriate).
2. Ability to formulate an independent or counselor assisted structured job search.
3. Exploration (through work sampling or situational assessments) of the skills, abilities, and characteristics necessary to achieve targeted job and residential goals.
4. Ability to function on a community-based employment worksite.

A vocational assessment is scheduled after the aforementioned steps have occurred. The primary prerequisite prior to entry into the program should be the establishment of reasonable immediate job goals. Job goals may include work in supported employment situations, but may also involve return to a previous line of work under supervision of a job coach. Second, the referral must be willing to state and accept both a primary and secondary job goal before further action is taken. Third, an immediate residential or living arrangement goal, which is reasonably achievable given potential resources, must also be identified.

During the course of the assessment, the employment training specialist is actively involved in planning and review of evaluation findings. This person is also available for on-the-job interventions, assisting with behavioral shaping and programming, and providing transportation or other required services when needed. The assessment of the referred person's abilities, strengths, and limitations first takes place in situational assessments in protected situations and then at community-based worksites relevant to their identified job goals.

### **Community-Based Employment and Training Stage (Steps 4-5)**

Training and transition planning are central to the philosophy of this model. Training at the job site begins during assessment. In many cases, the job site used in the assessment will be the targeted supported employment job site. Work supervisors serve as primary trainer-supervisors, with the assistance of the employment training specialist who provides initial training, job specific adaptive aids or work site modifications. The employment training specialist lends assistance in management of problem behaviors and assists by working on problem situations. This treatment-training program is intended to provide whatever services are necessary to make the initial transition to the job site and to begin to provide long-term and ongoing rehabilitation services. Coordination with speech, physical, and occupational therapies, medical or drug treatment programs, psychological or psychiatric treatment, engineering or adaptation, activities of daily living and other services as necessary are arranged at this time.

### **Maintenance (Steps 6-7)**

Maintenance requires transferring primary responsibility from the employment specialist to the long-term maintenance job coach and insuring that necessary supports are in place. The employment training specialist continues as the link with the overall rehabilitation team. These persons functions as an interim case manager and works with the rehabilitation team from intake through placement. The long-term job coach, whenever possible, is introduced to the client at the intake interview, in order to become familiar with them from the onset.

Both the job coach and the employment training specialist are involved in the vocational evaluation to some degree, with the employment training specialist having a greater role in assisting the evaluator in tasks which were time demanding or which required specialized attention. When the person was faded to job maintenance, the employment training specialist was available as necessary when problems arose. Typically, several long-term job coaches should be available for providing long-term job services to the head injury referral. Whereas each site may have one employment training specialist for training, many sites will have access to several job coaches to whom the person may be transferred for longer term support services.

For individuals who require ongoing supported employment after the

initial phase-in period (which occurred in the majority of Project HIRE cases), a maintenance job coach is gradually introduced. The maintenance job coach begins working with the person by observing their work, social skills, and behaviors at the transitional employment site. Once transition to the long-term site occurs, the maintenance job coach typically is familiar with the person and anticipates the types of work problems likely to occur and follow-up schedules and interventions necessary.

After transition to long-term supported employment, the employment training specialist provides the initial orientation and training to the work supervisor in cooperation with the long-term job coach. The employment training specialist gradually fades involvement, but remains available for a period up to one year during follow-along status or as an immediate resource if necessary. All persons served, however, continue to have immediate re-access to the program for job coaching and/or intervention from the employment training specialist, who in turn will coordinate these activities with other treatment team members (e.g., physicians, psychologists, physical therapists).

The following are the types of support that need to be in place in the maintenance stage:

1. **Financial supports.** The Community Advisory Committee can be used to examine each supported employment situation to secure the appropriate funding stream. A third party to finance long-term ongoing support services should be sought whenever possible. The services of the employment training specialist may be funded through a state vocational rehabilitation agency, an insurance carrier or other third party funding agents, or through fees generated by the services components. The latter will rarely be the case for most service providers.
2. **Employment supports.** A number of support staff need to be available for both the situational assessment, as well as transitional and long-term supported employment program elements. These support staff may include peer workers (such as a work buddy or job mentor) to aid the worker, transportation and residential services staff, local support groups, and family members.
3. **Other support needs to consider.** It should be expected that many persons transferred to long-term job coaches work with

community organizations that also serve other disabilities. The typical community-based vocationally oriented, not-for-profit rehabilitation facility serves an average of five to eight persons per year in supported employment situations at any given time. Therefore, specifics regarding rehabilitation needs of persons with a traumatic brain injury must be a primary responsibility of the employment training specialist providing assistance and behavioral intervention. Replacement worker services to fill the role of an employee who is not available for work on a particular day must be preplanned, and may be able to be arranged through local resources, and on occasion the involvement of casual employees or sheltered workers from rehabilitation facilities may be used.

### **General Characteristics of Individuals Served in Project HIRe**

**Demographics.** Table 4 presents data describing the characteristics of the persons served in the project. In total, 27 persons were served in some capacity by Project HIRe. Of these, 19 were male and 8 were female. The average age at the referral to the program was 25. A considerable amount of variation between ages is evident, with the youngest person being 18 and the oldest being 51. All persons in the sample were white. This is a cultural phenomena of the midwest and the rural areas included in this study. Marital status for most persons, prior to injury to the time of entry into the project remained approximately the same.

**Coma and Amnesia.** The period of time in a coma and the period of post-traumatic amnesia are typically indicators of the severity of the resulting head injury. Since the information collected was provided by significant others within the head injured person's life, the data may not reflect the accuracy that would have been obtained had hospital records been examined. Hospital records were examined whenever possible to verify the family information and it was found that families were accurate in describing both the coma period and the amnesia period. In many cases, since persons were served in small town hospitals, accurate records of both the length of coma and amnesia period were not available. The average coma length was approximately 32 days, with wide variation being reported among the various subjects. It is curious to note that the average number of days described for amnesia was 16, again with a fairly wide standard deviation being reported. Typically, research literatures suggests that the post-traumatic amnesia period may be 1.5 to 3 times that of the coma period. In this project, the unexpected

short duration of the amnesia period was felt to be related to two primary factors. The individuals with the longest coma periods (which tended to bring the average of number of days in coma higher) for the entire group were not reported. It was difficult for the family in many cases to distinguish when the person emerged from a period of post-traumatic amnesia and which of the amnesic type difficulties were related to memory deficits because of the severe nature of the head injury. For this reason, family members and significant others did not wish to report coma time due to uncertainty. A second factor for the apparently short post-traumatic amnesia periods in relation to the long comas periods was that the period of post-traumatic amnesia is more difficult to quantify, and therefore may be underestimated in the reporting of this data.

**Cause and Severity of Injury.** The data on Table 4 also reveals that the majority of persons studied were considered to have a closed head injury. Seven out of 13 also had a skull fracture as a result of the injury, suggesting the relative severity of the blow to the head that was sustained. Also, the majority of the injuries were sustained in motor vehicle accidents, with one-third of all cases related to alcohol use.

A review of the information regarding the nature of the initial brain injuries and the types of problems being exhibited pointed out the fact that all persons served in this project had significant and severe injuries, whom without support of job coaches and case managers would likely not have the opportunity to access or re-access competitive employment in community-based situations. The general findings of the project, however, were that it was not necessarily the degree of physical disablement that precluded people from working as much as the factors such as lack of insight into the nature of their problems, interpersonal problems, and social and adaptive behavior difficulties.

People who were less predictable in their behavior tended to be the ones that had the most problems. For example, two of the more severely disabled persons from both a cognitive skills and physical skills perspective were very predictable in the manner in which they interacted with other persons. They, therefore, could be managed at the worksite by working around these difficulties. The persons who exhibited wide swings in mood and style of interactions seemed to "catch their employers off guard" and were more likely to exhibit work related problems and work termination because of these behaviors. Employability, therefore, is not only a function of severity of disabilities, but stability of the disability as well.

**Table 4**  
**Personal Characteristics and Accident Information**

<b>Characteristic</b>	<b>Frequency (N=27)</b>	<b>Accident</b>	<b>Frequency (N=27)</b>
<b>Sex</b>		<b>Injury was Considered</b>	
Male	19	Closed head injury	21
Female	8	Open head injury	1
		Skull fracture sustained	7
<b>Race</b>		Uncertain	1
White	100.0%	No response	4
Other	0.0%	<b>Cause of Injury</b>	
<b>Marital Status Prior to Injury</b>		Car w/seat belt	3
Single	16	Car w/out seat belt	4
Married	5	Cycle w/out helmet	3
Divorced	1	Bicycle w/out helmet	1
Separated	2	Other vehicle	2
No Response	3	Hit by car	2
<b>Marital Status After Injury</b>		Fall	2
Single	15	Other	6
Married	7	No response	2
Divorced	3	<b>Alcohol Related Accident</b>	
Separated	0	Yes	5
No response	2	No	10
		Unknown	5
		No response	7
		<b>N</b>	<b>Mean</b>
		<b>Median</b>	<b>Std Dev</b>
<b>Age</b>			
Injury	25	21.68	18.0
Referral	25	30.40	29.0
			11.371
			9.866
<b>Coma and Amnesia</b>			
Number of days in coma	16	31.875	21.00
Length of amnesia	10	16.00	17.50
			42.658
			14.915



## **Descriptors of Traumatic Brain Injury at Referral**

**Physical.** At the time of referral into Project HIRe, information was gathered from family members or significant others regarding their perception of the problems encountered by the head injured person. Data was collected using a Family Interview Form. Problem areas were divided into six categories for convenience in reporting these data. An examination of Table 5 will demonstrate the nature and severity of the problems being reported. Of the physical problems listed, balance was the most common problem, followed by difficulties with walking and lifting. Note that none of the subjects in this study reported spinal cord injuries.

**Sensory.** Within the sensory motor area, 78 percent reported difficulty with coordination, as the highest incidence of all difficulties listed. Over a third reported having seizures, and an examination of this data shows that the majority had a history of seizures, but all of them were either well controlled or in remission at the time of placement into competitive employment. Well controlled seizures were defined as being of relatively low incidence (i.e., less than two times per year), and with adequate pre-ictal warnings in the form of an aura. Finally, well controlled seizures were determined to be controlled in the sense that the convulsions were of relative short duration.

**Cognitive.** Of the cognitive problems noted, memory difficulties topped the list at nearly 86 percent. This was followed by difficulties in visual-spatial skills and defining and carrying out goals, with nearly three quarters of the persons reporting difficulties in this area. All of the cognitive problems listed were admitted to by at least a third or more of the respondents, indicating the significance of the cognitive related deficits as sequela to these injuries.

**Emotional/Behavioral.** Emotional and behavioral problems were common, with three quarters of the persons reporting feelings of frustration, 60 percent reporting depression and over half of them reporting anxiety and anger. This is typical for persons with severe head injury, with frustration, depression and anxiety being the primary emotional behavioral problems exhibited. Few of any of the subjects indicated difficulty with any of the psychotic symptoms such as paranoid behavior or hallucinations. Alcohol and chemical abuse was reported to be a problem in a full 17.4 percent of all cases identified.

**Table 5**  
**Problems Identified for Persons Entering Project HIRe**

Problem Areas	Percent Reporting	Problem Areas	Percent Reporting
<b>Physical (N=24)</b>		<b>Cognitive (N=20)</b>	
Balance	60.9	Memory	85.7
Walking	43.5	Visual Spatial	75.0
Lifting	34.8	Defining and Carrying	
Spinal Cord Injury	0.0	Out Goals	73.7
		Attention	57.9
<b>Emotional/Behavior (N=23)</b>		Self-Monitoring Behavior	55.0
Frustration	75.0	Expressive Language	52.6
Depression	60.9	Receptive Language	50.0
Anxiety	54.2	Sequencing Events	47.4
Anger	54.2	Analyze Social Situations	42.1
Alcohol/Chemical Abuse	17.4	Writing	33.3
Paranoid/Suspicious	12.5	<b>Social Adjustment (N=25)</b>	
Out of Control	12.5	Poor Judgement	56.0
<b>Sensory/Motor (N=24)</b>		Awkward or Uncomfortable	44.0
Coordination	78.3	Irritable	36.0
Seizures	34.8	Impulsive	36.0
Visual	29.2	Abandoned/Rejected	
Pain Perception	17.6	by Friends	32.0
Other	17.4	Immature	28.0
Smell	5.0	Aggressive-Nonassaultive	20.0
Hearing	4.3	Other	8.3
Taste	0.0	Aggressive-Assaultive	8.0
<b>Mobility (N=25)</b>			
Walks Independently	77.8		
Crutches/Walker/Cane	11.1		
Standard Wheelchair	3.7		

**Social Adjustment.** Social adjustment problems were identified in approximately half of all persons, and the majority were having difficulties with poor judgement and awkwardness in social situations. Approximately a third of the population were described as being irritable, impulsive and feeling as though they were being rejected by others. Two people were found to be aggressive and assaultive toward other individuals. These persons needed to be placed in situations in which physical aggressiveness would not place other workers in any immediate danger.

**Mobility.** The mobility factors which were examined showed that the majority of all persons walked independently, with only 3.7 percent requiring a wheel chair, and 11.1 percent requiring some type of crutches, walkers or cane.

### **Service Needs At Referral to HIRe**

A determination of service needs were also made as the people entered the program (See Table 6). For the sake of clarity, service needs were divided into six areas. Among the employment needs, vocational evaluation services topped the list, with nearly half of the persons having received this service, while another nearly 26 percent were involved in or were in referral to evaluation. Work adjustment services and job placement and follow-along services were received by a quarter of the sample.

Eighteen and a half percent of the persons had previously been served in community-based employment, and nearly 15 percent were involved in a community-based employment situation at the time of referral to the project. These individuals had specialized needs involving assessment and community worksite supports that required additional assessment and services which were provided through this project.

Of the remaining services described, the ones that were reported as needed and received most frequently involved neuropsychological evaluation services, speech and language evaluation services, and therapies including physical and occupational therapies.

Table 6  
Service Needs as Identified by Family Members (N = 27)

Service Needs	Previously Received	Receiving at HIRE Start	Service Needs	Previously Received	Receiving at HIRE Start
<b>Diagnostic and Evaluative</b>			<b>Employment Related</b>		
Speech/Language Evaluation	59.3	3.7	Vocational Evaluation	48.1	25.9
Neuropsychological Evaluation	55.6	14.8	Work Adjustment	25.9	11.1
Visual	18.5	7.4	Job Placement/Follow Along Services	25.9	29.6
Hearing	18.5	3.7	Vocational Training	22.2	7.4
Other	3.7	3.7	Supported Employment	18.5	14.8
			Daily Living Skills Training	14.8	7.4
			Day Services	14.8	0.0
<b>Medical Oriented</b>			Sheltered Workshop Employment at Less Than Minimum Wages	11.1	7.4
Medical Care at Home	29.6	11.1	Special Adaptive Equipment or Devices	7.4	0.0
Epilepsy Services	7.4	14.8			
Attendant Care	7.4	11.1			
Nursing Services at Home	3.7	18.5			
<b>Therapy and Education</b>					
Physical Therapy	44.4	18.5	Independent Living Needs		
Speech Therapy	44.4	14.8	Group Home	11.1	3.7
Occupational Therapy	40.7	14.8	Supervised Living Arrangement	3.7	14.8
Recreational Therapy	33.3	29.6	Other	3.7	11.1
Cognitive Rehabilitation	33.3	18.5	Live-in Attendant	0.0	7.4
Education	22.2	7.4	Respite Care	0.0	7.4
Counseling/Mental Health Services	18.5	18.5			
Family Peer Support	18.5	22.2	Other		
Social Skills Training	11.1	11.1	Financial Assistance or Aid Accessible Community	18.5	25.9
Case Management	7.4	22.2	Transportation	3.7	14.8
Behavior Management Programs	7.4	14.8	Dependent Child Care Services	3.7	7.4
Alcohol and Drug Counseling	3.7	11.1	Sexual Counseling and Education	3.7	11.1

## **Employment and Educational Status at Referral**

The employment and education status of persons referred to the program is shown in Table 7. The majority of all persons (55.5%) had completed high school or a general education equivalency diploma prior to their injury. Of those who did not, all of the remaining persons completed their GED or actual high school course work to receive their high school diploma after their injury. Although 14.8 percent were noted to have been involved in vocational and technical training since their injury, none of the individuals attended college after their injury.

Prior to the injury, 11 persons were not employed in any manner, and at the time of the referral to this project, 12 were unemployed. Although 9 persons had been competitively employed prior to their injury, only 5 of those were competitively employed at the time of referral. Some of these individuals were employed but were having problems that required referral for employment support services and some were referred while in a community-based employment program because of additional needs secondary to the traumatic brain injury. Of the 12 persons who were reported as being employed at the time of referral, the vast majority (83%) were considered part time. For those employed previous to the injury, a large majority (67%) were considered full time.

Table 7 also suggests the effects of the traumatic brain injury on both short-term and long-term earning potentials of the head injured person. This information was provided by the family members and shows their concern over the serious effects on the earning potential. In the short-term, only 14.8 percent report little or no reduction in earning potential. These figures represent persons who had a significant head injury, but for whom referral back to a previous employer at the same or similar job was intended. The long-term effects were felt to be less severe for the majority of the persons served, notably because of the potential for improving work skills, and recovery process which family members felt would continue to occur. In summary, nearly three quarters of the families felt that there was a substantial reduction in short-term earnings, and approximately two thirds felt there would be deleterious affects on long-term earning potential of their affected family members.

**Table 7**  
**Education, Employment, and**  
**Earnings Prior to Referral**

Status Measure	Percents Prior to Injury	Percents Since Injury
<b>Education (N=20)</b>		
Grade School	7.4	0.0
High School and GED	55.5	48.1
College	7.4	0.0
Vocational Technical Training	3.7	14.8
<b>Employment (N=23)</b>		
Not employed	47.8	52.2
Community-Based Employment	52.1	34.7
Competitive (including supported employment)	39.1	21.7
Subsidized (JTPA)	4.3	8.7
Self-Employed or Homemaker	8.7	4.3
Sheltered Employment	0.0	13.0
Day Activity Center	0.0	0.0
Work Activity Center	0.0	4.3
Sheltered Employment	0.0	8.7
<b>Potential Impact of Traumatic Brain Injury on Earnings (N=27)</b>		
	Short-Term Earnings After Injury	Long-Term Earnings After Injury
No Effect	3.7	7.4
Mild Reduction	11.1	11.1
Substantial Reduction	25.9	33.3
Severe Reduction	48.1	33.3

## **Clinical Descriptors of Persons Entering Employment**

Information on a total of 23 clients was obtained on the Functional Assessment Inventory. This measure (Crewe & Athelstan, 1984) was designed to assess a person's functional abilities which are transferable to the employment settings. Table 8 illustrates the descriptive measures associated with the administration of the Functional Assessment Inventory. Although these ratings were made at the time of referral to the program, these factors tended to remain stable and therefore a good indicator of the nature of the problems that persons had on the job.

**Functional Limitations.** The distribution of scores within the category of cognitive skills, showed that the majority of the persons included in this study had significant problems with learning ability, memory, and spatial relations. To a lesser degree, some problems were evident in the areas of speech, reading, and writing ability, with the fewest number of persons having deficits in actual expressive language. For the most part, ability to retain new information on the job which is a function of both new learning ability and historical memory seemed to be the most problematic.

In the domain of vision, approximately 26 percent indicated minor problems and 9.0 percent indicated a moderate degree of problems. In regard to hearing, the majority (96.0%) had no problems. In the motor skills area, the greatest problems noted were in the area of motor speed, and to some degree, hand functioning. Upper extremity functioning was also problematic although a larger percentage reported having no problems whatsoever in this area. More than half of the respondents suggested that problems with ambulation or mobility existed.

Insofar as medical conditions, capacity for exertion, endurance and stability of conditions seemed to be the primary difficulties. Seventy four percent did not report any difficulty of a medical nature which caused loss of time from work.

From the perspective of vocational qualifications, all areas listed suggested significant problems, with the exception of the item entitled "Personal Attractiveness." The majority of the persons rated were judged to be without problems in this area, however, the areas including work history, acceptability to employers, skills, access to job opportunities and work habits were consistently rated as being a mild to significant problem. The majority also commented that some degree of

financial disincentive was present, which would also detract from the financial need to work.

**Table 8**  
**Severity of Impairments Rated on the**  
**Functional Assessment Inventory**

Functional Categories and Specific Sub-Categories	Percents and Extent of Impairment			
	None	Mild	Moderate	Severe
Vision	65.0	26.0	9.0	0.0
Hearing	96.0	4.0	0.0	0.0
Economic Disincentives	42.0	25.0	33.0	0.0
<b>Cognitive</b>				
Learning ability	4.0	25.0	33.0	21.0
Ability to read and write in English	33.0	42.0	25.0	0.0
Memory	0.0	12.0	48.0	40.0
Spatial and form perception	4.0	32.0	48.0	16.0
Speech	44.0	35.0	21.0	0.0
Language functioning	78.0	17.0	4.0	0.0
<b>Motor</b>				
Upper extremity functioning	57.0	13.0	30.0	0.0
Hand functioning	39.0	48.0	13.0	0.0
Motor speed	13.0	48.0	35.0	4.0
Ambulation or mobility	48.0	30.0	22.0	0.0
<b>Medical Conditions</b>				
Capacity for exertion	48.0	22.0	17.0	13.0
Endurance	57.0	26.0	17.0	0.0
Loss of time from work	74.0	22.0	4.0	0.0
Stability of condition	22.0	26.0	52.0	0.0



**Table 8 (Continued)**  
**Severity of Impairments Rated on the**  
**Functional Assessment Inventory**

Functional Categories and Specific Sub-Categories	Percents and Extent of Impairment			
	None	Mild	Moderate	Severe
<b>Vocational Qualification</b>				
Work history	17.0	46.0	16.0	21.0
Acceptability to employers	8.0	38.0	37.0	17.0
Personal attractiveness	54.0	29.0	13.0	4.0
Skills	8.0	4.0	67.0	21.0
Access to job opportunity	25.0	42.0	25.0	8.0
Work habits	16.0	20.0	60.0	4.0
<b>Adaptive Behavior</b>				
Social support system	65.0	22.0	13.0	0.0
Accurate perception of capabilities and limitations	0.0	28.0	28.0	44.0
Effective interaction with employees and co-workers	38.0	21.0	29.0	13.0
Judgement	13.0	33.0	42.0	12.0
Congruence of behavior with rehabilitation goals	54.0	25.0	17.0	4.0
Initiative and problem solving	12.0	21.0	17.0	0.0

**Strengths****Percent Judged to Have Strengths**

Physical appearance	0.0
Personality	25.0
Intelligence	17.0
Vocational skill	4.0
Education	8.0
Supportive family	12.0
Sufficient money	17.0
Motivation	25.0
Job available	8.0
Initiative	4.0

The adaptive behavior skills domain found the majority of persons to have social support systems adequate for vocational goals, and a congruence of behavior with rehabilitation goals. The greatest problems occurred in the area of accurate perception of capabilities and limitations, in which none of the persons were seen as functioning at an acceptable range. Judgement was also found to represent a significant problem, with 87 percent reporting some type of problem in this area. Problems with initiative and problem solving ability and failure to demonstrate effective interactions with employers and co-workers were problematic for most persons studied.

**Identified Strengths.** A review of the items under strengths, reveals that the persons being described are seen as having few vocationally relative strengths, with none of the identified areas being rated as a strength or asset in more than 25 percent of the persons. Motivation to succeed and having an exceptionally pleasing personality were the two items scored the highest, with 25 percent of the respondents being rated as having an asset in this area.

### **Vocational Adaptivity of Persons Entering Employment**

The Vocational Adaptivity Scale (VAS) (Thomas, 1988) was used to rate persons served on employment related skills. Vocational Adaptivity Scale ratings were made at the time of a community-based job trial by the work supervisor. Typically, work supervisors had an opportunity to observe clients for at least one to two weeks before making ratings on the Vocational Adaptivity Scale. Following the protocol established for use of the Vocational Adaptivity Scale, two independent raters provided input, and if differences occurred, the case manager mediated and determined the appropriate rating for each particular area. All participants were rated on demonstrated job search skills, interviewing skills, work related skills, supervisory relations and social adaptive behaviors as prescribed in the Employment Readiness Assessment Manual (Thomas & McCray, 1988). Results are reported on Table 9.

A Vocational Adaptivity Scale was completed for all persons who entered this project and were included in a vocational assessment and work trial. In total, Vocational Adaptivity Scale scores were available on 22 persons. The Vocational Adaptivity Scale consists of several parts, which include observations taken during interviews, observations while on a job, which include assessments of social adaptive functioning, interactions with supervisors and peers, and general work related skills.

**Table 9**  
**Scores from the Vocational Adaptivity Scale (VAS)**  
**for Project HIRe Participants**

	n	Mean <sup>1</sup>
Section I - Job Search Skills	23	2.34
Section II - Interview Skills	22	2.49
Section III - General Work Skills	22	2.01
Section IV - Social Adaptive Behaviors	22	2.85

<sup>1</sup> The mean scores listed are grouped by content areas of the Vocational Adaptivity Scale. A 5-point Likert scale was used, with 1 = unacceptable or poor, 2 = marginal, 3 = average or adequate, 4 = above average and 5 = very good or asset.

**Job Search Skills.** A review of Table 9 shows that the majority of all persons rated had significant difficulties in this area. Items dealing with job search knowledge, following through on job leads and producing letters and correspondence were particularly problematic to the vast majority of the persons rated. Despite the fact that many of these persons exhibited the apparent potential to conduct an independent job search, the majority of them lacked the cognitive skills to be able to follow through with this endeavor.

**Interviewing Skills.** Table 9 provides a summary of all persons rated on the interviewing skills portion of the Vocational Adaptivity Scale. Although the clients who were rated fared somewhat better in this area, significant problems were noted in appropriate use of telephone demeanor and language, demonstration of assertive personal approach in the interview, display of general knowledge of the job and company in which employment is being sought, and ability to keep pace and place in the interview. Display of courtesy towards the interviewer was one of the few items in which a majority of the persons functioned quite well, with only 18 percent rated as demonstrating marginal skills or needing improvement.

**General Work Skills.** The general work skills section of the

Vocational Adaptivity Scale is divided into those related to general work skills and those related to supervisory relations. Table 9 demonstrates the ratings achieved on the supervisory relations portion of the general work skills assessment. The vast majority of subjects functioned at a marginal level in each of these areas. Nearly a third of the persons rated had difficulties in following work supervisor's instructions accurately, working independent of the supervisor after initial training period, and profiting from instruction or criticism.

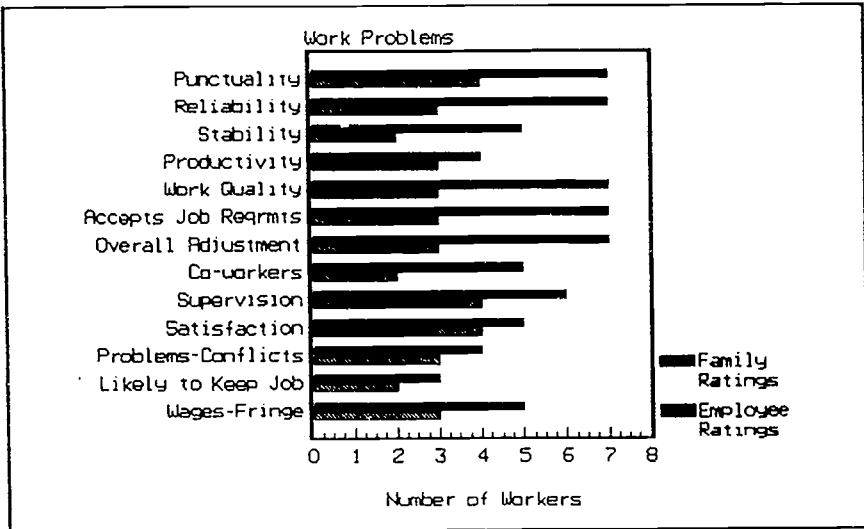
**Social Adaptive Behavior.** In the social adaptive behaviors category, the majority of persons rated had difficulty expressing themselves clearly and efficiently, displaying acceptable expression of emotions, maintaining a realistic opinion of achievements and ability, and displaying ability to being assertive. In this area, many of the difficulties that are exhibited are distributed among the various items depending on the nature of the problems that each individual showed. This phenomena is related to the extreme variability between persons regarding how the traumatic brain injury affects interpersonal relationship skills.

### **Problems Encountered in Employment**

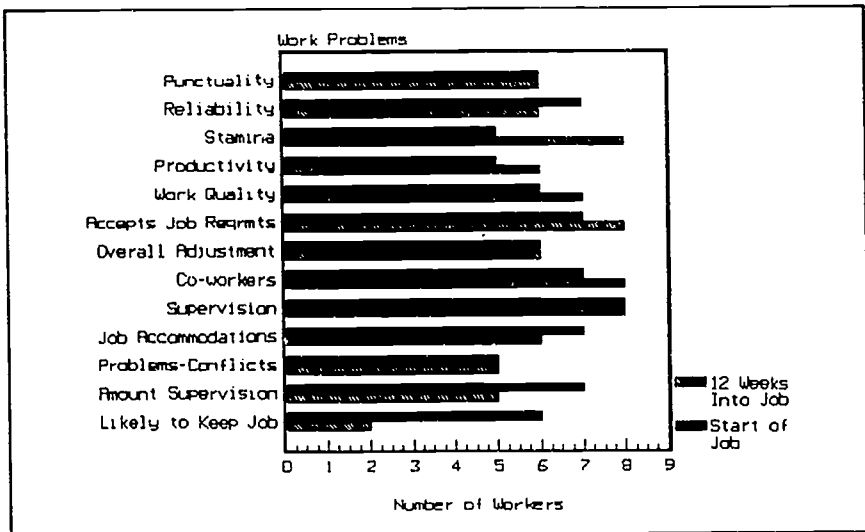
**Worker and Family Perceptions of Work Problems.** Data from both the employee and ratings provided by the family were available on seven persons from the original employment sample twelve weeks after initial employment began and are shown in Figure 1.

In each case, the subjects saw themselves as having less problems on the job than family members did. This inability to perceive the nature of the work problems turned out to be one of the primary difficulties in adjusting people to work. That is, people were unable to notice that they did encounter difficulties with punctuality, reliability, and stability.

**Comparison of Initial to Later Work Problems.** Figure 2 illustrates the differences between initial ratings of supervisors to ratings completed by the same supervisor twelve weeks into the program. The number of persons fell from 24 to 8, because of attrition. The fact that some persons dropped from the program and supervisors of other workers could not provide follow-up ratings because they had been placed in other jobs, resulted in a smaller number of follow-up ratings.



**Figure 1**  
Employee and Family Ratings of Work Problems  
After 12 Weeks of Employment



**Figure 2**  
Supervisor Rating of Problems at Start  
and 12 Weeks Into Employment (N = 8)

At the onset of entry into the project, work supervisors were asked to rate the head injured individual in thirteen areas of functioning deemed important to community-based employment. Each of the areas rated represented an abbreviation of the items included on the Vocational Adaptivity Scale which was completed prior to job placement. Figure 2 illustrates the primary problems identified by supervisors at the onset of community-based employment.

The areas of greatest concern to supervisors involved difficulties with problems and conflicts on the job and inadequate productivity, which were experienced by approximately half of all individuals being served. Additional problems which were found in approximately one third or more of the cases included difficulties with overall adjustment to work, work quality, stamina, amount of supervision required and to a lesser degree difficulties with reliability and punctuality. The least identified problem in this sample included the amount of supervision time required after an initial training period. This, perhaps, was one of the least concerns of the supervisors since at the onset of employment, an employment training specialist (transitional job coach) was available for initial job coaching and case coordination. As employment specialist responsibilities were transferred to the long-term job coach who typically had less time for intervention, the concern of supervisors and the amount of time they needed to spend with the person increased proportionately to the amount of on-the-job support which was gradually being reduced.

**On-the-Job and Off-the-Job Support.** Data was collected on the amount of on-the-job and off-the-job support provided to persons in this project, and is summarized on Table 10. Generally speaking, employment support services can be characterized as pre-employment support, on-the-job support and off-the-job support. The data for the amount of support services rendered includes each of these categories for the majority of all clients.

Pre-employment support services began when a person was referred into a program, and case management services and diagnostic and therapeutic services were provided. This included time spent by project staff in providing these direct services to the person. In some cases duplicative counts were included, although this was not a common occurrence. This happened when a person was being evaluated for therapeutic services while at the same time a job development specialist was working in the field to develop a job commensurate with job goals and work skills.

Table 10  
Forms and Amounts of Supports Used On- and Off-The-Job by 14 HIRe Subjects

Forms of Support Provided	Indianhead (n = 3)			ABC (n = 11)			Total (N = 14)		
	Percent Support Provided	Days Average Per Week	Hours Per Day	Percent Support Provided	Days Average Per Week	Hours Per Day	Percent Support Provided	Days Average Per Week	Hours Per Day
<b>Direct On-Job Forms of Support</b>									
A. Evaluation and assessment	22.69	5.88	1.41	47.83	8.81	2.65	40.67	8.42	2.45
B. Planning or counseling with worker	18.49	2.80	0.76	33.95	0.87	0.57	29.55	1.03	0.61
C. Behavior management or work adjustment	68.49	2.71	0.62	30.27	16.93	4.02	41.15	10.35	2.41
D. On-site job skills training	15.97	3.02	0.80	17.06	5.67	1.95	16.75	5.08	1.63
E. Monitoring productivity/quality	64.71	4.91	1.56	53.68	7.41	2.51	56.82	6.63	2.21
F. Job accommodation/modification	25.63	3.41	0.95	5.18	1.23	0.52	11.00	2.46	0.80
G. Transportation client to job	16.39	3.17	0.73	4.18	1.25	0.55	7.66	2.11	0.66
H. Employer training or intervention	11.34	2.05	0.76	2.17	0.52	0.44	4.78	1.25	0.66
I. Co-worker training or intervention	13.03	1.25	0.44	1.17	1.92	0.82	4.55	1.39	0.51
J. Other support (e.g., family problem)	0.00	0.00	0.00	0.52	1.56	0.61	0.52	1.56	0.52
<b>Indirect Forms of Support</b>									
A. Job analysis/observation	25.96	0.80	0.24	3.49	1.27	0.76	6.94	1.08	0.46
B. Job development	25.00	1.04	0.32	10.82	1.06	0.63	13.00	1.06	0.54
C. Other on-site observation	22.12	0.48	0.10	2.27	0.54	0.50	5.32	0.52	0.25
D. Interagency consultation	6.73	0.51	0.29	35.60	0.79	0.47	31.17	0.78	0.46
E. Coordination of services	16.35	0.51	0.21	28.62	0.83	0.55	26.74	0.81	0.52
F. Travel time required (Job Coach)	46.15	1.75	0.40	28.80	1.35	0.60	31.46	1.40	0.56
G. Data collection and paperwork	71.15	0.80	0.27	47.99	1.17	0.82	51.40	1.12	0.71
H. Training/staff education/reading	4.81	1.33	0.80	1.57	0.47	0.47	2.07	0.69	0.59

Table 10 (Continued)  
Forms and Amounts of Supports Used On- and Off-The-Job by 14 HIRE Subjects

Forms of Support Provided	Indianhead (n = 3)			ABC (n = 11)			Total (N = 14)		
	Percent Support Provided	Average Per Week	Hours Per Day	Percent Support Provided	Average Per Week	Hours Per Week	Percent Support Provided	Average Per Day	Hours Per Day
<b>Off-Job Forms of Support</b>									
A. Housing and residential assistance	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00
B. Transportation (client)	15.38	3.25	1.08	1.27	0.79	0.59	2.09	1.41	0.80
C. Health and medical needs	0.00	0.00	0.00	5.54	4.39	2.39	5.22	4.39	2.39
D. Financial management	0.00	0.00	0.00	0.32	1.25	1.25	0.30	1.25	1.25
E. Job-seeking training/assistance	0.00	0.00	0.00	2.22	1.23	1.05	2.09	1.23	1.05
E. Supportive counseling/mental health needs	33.33	2.08	0.48	11.55	1.12	0.85	12.82	1.17	0.79
G. Planning with family/advocates/caregiver	2.56	1.00	1.00	4.27	0.67	3.47	4.17	0.69	0.49
H. Recreation and social development	56.41	3.74	3.74	58.39	5.94	1.50	58.27	5.52	1.62
I. Support groups (TBI, AA, divorce, etc)	5.13	2.12	2.12	1.74	1.71	1.09	1.94	1.81	1.25
J. Communication - speech	0.00	0.00	0.00	57.44	4.20	0.93	54.10	4.20	0.93
K. Cognitive rehabilitation organization - note-booking, visual spatial orientation	0.00	0.00	0.00	71.84	5.37	1.18	67.66	5.37	1.18
L. P.T., O.T.	0.00	0.00	0.00	38.61	1.65	0.86	36.36	1.65	0.86
M. Other interventions	0.00	0.00	0.00	2.06	1.83	0.85	1.94	1.83	0.85
<b>Totals for Forms of Support</b>									
Direct On-Job Support	97.14	8.74	2.53	61.52	12.36	4.26	68.64	11.45	3.77
Indirect Support	42.45	2.08	0.64	58.95	1.81	0.71	55.58	1.84	0.70
Off-Job Support	15.92	3.86	2.57	65.02	10.02	2.96	55.09	9.27	2.94



It, therefore, is possible that a person may have had ten, twelve or more hours of support services provided per day with varying amounts of support provided by different staff persons. An attempt was made to differentiate the type of support provided but because this did not happen on a regular basis further analysis of this data was not deemed necessary.

On-the-job supports typically involved transporting them to work, training them on the job, communicating with supervisors and providing telephone consultations to supervisors as necessary. All other support services were considered off-the-job support, such as meeting with families, making arrangements with other therapy or service providers for meetings and follow-up services which were provided at the job site.

### **Employment, Retention, and Earnings Benefits**

Table 11 demonstrates the average earnings for each respective individual by site, and also examines the types and settings of each job and the stability of the work. Because of the severity of the disabilities of persons served at the Indianhead site, wages tended to be somewhat lower. Despite the fact that the majority of all persons were involved on scattered supported sites at some point in the project, four months after the project ended, few people maintained competitive/supported employment. This trend was due to the fact that case managers and job coaches were reassigned to other duties due to the withdrawal of project dollars. After loss of individual placements or due to changes in work sites, wages also dropped to the point where nearly half of the people were earning at or below minimum wages.

### **Integration Benefits**

Table 12 summarizes the extent to which job coaches reported integration opportunities for 13 individuals. Opportunities for the supported employees to interact with nondisabled persons on the job was available in nearly 77 percent of the cases and off-the-job in 62 percent of the cases. Where opportunities were available on-the-job, they almost universally took place at work (92%) and to a fairly lesser extent during breaks and meals (69%). In 23 percent of the cases, interactions were known to take place outside work and 84 percent of the supported workers made attempts to interact with their co-workers off-the-job. According to job coaches reporting on the 13 supported workers, attempts by the supported worker to socialize with their co-workers were not reciprocated. This data represents data collected during the active

phase of Project HIRe. Data regarding integration benefits was not available at the four-month post-project follow-up:

**Table 11**  
**Employment Benefits for Last Job Placement at**  
**Replication Sites, 3 Months After Conclusion of Project HIRe**

Employment Variables	Indianhead Enterprises	Ability Building Center	Totals
<b>Number Workers</b>	3	10	13
<b>Job Characteristics</b>			
Average number of jobs	2	2	4
Average weeks of support	9.4	8.2	17.6
Total weeks worked	70	269	339
Total possible weeks worked	73	304	377
Percent Week Worked	95.9	88.5	89.9
<b>Employment Benefits Last Job</b>			
Average hourly rate	2.81	3.29	3.05
Average hours/week	23	19	21
Average weeks worked	15	19	17
<b>Wages Compared to Minimum Wage</b>			
Number Workers Above	2	5	7
Number at or below	1	4	5

1. Figures are based on n's of 3, 10, and 13, respectively, for the two demonstration sites. Persons placed during model development at the pilot site were not included in this table.
2. Minimum wage rates: 1989 - \$3.65; after 1990 - \$3.80.

**Table 12**  
**Opportunities for Integration Among**  
**Clients at HIRe Demonstration Site**

Integration Measures	Percentages of Jobs Providing Opportunities		
	Indianhead (n=3)	ABC (n=10)	Total (n=13) Percentages
Opportunity for interacting with non-disabled co-workers was available on job	100.0	70.0	76.9
Interaction took place on the job	100.0	90.0	92.3
Interactions took place during breaks/meals	100.0	60.0	69.2
Co-worker assisted person with job interview or networked	33.3	0.0	7.7
Opportunity for interacting off job with nondisabled co-workers was available	33.3	70.0	61.5
Interactions in social activities took place outside of work	0.0	30.0	23.1
Worker made attempts to interact with co-workers	100.0	80.0	84.6
Co-worker avoided worker during breaks or social occasions	100.0	100.0	100.0

Average Number of Jobs = 2

1. For all measures, except H, an answer of 'Yes' meant opportunity was available or used.
2. Percentages based on 13 subjects.

## Summary of the Findings of Project HIRe

**Nature of Head Injuries.** The majority of persons studied had a closed head injury. Also, the majority of the injuries were sustained in motor vehicle accidents, with one-third of all known cases related to alcohol use. Family members reported average coma length of 32 days and average number of days in amnesia at 16 (both with wide variations).

**Severity of Disability.** At all three of the sites involved in Project HIRe (including the original pilot site), persons with relatively minor traumatic brain injury as well as severe and catastrophic levels of brain injury were referred to programs. By and large, HIRe subjects were classified as having significant and severe disabilities based on the nature of the initial brain injuries and the types of problems exhibited following their injury. Without support of job coaches, case managers and client advocates, these people would probably not have had the opportunity to access employment in community-based situations.

**Employability of Individuals.** Employability appeared to be not only a function of severity of disability, but the stability of the disability as well. It was not necessarily the degree of physical disablement that precluded people from working as much as factors such as personal insight into the nature of their problems, extent of interpersonal work problems, and general social adaptive behavior difficulties. People who were less predictable in their behavior tended to be the ones that had the most problems. Persons with wide mood swings and styles of interactions with persons which seemed to "catch their employers off guard" were more likely to exhibit work related problems and were subsequently terminated because of these behaviors.

**Earnings From Community-Based Employment.** All sites reported placing people on jobs that were below the minimum wage. Those who were placed below the minimum wage tended to be individuals who were in training or apprenticeship programs in transitional work sites. The difficulties encountered in placing people at a competitive wage rate were related in part to the nature and severity of the disabilities of these individuals.

**Stability of Community-Based Employment.** Portions of the dollars provided by HIRe were used to partially support an employment training specialist's salary at both sites. The employment specialist

functioned in much the same manner at both sites, providing much off-job as well as on-job support. Once funding through HIRe ran out, the on-site support was no longer able to be carried out at the same level of intensity at either facility. Retention of community-based employment among the individuals drastically declined, presumably due to the reduction of systemic supports.

**Impacts of Community-Based Employment in Rural Settings.**

This project demonstrated that when adequate on-the-job and off-the-job support, along with job placement are provided, persons with severe and significant residual impairments and functional limitations as the result of a traumatic brain injury can be employed in community-based settings. In addition, other individuals who are not able to be competitively employed could be placed on community-based jobs at less than minimum wage, or in volunteer situations which may enhance their probability of community integration and independence in social and vocational functioning at a later date. Even though services may not be available in one central location in rural areas, if sufficient up-front case coordination is provided (e.g, assessments, therapies, linkages to services providers), support services in local communities may meet the employment related needs of many of these persons.

**Reasons for Failure.** Persons who tended to fail on the job were those who developed psychiatric related difficulties, medical emergencies, or those who did not demonstrate a motivation to continue. Since these traits tend to eliminate persons from community-based employment situations in urban settings as well, these were not particularly seen as significant barrier to employment caused by the rural environment. A major barrier to providing effective employment services in rural areas was the establishment of a long-term funding stream adequate to provide services necessary for sustaining the person on the job. This included the assistance of job coaches, independent living care-givers, persons to perform emergency and intervention services and services connected with crisis intervention.

**Problems in Delivering Services in Rural Areas.** The relatively low incidence of traumatic brain injury in rural areas due to a smaller population base represents a barrier to the provision of community-based services. Service providers tend to be less well trained, with less experience in working with large numbers of persons with traumatic brain injury, and therefore have less experiences to draw from in the provision of community-based services. Advocates for traumatic brain

injury survivors also face competition for dollars to finance programs for persons without the insurance coverage or available cash to independently fund programs. For this reason it is common to find persons with traumatic brain injury working in programs serving other disabilities.

#### **Characteristics of Persons With Traumatic Brain Injury.**

Persons served in Project HIRe were found to have multiple physical disabilities and resulting functional limitations in addition to the social, emotional and cognitive problems caused by the traumatic brain injury.

Primary difficulties tended to be in the areas of attention and concentration, memory, strength and coordination, stamina, psychosocial and interpersonal skills problems, limitations insofar as cognitive flexibility and insight into the nature of current problems all of which affected integration into stable employment.

Secondary emotional problems resulting from the aggregate of limitations further exaggerates problems in the work-place and created additional problems. This affected how and whether the individual retains employment and achieved satisfying integration with other workers.

**Unpredictable Outcomes.** In general, all clients who were willing to participate in this study and who were accepted using initial intake criteria were provided services. In some cases, the services ended after the intake, initial assessment, and referral to other programs or services. In other cases, referrals went all the way through the project model and through closure into competitive employment. It was difficult to determine from initial impressions whether an individual would be successful in competitive or community-based employment, as well as the types of supports they might require. Community-based job trials were therefore seen as a critical process for analyzing vocational assets and potential as well as determining what types of strategies to employ to offset work related barriers or limitations imposed by their disability.

**Pre-existing and Concomitant Factors.** Persons with pre-existing conditions of alcohol and chemical abuse, history of physical or sexual abuse; individuals who have concomitant psychiatric problems such as hallucinations, explosive disorders, or paranoid related behavior patterns; and persons who demonstrate patterns of conduct related to sociopathic tendencies demonstrate greater difficulty in integration both in the work force and in their social adaptive behaviors in the community. Persons

with these types of behaviors and characteristics are commonly referred to vocational rehabilitation through community mental health workers.

**Typical Traumatic Brain Injury Referral.** A "typical brain injury referral" to community-based employment programs is a misnomer. There are strong correlations between the severity of the injury, length of coma, length of post-traumatic amnesia period, and the extent of cognitive and physical impairments. However, these impairments, do not seem to predict either the extent or type of needed support or the likelihood of success in employment on a case specific basis.

### **Conclusion**

Although the Model described in this chapter was designed for use in non-urban settings, many of the approaches and instrumentation which were field tested appear to have wide applicability. Many of the features of the HIRe Model described in this chapter share common features with any community-based employment approach, and in that respect simply represent what the authors consider solid rehabilitation practices. For further detail regarding this model, readers are encouraged to see the book entitled "Head Injury Re-Entry Project: Final Report," (Thomas and Menz, 1993).

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## *Chapter 6*

### **BEHAVIOR MANAGEMENT OF PERSONS WITH HEAD INJURIES IN COMMUNITY-BASED VOCATIONAL SETTINGS: NEW CHALLENGES FOR PROFESSIONALS**

Gary R. Ulicny, Ph.D.

Persons with traumatic brain injuries frequently exhibit inappropriate or maladaptive behaviors (Prigatano & Fordyce, 1986; Wood, 1987). These behavior problems can include physical and verbal aggression, inappropriate sexual behavior, lack of motivation or initiation, self-injurious behaviors, and numerous other inappropriate or maladaptive behaviors. While the range and intensity of these behaviors are varied, even what appear to be insignificant behavior problems can hamper the person's ability to engage in competitive employment. Many experts in the area of brain injury rehabilitation contend that one of the primary reasons that persons with head injury fail in competitive employment is due to their inappropriate behavior (Ben-Yishay, Silver, Tiasetsky, & Rattok, 1987; Lezak, 1987). In addition to a person's failure on the work site, being labeled as a behavior problem can substantially affect his or her opportunities for competitive employment. Many programs that advertise vocational rehabilitation as one of their services do not accept individuals with behavior problems. Thus, many of these individuals never receive an opportunity to be exposed to vocational services, let alone work competitively.

Recent efforts in vocational rehabilitation have focused on attempting to integrate people with traumatic brain injuries into community-based, normalized environments. Data suggest that even individuals who experience severe traumatic brain injuries are capable of competitive employment, if they are provided with adequate support systems on the job (Wehman & Kreutzer, 1990). This technology, known as supported employment, focuses on moving persons with head injuries into community-based, real work experience as quickly as possible. Supported employment appears well suited to vocational training of individuals with head injury because it eliminates generalization of skills from simulated to real work settings. However, this approach also presents many challenges to professionals who are attempting to place individuals with behavior problems.

While community-based vocational settings present many opportunities for individuals with head injuries to interact with their nondisabled peers, these settings also minimize the amount of environmental control that professionals have. In simulated settings we have a great deal of latitude in providing structure, feedback, and reinforcement to our clients. In real work competitive environments, the reinforcement is often controlled by the setting itself. For example, many vocational settings pay employees twice a month, but we know that for many of the individuals we deal with who have severe cognitive

problems, this schedule of reinforcement would not be sufficient to maintain appropriate behaviors. In addition, the supervisory feedback structure is already in place at the real work setting. In order to attempt to minimize problem behaviors, professionals must be able to take advantage of these naturally occurring cues and reinforcers.

We cannot always be assured that these vocational placement sites will provide a friendly peer support system. There are numerous work site placements where co-workers or supervisors have felt some resentment toward the person with the disability. Most often, this resentment centers on the realization that a person with a disability might be able to do the same job that the co-worker is currently performing. Also, many supervisors may view having to supervise a person with a head injury as an extra burden that is not in their original job description.

Finally, and perhaps most significant, is the more normalized environment available at the work setting also provides more normalized social demands. Behaviors that may be forgiven in a structured rehabilitation setting often can create significant problems in a competitive work environment. The purpose of this chapter is to examine an existing technology that may assist us in placing individuals with traumatic brain injuries in community-based vocational settings.

### **Applied Behavior Analysis As a Tool for Designing Effective Interventions**

Applied behavior analysis is an attempt to establish a lawful science of human behavior (Baer, Wolf, & Risley, 1968). Formulated in the early lab work of scientists such as Watson and Skinner, applied behavior analysis has been demonstrated to be effective in a number of applied human interventions (see Jacobs, 1988, for a detailed historical overview of applied behavior analysis). The key to the effects of applied behavior analysis is establishing a functional relationship between desired changes in behavior and the intervention. Behavioral interventions from an applied behavior analysis perspective typically involve the introduction of environmental stimuli (e.g., antecedents, consequences) to attempt to either increase or decrease a behavior. A consistent aspect of applied behavior analysis interventions is ongoing reliable data collection. Analysis of this data permits the behavior analyst to determine if a functional relationship between the intervention and behavior has been established.

Because applied behavior analysis interventions take place in the competitive work environment and focus on training appropriate behavior as well as suppressing problematic behavior, they may have a number of distinct advantages over other treatments in community-based vocational settings. Two common interventions included psychopharmacological and psychotherapeutic approaches. While the psychopharmacological intervention may be effective in suppressing behavior, it may affect behaviors other than the target behavior. This can impede overall work performance, as well as suppress the inappropriate behavior. Second, the use of some drugs can create a severe safety hazard for the employee and a potential risk for the employer. Many of the medications currently prescribed for behavior management have side effects that could severely impede the head injured person's ability to work safely. Thirdly, the success of the psychopharmacological intervention depends on the client's taking the medication on a regular basis. As discussed earlier, community-based vocational settings present a fairly unstructured environment with few naturally occurring cues that would prompt the individual to self-medicate. Finally, and most importantly, psychopharmacological interventions used alone do not promote learning of appropriate behavior.

Another approach that has received some attention in the literature is the psychotherapeutic approach. Prigatano and Fordyce, (1986) have written extensively on this approach. They emphasize that in order for psychotherapeutic interventions to be effective, a psychotherapeutic milieu must be established. When placing an individual in a community-based vocational setting, the professional has very little control over how to structure the environment. It is often very difficult to manipulate or to shape the environment into a therapeutic one. As a result, the bulk of the psychotherapeutic interventions typically occurs in a different environment, requiring the generalization of behaviors learned in the simulated environment to the community-based, vocational setting.

While applied behavior analysis may have some advantages over other interventions in community-based vocational settings, effective behavior management often must take a very eclectic approach. Combinations of a number of interventions are often necessary to suppress inappropriate behavior and to establish appropriate behavior patterns. Thus, the key to effective behavior management is not always the type of intervention used. Insuring that the intervention that one uses is effectively reducing or increasing the desired target behavior as indicated by the data collection should be viewed as the broader goal.

## **Deciding When to Place an Individual With a Behavior Problem in a Competitive Employment Setting**

On numerous occasions I have heard professionals "...blame the behavior problems of a person with a head injury on the injury itself." For example, the individual who is aggressive is felt to demonstrate that behavior because he or she has a severe frontal lobe injury. While there is no doubt that a severe head injury may contribute significantly to initial instances of inappropriate behavior, the intensity at which that behavior becomes ingrained in the person's behavioral repertoire may be due to a large part on how the environment reacts to the behavior initially. For example, the individual who is permitted to escape from demand type situations because he or she becomes aggressive may be more difficult to treat in the future than the individual who is immediately redirected to complete the task required and reinforced for doing so.

In treating behavioral problems from an applied behavior analysis perspective, there is an assumption that all behavior serves a function. The identification of this function is critically important so that the design of the intervention can be related to the behavior's function. In addition, identification of the function permits the behavior analyst to look at replacing the inappropriate behavior with a more appropriate behavior that serves the same function (Evans & Meyer, 1985).

### **Steps in Conducting a Functional Analysis**

An effective functional analysis attempts to gather as much information as possible about the behavior and the circumstances under which it occurs. The data gleaned from this functional analysis allow the behavior analyst to make data based decisions concerning future placement of the individual with a behavior problem. Listed below are the steps in conducting an effective functional analysis (Evans & Meyer, 1985).

1. *Operationally define the behavior.* In order to institute a reliable data collection system, the target behavior must first be clearly and operationally defined. I often have gone to work settings where clients are having difficulty with a person's problem behaviors. When asked to describe exactly what behavior this client is exhibiting, the response is frequently subjective and unclear. It is critical that all observers of the behavior agree that they are indeed

seeing the same thing and recording the frequency reliably. Thus, this component is critical to carrying out the remainder of the functional analysis.

The key to reliable behavior observation is to define the behavior as simply and specifically as possible. For example, if you are dealing with a person who yells loudly when put in a frustrating situation, the behavior may be defined as "a loud angry yell audible from a distance of 50 feet."

2. *Develop a history of the problem.* In order to begin to make some decisions concerning the intervention that will be most effective with the previously defined behavior, it is important to develop a chronological history of the problem. This history should include an overview of the onset of the behavior and the circumstances under which it was initially exhibited. In addition, it is important to understand how long this behavior has been occurring. It is often more difficult to modify behaviors that have had a long reinforcement history. The best way to gather information for the historical overview is to obtain it from medical records and interviews with the client and family, staff, and significant others who have worked with the person.

Of special importance is noting any recent increases or decreases in the target behavior. This will allow you to make some decision as to whether or not the behavior is exacerbated by certain environmental events (e.g., arguments with spouse). Finally, it is important to document other interventions which have been tried and have been successful or unsuccessful in changing the behavior. It is also important to accurately describe under what conditions these interventions took place and to get some idea of the consistency with which these interventions were implemented (LaVigna & Donnellan, 1986).

3. *Prepare an ecological analysis.* An ecological analysis is an attempt to objectively describe the environment that surrounds the client when he or she is engaged in inappropriate behavior. This analysis should include the location where the behavior occurs; persons who are present when the behavior occurs; and the environmental features such as noise levels and lighting, opportunities for social interaction, and availability of reinforcers in the environment in which the behavior occurs. Chronicling all this information allows the

behavior analyst to then make decisions as to whether or not there is a pattern of environmental stimuli that appear to be contributing to the behavior. For example, in some cases clients act inappropriately with a particular staff member. If the ecological analysis indicates this to be the case, the intervention can be as simple as reassigning that staff member to another client in the program.

4. *Prepare an antecedent and consequence analysis.* Applied behavior analysis tells us that behavior is influenced predominantly by events that occur before the behavior (antecedents) and events that occur immediately after the behavior (consequences). The example of the client who behaves inappropriately only when a certain staff member walks into the room can be used to illustrate this point. This is an example of a stimulus or antecedent event that causes the individual to behave inappropriately. An example of a client whose behavior is controlled to a large extent by consequent events is that individual who, when placed in a demand situation, behaves inappropriately (e.g., aggressive) knowing that the staff member will reduce the amount of demands. Knowing what is either preceding or following a behavior is an important dimension in terms of the subsequent intervention that is designed. Thus, when conducting a functional analysis, it is critical to record these dimensions over a number of time when the behavior occurs.
5. *Conduct a reinforcement survey.* In order to design an effective intervention, it is critical to identify consequences that are reinforcing for each individual. While assumptions may be made concerning what consequences may be reinforcing, a consequence is only considered reinforcing if it produces a desired increase in the target behavior. Thus, any data from previous interventions that have been successful should be extremely useful in conducting a reinforcement survey. As previously mentioned, much of the information concerning what consequences may be reinforcing for a particular person will need to be determined by the client, family members, and staff. A number of texts give detailed presentations on conducting reinforcement surveys (Alberto & Troutman, 1986; Evans & Meyer, 1985; LaVigna & Donnellan, 1986). Moon, Goodall, Barcus, and Brooke (1986) provide a reinforcement questionnaire specifically aimed at identifying vocational reinforcers.

While a number of texts and authors have provided instructions for conducting reinforcement surveys, very little information exists on

identifying optimal schedules of reinforcement in vocational settings. A schedule of reinforcement refers to the frequency at which a reinforcer will need to be administered and still retain its optimal effectiveness. There are two major classifications of reinforcement. The first is a continuous reinforcement schedule, in which the reinforcer is delivered immediately following every occasion of the behavior. Intermittent reinforcement is the second type of schedule, in which the reinforcer is delivered on a variable or random schedule following the occurrence of the behavior. Very few vocational placements work on a continuous schedule of reinforcement. Thus, it will be critical to identify what level of reinforcers will be necessary for a client to maintain optimal performance and whether or not that level of reinforcement is even possible on a job site. One technique for identifying a schedule of reinforcement is reinforcement sampling (Alberto & Troutman, 1986). In reinforcement sampling, the behavior analyst examines the potential reinforcing properties of a number of varying consequences and reinforcement schedules across various work-related conditions. For example, the first week clients may be paid daily for work performed. This schedule may then be faded gradually until the client is on a weekly pay schedule. Changes in the target behavior (i.e., work performance) will let the behavior analyst know what schedule of reinforcement may be the most effective initially for that particular client.

### **Making Database Placement Decisions**

Armed with the information from the functional analysis, the behavior analyst should be in a position to begin to make a placement decision. One of the most critical aspects of the placement decision is the job match. The job match attempts to match specific characteristics of a client to a particular job. Moon et al. (1986) present systematic procedures for completing a successful job match. Their system involves two forms, one to analyze client characteristics and the other to analyze job characteristics. Once these forms are completed, the placement specialist attempts to identify along which dimensions the client characteristics match with the job requirements. In some cases, a non-match will exclude the person from taking that position (e.g., transportation). However, in some cases information is going to be much more subjective. Missing from the current job match literature is a valid objective assessment device that attempts to clearly analyze cognitive characteristics of both the client and the job. For example, few



assessment instruments attempt to objectively assess visual and auditory distractibility.

In addition to a paucity of objective assessment tools for cognitive skills, there are few assessment instruments that adequately assess behavioral problems and their eventual effect on job placement. Often the decision is made based on historical variables or on opinions of professionals who have worked with that particular client. Seldom are all variables taken into account in making a vocational placement decision for a person with an inappropriate behavior.

Listed below are a number of practical, thought-provoking questions that professionals could consider when attempting to place persons with inappropriate behaviors in competitive employment situations. Data necessary for answering these questions would be available through the functional analysis that should have been conducted prior to the placement decision. An expanded job analysis will need to be conducted to examine reinforcement schedules and contingencies, supervisory input, and co-worker attitudes.

1. *Does the behavior pose a threat to the safety of the client or co-worker?* Common sense tells us that we should avoid placing individuals whose behavior may present a safety risk to themselves or others in a competitive employment setting. One question that employers frequently ask is "how will this affect my insurance?" While data suggest that Workers' Compensation claims do not go up when persons with disabilities are hired, it is important that we as professionals attempt to protect both the client and the employer on the job site. Thus, a thorough analysis of the implications of the behavior in that particular job site needs to be addressed. For example, a client who is exhibiting physical aggression towards others may not be a good candidate for competitive employment unless the behavior is brought under control.

On the other hand, it is important that we do not oversensationalize behaviors and exclude the individual from an opportunity to participate in community-based employment. Decisions concerning whether or not the person is appropriate for placement should be made based on an overview of all data available and should involve the client, family, potential employers, and staff who work with or who have worked with the client in the past.

2. *Will the behavior interfere significantly with the client's ability to perform the job?* Competitive employment means just that. The basic premise of community-based employment is that the person with a disability (after training, adaptations, etc.) is able to perform the job at a competitive level. Thus, a critical aspect of matching clients with inappropriate behaviors to a job placement is whether or not they will be able to perform at a competitive rate. Many behaviors not only distract the employees but also interfere with production. It is important that this be taken into consideration during the matching process.
3. *Can the environment be modified to remediate the behavior?* In many cases, environmental modifications can be conducted which will allow the individual to perform the job effectively. For example, a person who has a problem dealing with individuals of the opposite sex may be placed in a department or job where he or she has very little contact with workers of the opposite sex, at least initially.
4. *Will the environment tolerate even a few occurrences of the behavior?* In some cases an inappropriate behavior may not create a noticeable distraction at the work site given the frequency at which the person is engaging in an inappropriate behavior and the environment in which the behavior occurs. For example, the author once placed an individual who had difficulty with inappropriate language on a construction site where his behavior was almost unnoticeable. However, there are a number of behaviors (e.g., verbal aggression, physical aggression, sexual inappropriateness) where one instance of the behavior will create a major distraction on the job site. If we are to move people with disabilities into competitive environments, we must be sensitive to the employer's needs. It is important that we not place individuals with inappropriate behaviors in positions which could potentially have adverse effects on the customer service aspects of employers.
5. *Is a job placement available that will accommodate the behavior?* In conducting an effective job match, it is important to determine whether or not the behavior presents a distraction to others on the job site. A young man whose inappropriate behavior involved loud singing at inappropriate times is a case in point. Functional analysis indicated that this occurred only when he was engaged in some activity such as a physically active work task and only when he was

not within close proximity of other people. A number of interventions were tried but proved unsuccessful because it was difficult to design an intervention for a behavior that occurred primarily in the absence of staff. Since the behavior did not cause problems when other individuals were in close proximity, staff needed to find a job placement that could accommodate this particular behavior. The eventual job placement that was located was a factory laborer position. The job involved the fabrication of light metal materials. This client's specific job was to run a drill press which involved a number of operations on metal materials. The drill press was located approximately fifty feet from the nearest co-worker and the factory had numerous machines operating at one time which was loud, requiring workers to wear ear protection. This example demonstrates that some behaviors, which may appear to be inappropriate, may be accommodated by a selected job placement.

6. *Can the behavior be modified using contingencies that occur naturally at the job site?* As part of our functional assessment, both the type of reinforcers that would be most effective with the client and the schedule of reinforcement necessary to maintain behavioral gains were examined. One of the questions that needs to be addressed in the job match is whether or not the naturally occurring reinforcements or contingencies (e.g., pay, supervisor praise, social interaction with co-workers) will be adequate to maintain minimum levels of the inappropriate behavior.
  
7. *If natural contingencies will not be effective initially, will artificial consequences be acceptable and not interfere with job performance?* If artificial consequences will be necessary to maintain job performance and reduce inappropriate behavior, the placement specialist must ask him/herself whether or not these artificial consequences will interfere with job performance. For example, for a particular client a work break along with a soda or some other type of food item may be the most reinforcing event. The question that must be addressed is "Will this person work at a competitive rate with a number of breaks spread throughout the day?" The placement specialist must also ask "Is it inappropriate to use consequences that may not be acceptable in that particular environment?" For example, if the most reinforcing thing for a particular client is a food item after performing each task this may interfere with job performance and may draw understandable negative attention to the person.

There is a great deal of debate and controversy over the use of restrictive procedures. However, we must recognize that many vocational sites employ the use of restrictive procedures with nondisabled employees (e.g., verbal reprimands, lost wages, termination).

In the case of the use of restrictive procedures for persons with head injury, those procedures should not be unlike any other restrictive procedures that are in effect for other employees. For example, it would not be appropriate to time a person out for instances of inappropriate behavior where other employees would not be reprimanded in the same fashion and the time out periods would reduce the production of that individual.

### **DESIGNING EFFECTIVE INTERVENTIONS**

Once a functional analysis and job match are complete, the behavior analyst is ready to design an intervention for remediating the inappropriate behavior. Thus, it must incorporate information concerning the replacement of the inappropriate behavior with a more appropriate behavior. Reinforcers likely to be the most effective in the work environment must also be identified. How the specific intervention is designed depends on the data gleaned from the previously described procedures. In addition, a number of job-related factors need to be taken into account when implementing these interventions. The key to the design of any intervention is that it must be based on the results of the functional analysis. While this chapter does not permit going into great detail about specific behavioral interventions, these approaches can be found elsewhere (see Alberto & Troutman, 1986; Evans & Meyer, 1985; Rusch, Rose, & Greenwood, 1988).

A number of factors must be taken into consideration when planning and implementing an intervention. Several key points to consider are listed below.

1. *Base the intervention on the results of the functional analysis.* The behavior analyst must seek to replace the inappropriate behavior with an appropriate behavior that serves the same function. For example, if a client is behaving inappropriately to receive attention, special consideration must be made in designing an intervention that provides access to attention based on appropriate behavior.
2. *Educate employers and co-workers.* Very few employers will have

had experience with persons with head injury in vocational settings, let alone those who have inappropriate behavior. It is extremely important that employers be educated and provided with information concerning what to expect. The placement specialist should be honest; he or she must describe the behavior in specific terms including the specific frequency of occurrence. It is extremely important that no surprises come up once the individual is placed on the job. The placement specialist must describe exactly how it is planned to increase or decrease the behavior (describe interventions). It is important that the employer know what procedures will be used and have some input into how disruptive this may or may not be on the job site. Finally, both supervisors and co-workers need to be educated as to exactly what they should do when the behavior occurs. Co-workers and supervisors can be valuable change agents to consider (Shafer, 1986).

3. *Design socially appropriate interventions.* A community setting severely limits the repertoire of the behavior analyst. As mentioned previously, significantly less control is provided at a community-based job site. Thus, intervention should be socially acceptable at the work place, age appropriate, easy to administer and fade, should not interfere with work performance, and preferably should be inexpensive.

All clients have the right to be treated with dignity and respect. All interventions whether positive or restrictive should be evaluated in direct relation to what other workers are exposed to on the job site.

4. *Use naturally occurring cues.* When designing interventions, the behavior analyst should take advantage of whatever cues are currently operating in the work environment. This may include placement of objects, use of co-workers, and existence of any mechanical devices such as lights or beepers.
5. *Program naturally occurring consequences.* The more natural the consequences employed in the intervention, the easier these consequences are to fade. For example, many reinforcing consequences may exist on the job site such as supervisor feedback and praise, paychecks, and social interactions with co-workers.
6. *Make data base decisions.* The cornerstone of any good behavioral intervention is a reliable and valid data collection system. Reliable

data analysis will allow the behavior analyst to make objective decisions concerning changes in the intervention, when to fade the intervention, and when an intervention is successful. All fading decisions should be based on data, not on intuition or convenience.

7. *Collect ancillary data.* It is also very important to collect ancillary data other than information solely pertaining to the problem behavior. This is true, for example, in a case where an inappropriate behavior is reduced but job performance remains unchanged. An important dimension to consider when collecting data is that of social skills. Individuals often fail on the job site due to inappropriate interactions with co-workers, customers, and supervisors. Most successful vocational placements include attention to social interactions.

## CONCLUSIONS

Remediating problem behaviors in community-based settings presents interesting challenges to vocational rehabilitation professionals. As more opportunities become available to persons with head injuries, we must insure that they are not unfairly denied opportunities to be competitively employed. This chapter attempted to provide a systematic process for analyzing behavior and designing socially acceptable interventions at community-based work sites.

The key to employing successful behavior change strategies is a commitment by professionals to implement reasonable and consistent interventions. While the last five years have been an exciting time for professionals who work with persons with head injuries, we must remember that we also serve a different customer. That customer is the employer. When we are placing individuals (especially those with inappropriate behaviors) into competitive work sites, we must put a great deal of time into analyzing the situation to insure that employers are not caught in a negative situation that will, in turn, jeopardize future opportunities for all persons with head injury. An appropriate job match will benefit the client and the employer and will make the job of the vocational specialist easier and more personally rewarding.

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## *Chapter 7*

### **MAINTAINING WORK AFTER TRAUMATIC BRAIN INJURY: EXPERIENCES FROM TWO NEUROPSYCHOLOGICAL REHABILITATION PROGRAMS**

**George P. Prigatano, Ph.D.**

## INTRODUCTION

The long-term physical and psychological outcome of traumatic brain injury (TBI) has attracted considerable study over the last 15 years, even though earlier reports in the literature suggested similar findings (Walker, Caveness, & Critchley, 1969). The seminal work of Bond (1975) and his colleagues in Glasgow drew attention to the importance of residual higher cerebral dysfunction and its negative psychosocial impact. Special interest subsequently emerged over the question of the employability of persons with traumatic brain injury who suffered moderate or severe injuries as predicted by their Glasgow Coma Scale scores (Jennett & Teasdale, 1981). The relevance of future employability to the economic status of the traumatic brain injury survivors, their family, and society at large is immediately obvious. Those who cannot work pose major management problems.

While only limited scientific literature exists on predicting employability after moderate or severe traumatic brain injury, clinical work with these people has led to an appreciation of the importance of certain variables as they relate to work re-entry. A comprehensive review of social and vocational outcome following traumatic brain injury demonstrates the profound effect of traumatic brain injury (Prigatano, 1992). This paper will focus on a single clinical observation and its ramifications from the perspective of rehabilitation: It is not difficult to help moderately or some severely injured young adult persons with a traumatic brain injury to obtain work soon after injury, but it can be exceedingly difficult to help them maintain a productive lifestyle several years after injury.

Several factors influence this observation. First and foremost from a clinical perspective, persons with head injuries, therapists, and family often have a limited understanding of the impact of a brain injury on higher cognitive functioning and personality. Consequently, many persons with head injuries may obtain work for which they are ill-suited. When they inevitably fail, neither they, their therapists, nor their family know what to do. In the worst scenario, people may psychologically "give up" socially and withdraw, eventually becoming socially isolated and dependent on others.

Consideration of seven factors drawn from the clinical experience of attempting to help traumatic brain injury survivors maintain gainful employment (see Table 1) or at least a productive lifestyle after

significant brain injury may help avoid this all too common outcome. These observations emerged from two neuropsychologically oriented rehabilitation programs conducted over the last 10 years. The first program was at Presbyterian Hospital in Oklahoma City; the second is underway at the Barrow Neurological Institute in Phoenix, Arizona.

**Table 1**  
**Maintaining Gainful Employment After Significant  
Traumatic Brain Injury: Seven Propositions**

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1. Without specialty programs, the psychosocial prognosis after severe traumatic brain injury is poor.
  2. Severity of brain injury limits the degree of recovery and the ultimate work outcome.
  3. Problems of impaired self- (and social) awareness are predictors of failure to maintain work.
  4. Approximately 50 percent of young adults with severe traumatic brain injury, who are independent in self-care activities, might be able to return to some gainful employment using specialty programs.
  5. An additional 20-30 percent can function in long-term productive voluntary work settings.
  6. Favorable outcome depends on establishing a therapeutic milieu that incorporates a work trial.
  7. Cognitive retraining and psychotherapeutic interventions are frequently necessary to establish a therapeutic milieu.
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**Proposition 1: Without Specialty Programs, the Psychosocial Prognosis After Severe Traumatic Brain Injury Is Poor**

Comprehensive psychosocial outcome statistics on long-term adjustment after moderate to severe traumatic brain injury are still lacking. However, the literature does offer some clinically relevant information. Early work (Gilchrist & Wilkinson, 1979) has suggested that approximately a third of persons with severe traumatic brain injury

are gainfully employed two to three years post-injury; this work is supported by our own research (Prigatano, Klonoff, & Bailey, 1987). However if the window of observation is extended from just two to four years post-injury to 10 to 15 years post-injury, the number of persons actually working appears to decline. For example, Thomsen (1984) reported that less than 10 percent of severely injured persons are gainfully employed 10 to 15 years post-injury. This statistic is supported by reports of experienced psychiatrists (Cope, 1988). Table 2 compares "productivity statistics" for traumatic brain injury survivors studied at the Barrow Neurological Institute with other reports.

**Table 2**  
**Productivity Statistics by Initial Severity**  
**of Traumatic Brain Injury**

Severity of Injury	Percentages, Status, and Time Post Injury			
	BNI Data (n=88)		Others	
Mild	27	Nonproductive 2-4 years post injury	34	Unemployed 3 months post injury (Rimel, et al., 1981)
Moderate	44	Nonproductive 2-4 years post injury	66	Unemployed 3 months post injury (Rimel, et al., 1982)
Severe	70	Nonproductive 2-4 years post injury	93	Disability pensions 15 years post injury (Thomsen, 1984)

From Prigatano, G. P., Klonoff, P. S., and Bailey, I: Psychosocial adjustment associated with traumatic brain injury: Statistics BNI neurorehabilitation must beat. *BNI Quarterly*, 3(1): 16, 1987. Reprinted with permission of the *BNI Quarterly*.

It can be seen that the number of traumatically brain-injured persons working several years post-injury may decline. If this is the case, what causes this trend? Rutter, Chadwick, & Shaffer (1983) have noted that the performance of brain-injured children on standard IQ tests improves during the first one to two years after injury (Figure 1). Despite this

cognitive recovery, new psychiatric disabilities increase exponentially (Figure 2).

Why do some people show worsening psychiatric status as they improve cognitively? Possibly as patients' cognitive abilities improve, they are allowed to attempt more and, for the first time, they experience social failures. During this time, they may also become partially aware of their difficulties but lack true insight into them.

Commonly encountered failures include difficulties controlling temper, inability to maintain friendships, inability to return the same level of academic or work competence, and trouble making new friends. People with brain injuries become frustrated with these difficulties and often externalize the cause of their failures. They do not properly understand their limitations or the responses they receive from others. Thus, they tend to blame others for provoking them or for evaluating their performance unfairly. This reaction compounds psychosocial difficulties and can even alienate their rehabilitation team. When their rehabilitation therapists become angry, discharge planning often ensues (Gans, 1983).

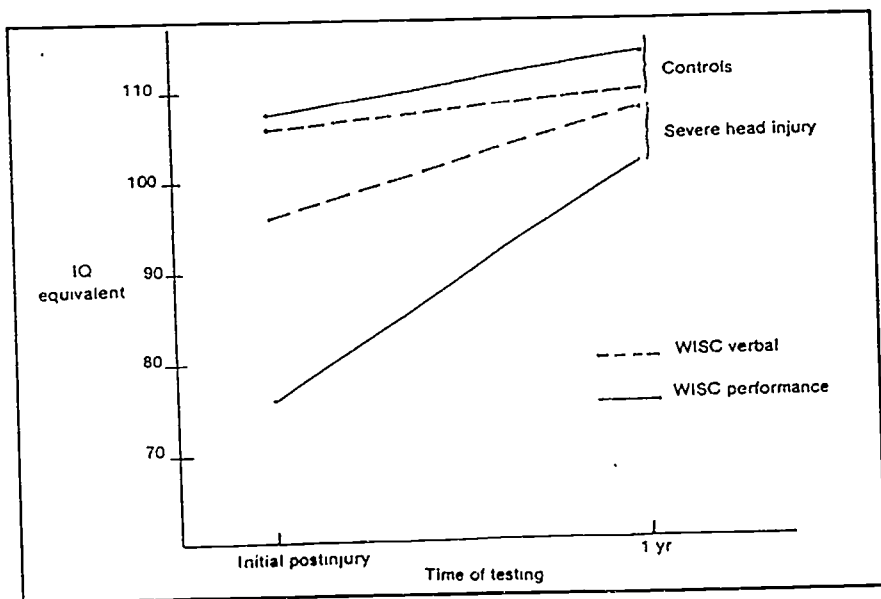
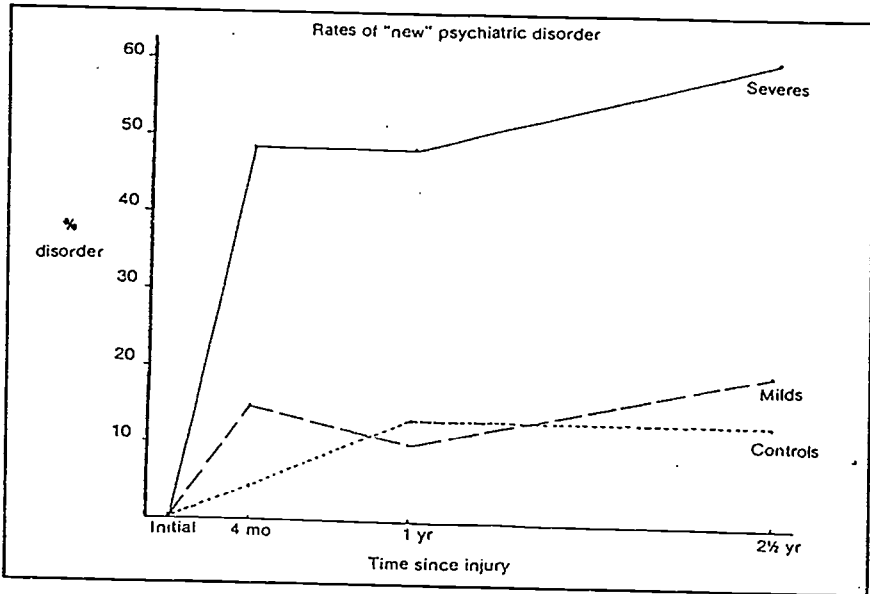


Figure 1

### Cognitive Recovery During the Year After Head Injury

Data from Chadwick, Rutter, Brown, Shaffer, and Traub (1981). Reprinted with permission from Rutter. In Rutter, (Ed.), *Developmental Neuropsychiatry*, New York, The Guilford Press, 1983.



**Figure 2**  
**Psychiatric Disorder Arising After Accident**  
**in Children With Orthopedic or Head Injuries**

Data from Brown, Chadwick, Shaffer, Rutter, and Traub (1981). Reprinted with permission from Rutter. In Rutter (Ed.), *Developmental Neuropsychiatry*, New York, The Guilford Press, 1983.

Traditional rehabilitation efforts have generally failed to address these psychosocial and neuropsychological problems adequately; consequently, specialty programs have been developed (Ben-Yishay, Rattok, Lakin, Piasetsky, Ross, Silver, Zide, & Ezrachi, 1985; Prigatano, Fordyce, & Zeiner, 1986). Compared to 30 percent of untreated traumatic brain injury survivors, 50 percent have been helped to return to work by these specialty programs when outcome is measured two to four years post-rehabilitation. However, the percentage of those working still declines over the years. For example, Ben-Yishay, Silver, Piasetsky, & Rattok (1987) reported that only one-third are working 36 months post-rehabilitation. Nonetheless, this 33 percent employment figure is markedly improved compared to the 10 percent figure reported for those untreated several years after injury (as suggested by Cope, 1988, and Thomsen, 1984).

The details of these programs' organization, methods, and goals are reviewed elsewhere (Ben-Yishay et al., 1985; Prigatano, Fordyce, & Zeiner, 1986; Prigatano, 1989). These few available studies support the

notion that such specialty programs are needed to improve the psychosocial adjustment of moderately or severely injured traumatic brain injury survivors. Traditional rehabilitation does not address their needs adequately.

**Proposition 2: Severity of Brain Injury Limits the Degree of Recovery and the Ultimate Work Outcome**

The length of post-traumatic amnesia (PTA) is significantly related to memory disturbances and work capacity (Bond, 1975) and has long been used as an index of the severity of brain injury (Russell, 1971). Humphrey and Oddy (1980) and Ben-Yishay et al. (1987) have listed studies that address work status post traumatic brain injury. In general, severity of injury is related to work status, but it is complicated to predict which individuals will and will not work after traumatic brain injury for several reasons.

Certainly the pre-injury level of cognitive abilities and the residual neuropsychological deficits, including personality disorders, are important predictors. The author has never found an adult with an admitting Glasgow Coma Scale score of 3, 4, or 5 to return to full-time, competitive, gainful employment. The possibility is not excluded, but is less likely, that severely injured people will return to full-time, gainful employment. Some of these individuals, however, have been able to achieve a productive lifestyle by engaging in voluntary work activities or by working in a protected employment setting. (The reader is referred to Kay, Cavallo, Ezrechi, and Newman [1988] for an annotated bibliography on research dealing with vocational outcome after traumatic brain injury.) While some persons with traumatic brain injury can be helped to adjust to injuries and to achieve a level of productivity, it must be remembered that severity of injury will limit outcome.

**Proposition 3: Problems of Impaired Self- (and Social) Awareness Are Predictors of Failure to Maintain Work**

Survivors of traumatic brain injury suffer from a variety of cognitive and personality disturbances secondary to heterogenous brain insults (Prigatano, Fordyce, & Zeiner, 1986; Brooks, Campsie, Symington, & McKinlay, 1987; Elsass & Kinsella, 1987; Godfrey, Knight, Marsh, Moroney, & Bishara, 1989; Ben-Yishay & Prigatano, 1990). It has been the author's clinical impression that personality disorders are particularly predictive of failure to maintain work (Prigatano, 1987a)

Alterations of self-awareness, which are perhaps a mixture of both cognitive and personality disturbances (Prigatano, 1991; Prigatano, Fordyce, & Zeiner, 1986), appear to relate to poor long-term work and psychosocial outcome. Many clinical vignettes could be cited to support this contention. For example, I have followed a patient for 6-1/2 years post-traumatic brain injury. He continues to report failures in maintaining various jobs but has minimal insight into his contribution to these failures. This person is adequately motivated to work. On his own, he has sought out a dozen jobs in the last four years, including new vocational training. With each new failure, he externalizes the blame and then attempts a new task. This person, who has a severe bilateral cerebral injury with extensive right hemisphere damage, is a classic example of how impaired awareness of residual strengths and limitations after brain injury results in failure to maintain employment. Despite repeated efforts to improve his social and self-awareness, no substantial change has occurred. Ben-Yishay's recent experimental results (reported in Ben-Yishay & Prigatano, 1990) provide empirical evidence of the importance of social adaptation skills and self-awareness in predicting the employability of persons undergoing neuropsychologically oriented rehabilitation. These data will be discussed below.

From our early rehabilitative work, we noted that persons described as "treatment failures" felt they were totally aware of their residual neurobehavioral problems at the end of rehabilitation while staff members felt these persons were grossly unaware of their residual difficulties. In contrast, those described as "treatment successes" stated that they were not fully aware of their residual neurobehavioral problems, and the rehabilitation therapists' ratings showed a close concordance (Prigatano, 1991). Self-ratings of behavioral competencies are not related to whether they are vocationally active, but therapists and family ratings are related to this outcome measure (Fordyce & Rouche, 1986). Despite the importance of this variable to maintaining work and social relationships, little research has been conducted until recently (McGlynn & Schacter, 1989; Prigatano & Schacter, 1991; Prigatano, Altman, & O'Brien, 1990; Prigatano & Altman, 1991).

**Proposition 4: Approximately 50 Percent of Young Adults With Severe Traumatic Brain Injury Who Are Independent in Self-Care Activities Might Be Able to Return to Some Gainful Employment Using Specialty Programs**

As noted, the work of Prigatano, Fordyce, Zeiner, Roueche,



Pepping, & Wood (1984) and Ben-Yishay and his colleagues (Ben-Yishay et al., 1985; Ben-Yishay et al., 1987) suggests that 50 percent of survivors of treated head injury are working two to four years post-rehabilitation. These individuals, for the most part, have been independent in their self-care skills but were, for one reason or another, unable to return to gainful employment without participating in a specialty program. Many of these people had gone through traditional rehabilitation and were from six months to eight years post-injury.

Specialty programs seem to help people to use their residual abilities more efficiently rather than reversing neuropsychological deficits (Prigatano et al., 1984; Ben-Yishay et al., 1985). Some have also been helped to face (accept and be aware of) residual impairment and disabilities. As discussed below, attaining such acceptance enhances an ability to adjust and helps maintain a level of work that may have seemed demeaning or not sufficiently meaningful before injury.

It should be remembered, however, that this 50 percent figure for employability may still decline several years after rehabilitation. Awareness and acceptance is a difficult process that not all people achieve. Failure to do so can be as much a function of pre-morbid personality development (structure and dynamics) as it is of residual cognitive and personality disabilities secondary to brain damage. Some people with severe brain injuries can accept their fate while others resist and reject it. Depending on family resources (financial and emotional), this process can continue indefinitely.

Eventually, however, the realities of life have to be reckoned with. If done productively, even voluntary work can be a meaningful adjustment for certain severely injured people. Elsewhere, it has been argued that "work, love, and play" are living symbols of normality that persons with brain injuries must re-incorporate into life to cope with the issue of "lost normality" after brain injury (Prigatano, 1989).

**Proposition 5: An Additional 20-30 Percent Can Function in Long-Term Productive Voluntary Work Settings**

The initial neuropsychological rehabilitation program at Presbyterian Hospital in Oklahoma City had the expressed focus of returning persons with traumatic brain injury to gainful employment; the Adult Day Hospital for Neurological Rehabilitation at the Barrow Neurological Institute has added a second goal. Those unable to attain gainful

employment have been worked with to achieve home (i.e., self) independence and, when possible, to maintain a productive lifestyle by engaging in meaningful voluntary work. To date an additional 20 to 30 percent of those served have achieved such an outcome.

In some cases, this achievement has been a major contribution to the person and the family's quality of life. One person, for example, uses the ongoing psychotherapeutic support of a neuropsychologist who actively helps the person manage his extremely poor memory and delusional ideation. In contrast, others (and families) reject voluntary work as "stupid" or "giving away free labor." They have yet to learn that the only "stupid" aspect of their situation is giving up active involvement with life--engaging with and helping others as well as themselves.

Future research from the Adult Day Hospital for Neurological Rehabilitation at the Barrow Neurological Institute will assess which patients maintain voluntary work activity, its impact on their daily management, and the long-term financial expenditures of the family and third-party payors. People who can actively engage in work activities outside the home require less daily management; consequently, the cost of their long-term care should decrease substantially. Many others also avoid psychiatric hospitalizations by maintaining a sense of productivity within the context of voluntary work.

**Proposition 6: Favorable Outcome Depends on Establishing a Therapeutic Milieu That Incorporates a Work Trial**

Ben-Yishay and his colleagues (reported in Ben-Yishay & Prigatano, 1990) have recently provided empirical evidence that the ability of persons with traumatic brain injury to learn from group interaction can contribute significantly to a positive vocational outcome. This has likewise been our experience (Prigatano, Fordyce, & Zeiner, 1986). In a retrospective predictive analysis of vocational outcome, Ben-Yishay et al. (1985) found four variables contributed to a multiple R of .81: duration of coma, involvement with others (i.e., ability to relate to and empathize with others), regulation of affect, and verbal abstract-reasoning factor. Length of coma accounted for only 7 percent of the variance (in this patient group), and the neuropsychological variables of abstract reasoning and information processing accounted for 12 percent of the variance; in contrast, involvement with others, regulation of affect, and acceptance/awareness accounted for 42 percent of the predicted

variance for vocational outcome.

Establishing a therapeutic milieu creates a treatment environment that can foster honest dialogue about the effects of brain injury while providing a realistic strategy for coping with the consequences of injuries. The consequences are both impersonal and personal. To some degree, all people with brain injury experience memory deficits, judgment problems, poor hand-eye coordination difficulties, and decreased reaction times--impersonal deficits that reduce employment options but seldom make it impossible to work.

A voluntary work trial can be a vital component of rehabilitation. It allows the person to begin to experience a sense of productivity and thereby partially recapture his or her lost sense of normality (Prigatano, 1989). The work trial uncovers potential difficulties not seen in simple cognitive retraining or psychotherapeutic exercises. It helps patients, therapists, and families to gradually appreciate the realistic effects of brain injury on employability.

If people begin to accept their limitations during rehabilitation, they are more likely to adjust to their traumatic brain injury and, hence, will be more likely to maintain work later. The therapeutic milieu also helps people cope with more personal aspects of brain injury, and this is precisely the goal of individual cognitive retraining and psychotherapy.

**Proposition 7: Cognitive Retraining and Psychotherapeutic Interventions Are Frequently Necessary to Establish a Therapeutic Milieu**

By performing tasks that reveal cognitive deficits (and strengths), people can begin to learn about their impairments and cope with the catastrophic reaction produced by these difficulties (Prigatano, Fordyce, & Zeiner, 1986; Prigatano & Klonoff, 1988). Guiding a person through this learning process requires sensibility and practical thinking from therapists--regardless of their discipline (Prigatano, 1987a). As people become more aware of their residual strengths and disabilities, they can be helped to use compensatory strategies and to alter their home and work environments to accommodate their disabilities. Carl Gustav Jung emphasized that man cannot tolerate a meaningless life (Jaffe, 1984). This statement is true whether we are brain-injured or not. Traumatic brain injury does not prevent people from needing to recapture a sense of meaning in life, even when their memory and abstract reasoning are

substantially impaired. As noted elsewhere (Prigatano, Fordyce, & Zeiner, 1986), the damaged brain recovers from coma by asking the question, "Why did this happen to me?"

It is crucial to the rehabilitation process that people who have been traumatically brain injured have an opportunity to discuss the impact of the brain injury in their life. From this discussion and various rehabilitation activities, important symbols must be rediscovered to help them reestablish a sense of lost normality. As discussed elsewhere (Prigatano, 1989), the symbols of work, love, and play may be crucial to this process. The present chapter focuses, of course, only on the component of work. If work is achieved, however, then the individual will also achieve a level of independence that permits love and play to be seriously considered.

This combination of cognitive retraining, psychotherapy, voluntary work trial, and therapeutic milieu that fosters a treatment alliance among multiple therapists and patients as well as among therapists helps establish a true therapeutic environment that can assist people to re-embrace life and maintain a productive lifestyle.

Although there may be short cuts to this process in any given case, the ultimate adjustment to brain injury is long and difficult. Activities such as supported employment are useful adjuncts to rehabilitation but, in my opinion, in and of themselves, cannot help individuals maintain gainful employment over many years. People who have sustained a traumatic brain injury notoriously lack the self- and social awareness needed to maintain a job during the inevitable ups and downs of any employment situation. Some, however, can learn to appreciate the broader implications of their brain injury and better endure the inevitable difficulties of working. Consequently, they can maintain work while others give up with a sense of frustration and hopelessness.

### SUMMARY

Seven factors that can affect a person's recovery from traumatic brain injury have emerged from clinical experiences of attempting to return young adults with traumatic brain injuries to a productive lifestyle. Although many can obtain employment after injury, others will either give up or be fired if they are not helped to understand and accept the level of work that they can actually do. People also need help in accepting their personal tragedy associated with traumatic brain injury.

By helping them achieve a level of employment that matches their ability and by helping them to reestablish a sense of meaning in their life in the face of their brain injury, their quality of life can be improved substantially and their ability to maintain work several years after brain injury clearly enhanced.

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## *Chapter 8*

### **LONG-TERM CASE MANAGEMENT: A REHABILITATION SYSTEM AND COMMUNITY PROVIDER PERSPECTIVE ON HANDLING CRISIS AND NON-CRISIS PROBLEMS**

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## INTRODUCTION

Change is an inevitable component of life for all people. If we feel dissatisfied with our work, living situation, social networks, or leisure endeavors, we may opt to alter our path in an effort to become more gratified. Unexpected crises, problems, or challenges can also affect various areas of our lives, including job performance and work stability. For the individual with a traumatic brain injury, challenges and changes that are natural to the life process can create significant setbacks if a structured support system is not in place. Cognitive, physical, and psychosocial limitations can directly affect problem-solving abilities for this population. While support and structure are generally offered within the rehabilitation setting, often provisions for facilitating future changes may not be addressed prior to and after discharge. A preventative approach to meeting and managing challenges can begin for the person with a traumatic brain injury within the rehabilitation system and continue upon following return to the community.

For persons with traumatic brain injury, having at least one individual identified to assist with the "management" of their lives can be crucial. Within a rehabilitation framework, this key person is often the case manager. However, following a person's discharge from the therapeutic program, there often fails to be an assumption of the case management role by someone in the community. To ensure continuity of treatment over time, the case manager role should be assumed by a family member, job coach, community member, or significant other. Training this person relative to the responsibilities of case management and educating him/her specific to the clients on-going needs are essential in order to facilitate and assist with adaptations to future changes.

In order to assist the person with a traumatic brain injury in managing challenges effectively, the case manager must appreciate the viewpoint of all parties involved while planning and providing for consistency during transitional periods. Crisis situations must be addressed not only in isolation but also with consideration of how they might impact other areas of an individual's functioning. A family crisis or changes in routines or support systems can ultimately impact personal stability, including maintenance of a job. A holistic approach to managing and meeting challenges is a key component for effective intervention. Maintaining the role of a long-term case manager as the adaptor, facilitator, and partner in charge with the person who has a traumatic brain injury can increase the likelihood of success and

longevity within the work place as well as other areas of the person's life. This chapter will describe the role of the case manager within the rehabilitation setting and outline a rehabilitation model aimed at future crisis prevention. The results of a survey reflecting what constitutes a crisis from the perspective of the person with a traumatic brain injury and his/her significant others will be reviewed, along with preventative measures for each party. Finally, strategies and trends in long-term case management services will be established, with particular emphasis on the impact these services can have on job stability for the person with a traumatic brain injury.

### **CASE MANAGEMENT WITHIN THE REHABILITATION SETTING**

Different definitions have been compiled to describe the area of case management. Shueman (1987) contends that case management "lacks precise conceptual or operational definition. In the absence of a definition, case management typically describes a range of activities that can vary from routine, minimally professional referral services, to primary nursing, to comprehensive care plan development, oversight, and monitoring." Mattson (1988) described case management as the "coordination of treatment needs with available resources to assure quality care and positive outcome utilizing cost effective methods." Case management is viewed by Shipske (1987) as "a problem-solving process through which appropriate services to individuals and families are assured." Wagner (1987) states, "At an agency level, case management may be defined as a strategy for coordinating the provision of services within that system." A case manager's role within the rehabilitation setting, typically, is to advocate for the client, as well as to act as a liaison with family, funding source, and other external collaterals. In addition, the case manager coordinates the therapeutic services provided by the internal rehabilitation team in order to ensure a quality and interdisciplinary treatment plan for those individuals served. Coordination may extend beyond the rehabilitation facility, resulting in external referrals as indicated by the needs of the person with a head injury. The priorities of the clients, their family, clinicians, the funder, and referral sources must all be considered and integrated in an unbiased manner by the case manager. The goal of case management services is to blend the objectives of all involved parties in an effort to achieve the overall outcomes desired.

Within the field of traumatic brain injury, these desired overall

rehabilitation outcomes are typically centered around optimizing the potential of the person with a traumatic brain injury for independent living, participation in productive work activity, and community reintegration (Moore, 1988). Along with steering the person's program to meet these destinations, the case manager is also responsible for ensuring that the clients, the family, and/or the significant others are educated and trained regarding the fundamentals of the case management process prior to a client's discharge from the rehabilitation setting. This "passing of the baton" is a key component for the maintenance of client outcome goals, including work stability, over time.

### **Preventative Measures: Real Life Rehabilitation and Early Discharge Planning**

McMahon and Frasher (1988) state that the "intent behind case management is to move the individual with a head injury from the hospital, back to the community and, if possible, into employment or some gainful activity." In order to realize this intention, rehabilitation efforts at every stage must continually strive to achieve positive and realistic future outcomes, while providing treatment in functional and naturalistic environments that simulate a future living situation of the person. Discharge planning is a phase of rehabilitation programming that is often neglected, yet critical for meeting the future needs of the individual with a brain injury (Deutsch, 1988). Planning for discharge can actually begin as early as the referral phase prior to a client's admission to a rehabilitation program, with continued refinement occurring throughout the evaluation, treatment, and transitional phases. This is a preventative measure to ensure that the rehabilitation plan is congruent with the ultimate desires and abilities of the individual being served following discharge. In order for a person to complete his/her rehabilitation program and, consequently, attain his/her established outcome goals, a number of complex and integrated systems must come together, work efficiently, and hold accountability. The role of the case manager is to orchestrate the rehabilitation team: the person with a traumatic brain injury, family, sponsor, and/or significant others. The case manager must get this team to agree upon future outcome goals that are established at every phase of treatment in an effort to avoid possible misalignment once the client is discharged from the rehabilitation setting.

### **Orchestrating A Rehabilitation Plan**

As a preventative measure to help avert future crises, the case

manager, the person with a traumatic brain injury, the family, the clinical team, and others should ensure that outcome goals are identified and stated in terms of an individual's abilities to perform tasks that exist in the real world. Rehabilitation facilities that offer a residential component can identify these goals in the three major areas of a person's life: the living environment, the community, and the work place. After discharge, each respective setting--the residence, the local community, and the volunteer or work placement site--then becomes the therapeutic milieu for obtaining data and providing direct training (Moore, 1988). Outcome goals reflective of each of these three areas should be projected for several months beyond the anticipated discharge date in an effort to ensure that all plans have been coordinated prior to transition and will remain in place over time. An Individualized Rehabilitation Plan (IRP) can be used as a map of treatment, with the outcome goals extending beyond discharge as the ultimate destination. Efficient and timely rehabilitation plans that account for an individual's abilities in major life areas can act as a prevention of client crises in the future. To encourage early and realistic discharge planning, key elements must be addressed within each stage of the treatment process by the case manager and the rehabilitation team. While there are other models available and utilized for rehabilitation programming, a proactive rehabilitation system is one that incorporates a person's pre- and post-injury abilities and patterns from the initial referral to the follow-up stages. With this approach, realistic planning can occur with provision for change and anticipation for the future. The following guidelines are derived from a rehabilitation model used by the Center for Comprehensive Services, Inc. (1990):

**I. Referral/pre-admission phase**

- A. Gathering of information by admissions
  - 1. Evaluation from previous placement
  - 2. Sponsor's reason for referral/funding constraints
  - 3. Home community information
  - 4. Client/family goals
- B. Preliminary outcome goals established by admissions
- C. Initial Individualized Rehabilitation Plan (IRP) established by admissions

**II. Between admission and completion of evaluation phase**

- A. Conceptualize client prior to injury
  - 1. Address pre- and post-injury personality and behavior

2. Previous work status and attitude
  3. Previous living situations and contribution to the home
  4. Pre-injury social structure and recreational pursuits
- B. Conceptualize the client's strengths and functional limitations/barriers to rehabilitation

### III. Evaluation phase

- A. Outcome goals refined for consistency with evaluation information
- B. Case manager shares client, family and sponsor responses to treatment plan thus far for continued blending of goals with all parties
- C. Client is evaluated both formally and informally in the areas of daily living, ability to integrate into the community, and vocational potential
1. Evaluations occur in vivo (i.e., in the residence, community, and work sites for functional skills assessment)
  2. Information is gathered from client, family, and others related to home community resources and potential job placements post-discharge
  3. Data are obtained relative to client's pre-injury and current style with meeting challenges/crises

### IV. Treatment Phase

- A. Continued refinement of Individualized Rehabilitation Plan/outcome goals to include specifics for discharge plan
- B. Case manager reviews treatment focuses of team for alignment with outcome goals and discharge plan
1. Treatment must reflect the survival skills the client will need post-discharge given the resources anticipated
  2. Transdisciplinary team priorities are established and in line with discharge plan
- C. Case manager reports on sponsor, client, and family considerations and negotiates for changes in light of this information
1. Case manager facilitates clarification of the client, family, and sponsor roles following discharge
  2. Identification of *long-term* case manager is made if an insurance or independent case manager will not be

available post-discharge

- D. Strategies are identified and implemented to compensate for limitations/barriers to success
  - 1. Information is obtained through staff observation and client/family report relative to how client is dealing with challenges, and strategies are refined as needed
  - 2. Teach client the indicating signs leading to a potential crisis
  - 3. Teach the client to ask for assistance from the case manager or significant other prior to a crisis

**V. Pre-discharge phase**

- A. Client's living, vocational, and recreational programs should reflect discharge community (such as level of supervision, types of support needed, etc.) as accurately as possible
- B. Discharge plan is set up and agreed upon by client, family, and sponsor
- C. Consider what the client needs to survive in the living, community, and vocational placements
  - 1. Strategies/systems established particular to each environment
  - 2. Adaptive equipment as indicated for each setting
  - 3. Home programs developed for independent follow-through
    - a. Physical fitness
    - b. Behavioral self-monitoring
    - c. Living/leisure skills
    - d. Vocational "homework"
  - 4. Resource book for home community obtained for specific information/resources
- D. Contact should be made and support established with
  - 1. The vocational placement job coach/work mentor
  - 2. Local community mental health
  - 3. Companion/aide/tutor identified for home program facilitation and/or for long-term case management
  - 4. YMCA/Sports Center
  - 5. Clergy
  - 6. Local Head Injury Support Group
  - 7. Local Center for Independent Living
  - 8. Department of Rehabilitation Services or its equivalent
  - 9. Outpatient Services established with local hospital/community/rehabilitation facility

- E. Education and/or training of the family and long-term case manager should take place (intensive training provided by rehabilitation team in the home environment or at the providing facility)
- F. Consider the following as they relate to long-term management
  - 1. Eligibility for SSDI or other government subsidies
  - 2. Review of medical status/medications
  - 3. Check on guardianship status
  - 4. Set up driver's evaluation if indicated
  - 5. Establish money management systems if appropriate (checking/savings)
  - 6. Client's post-discharge schedule (daily and "big picture")

## **VI. Discharge**

- A. It is anticipated that a person with a traumatic brain injury will meet his/her outcome goals by three months post-discharge
  - 1. All support is in place for the attainment of these goals
  - 2. Specific recommendations in all areas have been followed with future appointments scheduled
  - 3. Long-term case manager has been trained specific to role and client needs
  - 4. Records have been forwarded to new "team"

## **VII. Follow-up**

- A. One-month post-discharge follow-up by rehabilitation case manager with long-term case manager, client, and/or significant others
  - 1. To review discharge recommendations and follow-through
- B. Three-month post-discharge follow-up by rehabilitation case manager with long-term case manager, client, and/or significant others
  - 1. To review client status with set outcome goals
- C. Six-, nine-, and 12-month post-discharge follow-up by rehabilitation facility program evaluation department with long-term case manager, client and/or significant others
  - 1. To review client status with set outcome goals
  - 2. Information obtained is forwarded to rehabilitation case manager for intervention as indicated



## LONG-TERM CASE MANAGEMENT

Most rehabilitation facilities employ a case manager and/or clinical team leader who assumes accountability for overseeing a new referral while involved in programming. Following discharge, however, there often fails to be one key individual identified for the maintenance of the case management role. Funding limitations may prevent the securing of a professional case manager after rehabilitation dollars are spent in the acute and post-acute settings. Training of significant others may not be completed by the transitional and discharge planning phases, or aspects of the individual's and/or family's denial can result in the view that case management services will not be needed in the future. Life care plans are typically set according to the level of functioning and the family and community resources available at the time of discharge. Often, provisions for facilitating and embracing future change are rarely addressed within most individualized rehabilitation plans.

The distinctions between case management as a therapeutic discipline within the rehabilitation setting and long-term case management services are not significant in nature. The primary variations involve the focus of the intervention, the role of the individual providing the service, and the duration of service delivery. Long-term case management can be described as the continued coordination of an individual's life needs with available resources, implementation and ongoing refinement of personal skills and compensatory strategies developed in rehabilitation, and anticipation and management of crisis and change.

### Focus of Long-Term Case Management

The focus of long-term case management is to move the person with a traumatic brain injury away from dependence on medical and rehabilitation professionals to the position of inter-dependence with associates and the community at large. Particular emphasis is placed on assisting with the modification of the person's view of him/herself as a recipient of rehabilitation treatment to that of an independent participant in the life of the community. Autonomy in the areas of daily living, work activities, and social/recreational pursuits continues to remain a primary focus, with the long-term case manager acting as a support for ongoing changes.

## **Types of Long-Term Case Managers**

**Professional Case Managers.** The individual identified to act as a long-term case manager may be a professional, para-professional, family member, or community member. Professional services may be provided by rehabilitation facilities through follow along for an interim period post discharge, although direct contact can be difficult given distance and funding considerations. Insurance companies may employ an internal case manager within their corporation; however, intervention is often limited by policies and/or laws governing the coverage in place. The independent case manager acts as an alternative professional and may be retained by a third party or family to coordinate benefits among insurance carriers and state and federal resources (Mattson, 1988). Professional case managers can also be secured through direct referral to a medical, rehabilitation, or mental health facility when financial support is available. Training specific to individual needs, as well as knowledge and expertise in the area of traumatic brain injury, is necessary for the professional.

**Para-Professionals as Long-Term Case Managers.** Unfortunately, funding limitations are often a consideration for those persons with traumatic brain injury who are in need of long-term case management services. A number of alternatives are available in this instance, including the use of cost-effective para-professionals, such as companions, aides, tutors, or job coaches. Para-professionals might bring previous expertise in working with disabled populations, as well as skills in alternative areas, and the flexibility to act in a variety of different roles. In general, some desirable characteristics to search for in a long-term case manager involve efficiency, good organizational skills, and an ability to communicate in an effective manner (Mattson, 1988). Proficient case managers also demonstrate a keen eye for detail and are resourceful and timely with tasks at hand. In addition, the case management role demands an unbiased and proactive approach while integrating and negotiating among various constituents.

Para-professionals may be screened in light of previous work or academic experience that by nature called forth such characteristics. They can also be selected specific to the individual's interests and/or long-term care needs. For example, if the person with a traumatic brain injury is employed in a sheltered or protected work environment with the staff supervisor available but continues to experience difficulties in his/her free time, the most appropriate para-professional may double in

the role of a companion or facilitator of leisure activities. University students studying in therapeutic recreation or physical/occupational therapies may be ideally suited for this position. If the individual needs additional support in his/her vocational placement, a co-worker or person working in a similar capacity elsewhere may be secured to provide on-site assistance. For individuals requiring direct monitoring when performing tasks of daily living, homemakers and nursing facility aides may be well-suited for the job. The para-professionals as long-term case managers may also interchange their roles within the home, community, and vocational settings, depending on what is needed. Observing the client across various environments will be helpful to a case manager for trouble-shooting challenges unforeseen as well as for networking with alternative resources in a timely manner. Naturally, training and education relative to the individual being served and the foundations of the case management process are essential for the success of the para-professional in the case management role. Specific training must also occur with each turn-over of this job position so that a continuous "passing of the baton" will be maintained over time.

**Family, Friend, or Community Volunteer As Long-Term Case Manager.** A family member, friend, or community associate might also be trained to provide case management services. In many cases, the family ultimately maintains responsibility for its loved one following structured rehabilitation efforts. Unfortunately, it is often difficult to balance the various roles. It is suggested that in addition to the formal training obtained by the previous case manager, the family and client also obtain individual support to enhance overall communication and alignment. Also, a friend or volunteer (such as a church or community group member) can be trained in the case manager capacity in the same manner as family or para-professionals. Again, the key elements for success include early identification of the individual designated for the long-term case management role and direct training by rehabilitation professionals prior to a client's discharge from treatment.

**Client as Case Manager.** Ultimately, the goal of rehabilitation treatment is autonomy for the person with a traumatic brain injury (the identified "client"). In some cases it is possible for individuals to manage their own lives, while others may be most independent when an external support system is available on which to rely. All people depend somewhat upon natural supports such as family, friends, and professionals to assist them in coping and managing life issues; this is the same for the person with a traumatic brain injury. Environmental

supports in the form of work and community systems also provide structures for daily functioning. Just as training must occur for the professional, para-professional, and/or significant others in the role of long-term case manager, persons with a traumatic brain injury must also be given the tools for the management of their lives. This training should be a part of the rehabilitation process with education provided relative to the brain injury itself; it should include what to anticipate in life given the manifestations of the injury. The person with the head injury should also be a part of an educational process involving how to anticipate and predict personal challenges and how to identify resources available to him/her as needed. Learning to ask the appropriate questions and obtain the necessary information prior to a crisis developing is an essential component of daily management for all people. Seeking outside assistance is a natural avenue for support when changes or challenges occur in anyone's life, including the life of a person with a traumatic brain injury.

### **Training a Long-Term Case Manager**

"Passing the baton" from the rehabilitation case manager to the long-term case manager is a crucial component of the rehabilitation process. Early discharge planning, clear and agreed upon outcome goals, and identification of the long-term case manager and his/her anticipated role are all important factors in laying the foundation for this transition. Nevertheless, this is typically a difficult process given the number and dynamics of the individuals involved as well as the geographic distances among all parties. Training of the long-term case manager should occur prior to the client's discharge and may take place at the rehabilitation facility providing service. In this manner, the long-term case manager can observe the person in therapeutic sessions and be taught specific compensatory strategies by clinicians. The rehabilitation case manager can offer information to the long-term case manager relating to the client, family, employer, funder, and potential resources. Training can begin prior to a visit to the rehabilitative facility with the forwarding of rehabilitative reports to the potential long-term case manager along with articles and videos about traumatic brain injury. It is advisable for the long-term case manager to attend the facility's discharge conference in order to familiarize him/herself with the client's past and present functioning, significant family members, and funding representatives.

If it is impossible for the long-term case manager to visit the

rehabilitation setting, the rehabilitation case manager or an alternative clinician should visit the client's home environment as a part of the discharge plan. In this instance, the person with a traumatic brain injury should accompany the rehabilitation case manager to the home locale so that on-site training of the long-term case manager can occur in the home, work, and community settings. If direct visitation is not feasible at either the rehabilitation or home locations, training of the long-term case manager must be facilitated through written communication and telephone conferences among all parties.

The content of long-term case management training should consist of knowledge about:

1. The foundations of traumatic brain injury
2. Implications of the brain injury specific to the person served
3. Compensatory strategies proven effective with the person served in all situations and environments
4. Information relative to trigger situations and previous crises the person served has experienced, as well as future challenges anticipated
5. Resource information including family, funder, professionals and employment contacts significant to the person served
6. Directory of professional and community resources for utilization in the home environment as needed
7. Case manager's role
  - a. Effective communication
  - b. Timely and efficient services
  - c. The art of negotiation
  - d. Client advocacy
  - e. Maintaining the "big picture"
  - f. "Passing the baton" in the future

### **Duration of Long-Term Case Management Intervention**

The duration of long-term case management services is generally based on the needs of the individual. For some, support is necessary only during the adjustment period following discharge from a rehabilitation facility. Others may operate with increased independence throughout their lives when a support system is in place. Of importance is the concept that alternative support and intervention remain available at any point in time, particularly as challenges or changes occur in the life of a person with traumatic brain injury. As this person's skills and

utilization of strategies increase over time, fading of the external case manager role should be facilitated if possible. Autonomy should always remain the goal for both the person with a traumatic brain injury and the long-term case manager.

### **WHAT CONSTITUTES A LONG-TERM CHALLENGE FOR PERSONS WITH TRAUMATIC BRAIN INJURY**

Problems or challenges may manifest themselves differently. The important issue is not the challenge itself, but the manner in which the challenge is responded to and the ramifications this response elicits. For persons with head injury, "change" alone becomes a challenge. Change in a schedule, routine, or task may create a dilemma to a person with a traumatic brain injury. For example, a person who was able to return to work had perfect "on time attendance" until the bus transportation system he used to get to work changed its schedule by fifteen minutes. After the employee arrived at work fifteen minutes late for two weeks, the supervisor became concerned and talked with the employee about his "lateness" problem. When it was identified as a transportation problem as opposed to an attitudinal or motivational problem, the supervisor called the case manager, and the case manager was able to assist in working out a new transportation schedule.

Of all types of changes, however, "people change" creates one of the greatest challenges for persons with head injury. "People change" refers to a switch or replacement of an individual with whom the person primarily interacts around a specific situation. A personnel change of primary therapist, job coach, case manager, supervisor, housemates, etc., may create a sense of loss and anxiety for the person with head injury. It also can create a loss of continuity, especially if one of these individuals is the "change agent," that is, the person who facilitates effective transition. For example, a person with a head injury who was able to maintain competitive employment at Wendy's Restaurant for several years had a good work performance until her supervisor was transferred. The new supervisor was not invested in maintaining the consistency in this employee's work plan. Soon thereafter the employee's performance significantly decreased, and several months later she was fired.

The primary role of long-term case management for the person with head injury is to assist the person to manage change effectively. In order to do this, case management must maintain an unbiased and global

perspective. This means that a viewpoint from the following parties must be considered and integrated: the person with head injury, the family (or significant other), the professionals (if they continue to be involved) the funding source, the referral source, and the employer (whether in a competitive, non-competitive, or community-based rehabilitation facility). Each of these parties often has a different set of criteria for what constitutes a challenge. The following statements were made during a survey utilizing structured interviews from each party about what it would consider a crisis related challenge:

**WHAT CONSTITUTES A CRISIS-RELATED CHALLENGE  
(Schmidt, 1988)**

- I. A crisis from the perspective of a person with traumatic brain injury
  - A. Social isolation
  - B. Lack of significant other relationship
  - C. Absence of something meaningful and productive to do each day
  - D. Dependency on others
  
- II. A crisis from the perspective of the family
  - A. Absence of adequate rehabilitative or long term services
  - B. Absence of something meaningful and productive for the loved one to do with his or her life
  - C. Lack of financial resources to support their loved one with head injury
  - D. Chronic stress over the above
  
- III. A crisis from the perspective of the professional
  - A. The client's cognitive and psychological deficits do not respond to treatment interventions
  - B. The client does not want to comply with treatment
  - C. The client seriously regresses in the discharge environment after having been successful in the treatment environment
  
- IV. A crisis from the perspective of the employer
  - A. The employee can't "keep the pace," and quality or speed of

- work is impaired
  - B. Chronic absenteeism or lateness
  - C. Bothering other workers
  - D. Not staying at the designated work area
  - E. Inflexibility or unwillingness to take on new responsibilities when asked by the supervisor
  - F. An attitude of "bossiness" toward superiors
- V. A crisis from the perspective of the funding source
- A. Having spent significant dollars on rehabilitation with the expectation that the person will become independent; the person regresses post-discharge creating a need for more money to be spent for services to stabilize the client and bring him or her back to the discharge status
  - B. Anytime the "rehabilitation troops" have to be called back to do the work that the funding source believes they have already paid for

It is the role of the case manager at any point in the recovery continuum or cycle to hold the "big picture" in mind as well as to assist others working on the case to see how all perspectives are integrated. The case manager must be able to respond to all "parts," or individual views, while creating a rehabilitation and long-term plan that addresses the gestalt.

### LONG-TERM CASE MANAGER'S ROLE IN IMPACTING A CRISIS-RELATED CHALLENGE

This chapter has already identified the person with a head injury (client), family, professional, employer, and funding source perspectives on what criteria constitute crises or challenges for a person with a traumatic brain injury. We have also discussed the philosophy of functional "real life" rehabilitation as a preventative measure to decrease and/or prepare for crisis situations. The focus of *intervention* for the long-term case manager is to prevent the crisis from occurring for any of the concerned individuals. Intervention techniques are identified from each perspective:

- I. Preventing the client's crises

216

- A. Identification and establishment of a social network



214 / Case Management

- B. Identification and establishment of productive activity
- C. Identification of systems to decrease dependency on others

II. Preventing the family's crises

- A. Identification and education of family related to individual's need of long-term rehabilitation services
- B. Identification of productive activity and education of what can constitute "meaningful" work
- C. Establishment of psychological support for family and client
- D. Exploration of alternative financial assistance
- E. Identification of resources to relieve chronic stress

III. Preventing the professional's crises

- A. Exploration of alternative treatment techniques for increased client response
- B. Understanding of disability and establishment of treatment geared toward realistic goals
  - 1. Implementation of motivational/behavioral contingencies to enhance follow-through
- C. Case manager anticipates and assists with adaptation to change

IV. Preventing the employer's crises

- A. Establishment of step-by-step analysis of work tasks with review of completed products at each step
  - 1. Re-engineering of work duties and/or work environment to promote speed and increase quality
- B. Exploration of reasons for absenteeism or lateness
  - 1. Review of morning routine with provision of checklist strategies to increase timeliness
  - 2. Examination of transportation system utilized and alternatives available to decrease lateness
  - 3. Investigation of physical and mental health status with appropriate intervention to avoid absenteeism
- C. Data collection regarding problem behaviors, with behavioral strategies initiated and carried through by client, co-workers and supervisor
- D. Designated and rigid break times identified, with contingencies in place to increase on task behavior at work station
- E. Case manager receives input from work supervisor related to

the nature of any new responsibilities with task analysis and schedule for completion developed

- F. Case manager provides education to employer relative to behavioral strategies for responding to "bossiness"
  - 1. Client is coached by job coach/case manager relative to effective work behaviors and strategies for self-monitoring interactions
  - 2. Case manager receives feedback from employer regarding client performance and reviews with client at regular intervals
  
- V. Preventing the funding source's crises:
  - A. Proactive and realistic discharge planning by initial case manager and team during rehabilitation process
  - B. Exploration of state, federal, and regional community services available for minimal to no cost
  - C. Significant other trained in long-term case manager role for continued management of client needs

**BARRIERS TO VOCATIONAL RE-ENTRY  
AND EMPLOYMENT STABILITY:  
IMPLICATIONS FOR THE ROLE OF CASE MANAGEMENT**

We have stated in this chapter that the role of the case manager is to (a) plan for and provide continuity between transition points for the person with head injury. This can be referred to as being the "change agent" and (b) provide the gestalt and steer the rehabilitation and long-term planning efforts from this perspective including training a significant other as the long-term case manager for the future.

There is probably no area more critical in which to have both aspects of the case manager role implemented than that of returning and maintaining persons with head injury at the work place. The work place is the most challenging social environment in which individuals interact. It requires one to read and respond appropriately to subtle social cues, to manage authority figures, and to successfully engage peers. In addition to the social demands of the work place, a successful worker must be able to perform his/her job. The work place is more forgiving of performance problems when a worker is skilled at managing the social milieu of work and, likewise, less forgiving when a worker does not get along well with co-workers or supervisors. Therefore, the worst possible

scenario for any worker is to have job performance problems and inappropriate work behaviors.

The "hallmarks" of head injury for many individuals are the challenge of managing and monitoring behavior appropriate to the social demands of a situation and a slowed response time for processing information (Prigatano, 1987); therefore, the work place often presents some of the greatest challenges for people with head injuries. It is the authors' belief that the case manager's efforts to assure continuity and integration among all concerned parties will significantly influence job stability and success.

A follow-up study of individuals with head injury placed in both competitive and non-competitive work situations indicated that those individuals who were still working after three years had someone in their life who was providing case management functions (Schmidt, 1988). Often this individual was a family member.

#### **PREDICTED CHALLENGES VS. ACTUAL CHALLENGES IN MAINTAINING WORK FOR PERSONS WITH TRAUMATIC BRAIN INJURIES**

Over the years the literature has identified variables predicted to interfere with returning persons with traumatic brain injury. Listed below are the ten most frequently cited reasons for poor success in vocational re-entry (Oddy, Humphrey, & Uttley, 1985; Van Someran & Vanderberg, 1985; Ben-Yishay, Silver, Piasetsky, & Rattock, 1987; and Frasier, 1987).

1. Memory problems
2. Changes in personality
3. Loss of emotional control
4. Problems in concentration
5. Slowness in mental processing
6. Social isolation
7. Spontaneity
8. Tendency to fatigue
9. Lack of awareness regarding the implications of their head injury
10. Unrealistic expectations concerning the type of work for which they were suited.

In contrast, the following list identifies common barriers to maintaining work stability over time for people with brain injuries (Ben-Yishay, 1987; Wehman, 1987; Schmidt, 1988). The difference

between predicted barriers to returning people with head injuries to the work place and actual barriers to *maintaining* them at work is noteworthy as it directly relates to the need for long-term case management.

1. Alcohol/substance abuse
2. Behavior outburst and rigidity on the job
3. Forgetting to consistently
  - a. Apply compensatory strategies
  - b. Apply mnemonic aids
4. Financial disincentives to work
  - a. Litigation pending
  - b. Social security benefits
5. Did not like the job
6. Speed of performance was too slow
7. Changes in the support system
  - a. On the job
  - b. In the residence
8. Lack of transportation to and from the work place
9. Socio-economic conditions
10. Changes in supervision
11. Pre-morbid personality and lifestyle

The first list cites barriers for vocational re-entry that are indicative of the physical, cognitive, and psycho-social manifestations of a traumatic brain injury. The second list describes barriers to work stability that include only a few elements directly related to the resulting impairments of a brain injury, with the remaining barriers reflecting pre- and post-injury lifestyle issues. What may be learned from comparing the above lists is twofold: (1) What often looks to be a major barrier for real life situations in a clinical setting is misleading. A goal of rehabilitation should be to assist individuals in their adaptation to real life challenges; therefore, much of rehabilitation must occur in real life environments. (2) The second factor is that ongoing case management efforts must be proactive, preventative, and holistic in order to have the greatest value for the person with traumatic brain injury at the work place. For the long-term case manager to be effective in maintaining work stability, consideration should be given for the use of strategies to circumvent these barriers. Table 1 indicates the strategies case management should use in managing or preventing the barriers to maintaining work stability.

**Table 1**  
**Strategies Used to Maintain Work Stability for Persons**  
**With a Traumatic Brain Injury**

BARRIER	CASE MANAGEMENT STRATEGY
1. Alcohol/substance abuse	Identify tendency during rehabilitation; engage AA resources; teach alternate stress management techniques.
2. Behavior outburst and rigidity	Teach self-regulation strategies during rehabilitation; use work situations as a part of rehabilitation and test all strategies at the work environment to minimize anything that triggers the outburst. Train work supervisor to respond effectively. Implement routine follow-up with client and supervisor.
3. Forgetting to apply compensatory strategies or mnemonic aids	Place mandatory cues in the work place, e.g., attach checklists to the time card. Teach a co-worker to cue or if appropriate, have the supervisor cue. Educate the supervisor on the person's "blueprint" to successful performance. Establish a routine follow-up procedure.
4. Dislikes job	Utilize occupational trials as a part of rehabilitation to solidify and verify work interest. Routinely follow-up and supervise/assist in exploring job options.
5. Speed of performance is slow	Identify work situations where speed is not the highest priority. Work with supervisor on identifying an acceptable performance speed. Ensure proper environmental cues are implemented to maintain performance rate.

**Table 1 (Continued)**  
**Strategies Used to Maintain Work Stability for Persons**  
**With a Traumatic Brain Injury**

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BARRIER	CASE MANAGEMENT STRATEGY
6. Changes in support systems on job and in residence	Teach persons to initiate contact with case manager when personnel changes occur. Orient new personnel to the "blueprint," e.g., compensatory strategies, environmental cues, and structuring needed for optimal functioning.
7. Lack of transportation to and from workplace	This should be evaluated previous to work placement. Working with community-based agencies to access public transportation is a high priority.
8. Socio-economic conditions	Adopt a realistic attitude in discharge planning.
9. Changes in supervision	Utilize approach stated in #6. Also, regular follow-up at the workplace may allow this type of change to be anticipated. Pre-planning for change will diminish its disruption.
10. Pre-morbid personality and lifestyle	Utilize realistic rehabilitation planning and discharge management. Develop a discharge placement plan which recognizes the person's pre-morbid characteristics.

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**SUMMARY AND DISCUSSION**

In this chapter the importance of case management services within the rehabilitation setting has been established for the person with

traumatic brain injury. The role of case management must be proactive and preventative, with a holistic approach to the individual and significant others being served. A crisis may be avoided when rehabilitation efforts are directed by realistic outcomes and timely discharge plans that are geared toward the future. Attention must be given to ensure the alignment of all parties involved throughout each phase of rehabilitation programming.

Unfortunately, the typical case management model has traditionally been facility-based. Often there has been little consideration for the extension of this position if indicated for the person with traumatic brain injury following discharge from rehabilitation treatment. "Passing the baton" from one case manager to the next is a key component for the maintenance of client successful outcomes, including work stability over time. A long-term case manager continues with the coordination of an individual's life needs with available resources, implements and refines personal skills and strategies developed in the rehabilitation setting, and anticipates and manages crisis and change. The primary role of the long-term case manager is to be the "change agent" for the person with a traumatic brain injury. In order to fulfill this role adequately, the case manager must maintain a holistic perspective, while continually striving for autonomy and independence for the person with a brain injury.

The extent to which a person with traumatic brain injury is able to maintain work appears to be directly influenced by the availability of someone carrying out the primary functions of a long-term case manager. Training of the professional, para-professional, family, or community member assuming the position of long-term case manager is essential. Education specific to individualized brain injury, anticipated challenges and intervention methods, and utilization of alternative resources is crucial for the person in the role of long-term case manager.

The need for case management is greater for individuals with a traumatic brain injury than for persons with other disabilities who have no brain injury. The contribution of a normal functioning brain is to process, synthesize, and integrate information in order to direct behavior. When the brain is injured, what was once integrated can become fragmented, and the person with brain injury lives in a world of fragmentation. To some extent, rehabilitation efforts may facilitate reintegration; however, there may remain a lifelong need within these individuals for a structured support system. This support system called case management provides an external structure whereby change may be

processed, synthesized, and integrated for the person living with traumatic brain injury.

### **FUTURE DIRECTIONS**

While there is little documentation available regarding future directions and implications for long-term case management, recent changes in the field of traumatic brain injury rehabilitation are noteworthy as they relate to this role. It appears that funding sources are creating a trend for earlier discharge and shorter lengths of stay, for persons who have a traumatic brain injury, in all phases of rehabilitation. It is becoming increasingly common to find people in post-acute rehabilitation or community-based settings that in the very recent past would have been viewed as appropriate candidates for acute rehabilitation. This trend indicates an even stronger need for case management to serve as the point of continuity between phases of rehabilitation.

With shorter lengths of stay at all levels of rehabilitation, the treatment team realizes increased pressures to facilitate the greatest gains in the shortest amount of time. This pressure creates an environment where clinicians feel they must produce measurable results as indicated by the achievement of successful client outcomes. Often clinicians feel that this "productivity" is the result of building a relationship with the person with a brain trauma injury and significant others. Therefore, the case manager's relationships will play an even greater role during this treatment era. It is anticipated that this trend may increase throughout the 1990s.

Due to the aforementioned factors, it is likely that there will be a movement toward increased reimbursement for case management services in the future, whereas other clinical-based services are likely to be streamlined. This is a distinctive change from the previous decade, where case management was viewed as an "extra" or extracurricular service. In the future, case management will likely be viewed as the vehicle that carries the person with a brain trauma injury through a brief series of rehabilitative services, while providing the pivot point for making these services have meaning in the person's life in the community. The trend for service provision within the home environment will also be a change to be anticipated in the future. This trend may decrease the number of clinicians working with the person with a brain trauma injury, which, in turn, could increase the need for



the case manager to not only be the coordinator of services but also the primary therapist. In addition, the current case manager role as liaison with family, professionals, funders, and others significant to the person with traumatic brain injury is anticipated to continue in the future.

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*Section III*

**PUBLIC POLICY  
DEVELOPMENT**

237

## *Chapter 9*

### **RETURN TO WORK: SUPPORTED EMPLOYMENT STRATEGIES, COSTS, AND OUTCOME DATA**

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## INTRODUCTION

Traumatic brain injury is now recognized as a serious national problem of epidemic proportions. Each year, between 400,000 and 500,000 people sustain a traumatic brain injury (Anderson & McLaurin, 1980; Frankowski, 1986; Jennett, 1983). Approximately 70,000 to 90,000 persons will experience injuries resulting in moderate-to-severe chronic disabilities which will hinder return to a normal lifestyle (Traphajan, 1988). As McMordie and Barker (1988) have documented, the financial burdens of severe traumatic brain injuries for these individuals, their families, and society are staggering. These costs may include medical and rehabilitation expenses, lost wages and independence, and ongoing income and medical maintenance.

A substantial portion of these costs stem from the inability of many severe brain injury survivors to return to stable, productive employment following the injury. Severe traumatic brain injury usually results in deficits of memory or executive function, physical or sensory impairments, psychosocial dysfunction, or any combination of impairments (Vogenthaler, 1987). Kreutzer and Morton (1988) indicate that these impairments most certainly contribute to the generally poor rates of post-injury employment and long-term job retention which have been documented for these individuals.

In recent years there has been an increased interest in improving the long-term vocational outcome of individuals who have survived a traumatic brain injury (Ben-Yishay, Silver, Piasetsky, & Rattock, 1987; Brooks, McKinlay, Symington, Beattie, & Campsie, 1987; Kreutzer, Wehman, Morton, & Stonnington, 1988; Wehman & Kreutzer, 1990; Wehman, Kreutzer, Wood, Stonnington et al., 1989). Studies in the vocational area can be categorized as either clinical intervention or survey. There have been many more of the latter type of study.

Brooks and his associates (1987); Jacobs (1988); Peck, Fulton, Cohen, Warren, & Antonello (1984); and McMordie, Barker, and Paolo (1990) are but some of the more recent investigators that have examined the vocational outcome of traumatically brain-injured survivors. Most clinical researchers have found that the unemployment rate of this population after injury is usually over 60 percent with some figures as high as 70-80 percent. In addition, as Brooks et al. (1987) reported, the length of time post-injury does not positively correlate with the likelihood of return to stable employment. These studies have set the stage for

efforts at clinical intervention programs which can hopefully improve vocational outcome.

In this vein, Prigatano and his colleagues (1983) have used a cognitive training approach; Ben-Yishay and his associates (1987) have used a holistic approach which incorporates cognitive training and occupational trials; Burke, Wesolowski, and Guth (1988) reported an intensive 24-hour residential program with behavior modification as a primary means of vocational training. Each of these approaches, while somewhat different, led to 35 to 50 percent employment rates for participating clients. What is similar about each approach is that intervention occurred *before* a job placement was made. Little or no intervention or assistance occurred while the person was employed, that is, few or no strategies were utilized to enhance job retention.

The purpose of this chapter is to describe how supported employment is being used to provide vocational intervention and training for survivors of severe traumatic brain injuries. This chapter serves to significantly update and extend two earlier reports (Wehman, Kreutzer, Stonnington et al., 1988; Wehman, Kreutzer, West et al., 1989). A key feature of supported employment is the use of an employment specialist, also known as a job coach, who provides training, counseling, and support for the client at the job site (Wehman, Kreutzer, Wood, Morton, & Sherron, 1988). Long-term follow-along support by the job coach allows for resolution of problems of skill generalization, slow production rates, and other behavioral deficiencies. Family and client support groups, substance abuse education and prevention programs, and psychotherapy complement vocational intervention efforts. This chapter presents vocational outcome data collected over a total period of 30 consecutive months. In addition, within the chapter, salient cost data will be provided.

## THE SUPPORTED EMPLOYMENT PROGRAM AT THE MEDICAL COLLEGE OF VIRGINIA

### Participants

The participants in our program were 53 individuals who had experienced severe traumatic brain injuries, consecutively referred to the Medical College of Virginia (MCV) supported employment program, and accepted for services. Demographic characteristics of this group are provided in Table 1.

**Table 1**  
**Demographic Information**

<u>Demographic</u>	<u>Percentages (N = 53)</u>	
<b>Sex</b>		
Male		84.9
Female		15.1
	<u>Mean</u>	<u>Range</u>
<b>Chronological Age</b>		
At Injury	23.6	4 - 64
At Referral	30.6	17 - 64
<b>Educational Level Obtained</b>		
Less than high school	28.3	
High school graduate	34.0	
Some college classes	28.3	
College graduates	9.4	
<b>Etiology of Brain Injury</b>		
Automobile accident	56.0	
Motorcycle/bicycle accident	12.0	
Pedestrian accident	5.0	
Fall	10.0	
Assault	7.0	
Gunshot	7.0	
Other	2.0	
<b>Duration of Unconsciousness</b>	52.9 days	0 - 182
<b>Residential Situation at Time of Referral</b>		
Parent's/other relative's home	49.1	
Own home	35.8	
Adult transitional home	7.5	
Supported/supervised living	7.5	
<b>Mean Length of Time Since Injury</b>	7.0 years	
<b>Percentage on Prescribed Medication</b>	44.0	
<b>Concomitant Significant Disabilities</b>		
<b>Cognitive</b>		
Memory	45.1	
Thinking, reasoning	29.4	

**Table 1 (Continued)**  
**Demographic Information**

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<b>Medical</b>	
Physical impairments	37.3
Seizures	19.6
Visual impairments	15.7
Physical weakness	15.7
Hearing impairments	5.9

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In order to be accepted for services, an individual must (a) be of working age (between 18 and 64), (b) have a history of severe head injury (score lower than 9 on the Glasgow Coma Scale on admission after injury), (c) have no evidence of active substance abuse, and (d) present strong indications that he or she cannot work without ongoing job support. These indications may be found in the individual's post-injury work history or in reports from the individual's family, physician, or rehabilitation counselor. Individuals are not excluded from the program on the basis of the nature or severity of their physical, cognitive, or behavioral impairments.

### **Instrumentation**

Information was obtained using two established data collection instruments: the patient information system developed by the Department of Rehabilitation Medicine at the Medical College of Virginia (MCV), and the Supported Employment Information System developed by the Rehabilitation Research and Training Center on Supported Employment (VCU-RRTC) at Virginia Commonwealth University.

**Medical College of Virginia Patient Information System.** The Medical College of Virginia patient information system is a data base which includes information from a series of questionnaires completed by a client's family members or primary caretakers. If a family member or primary caretaker is unavailable, the questionnaires are completed by the vocational rehabilitation counselor or another professional who is familiar with the patient. Questionnaires were completed via mail and/or structured interviews immediately following the client's referral to the supported employment program.



The information system contains data from a number of questionnaires. The Long Range Evaluation System (Granger, 1982) provides information about a client's ability to carry out activities of daily living including communication, ambulation, toileting, eating, and dressing. Pre- and post-injury alcohol use patterns are assessed via the abbreviated version of the Michigan Alcoholism Screening Test (Zung, 1979; Zung & Charalampous, 1975) and the Quantity-Frequency-Variability Test (Cahalan & Cisin, 1968). The General Health and History Questionnaire (Kreutzer, Leininger, Doherty, & Waaland, 1987; Wehman, Kreutzer, Sale, et al., 1989) provides comprehensive data regarding the nature and severity of injury, medications, and pre- and post-injury employment and education. Information regarding behavioral, cognitive, social, communication, and physical problems attributable to the client's head injury is also obtained.

Table 2 compares clients' work histories pre- and post-injury, including the percent who were competitively employed during each period, their mean hourly wage and work hours per week, and the mean monthly employment ratio. The monthly employment ratio, described by Wehman, Kreutzer, West et al. (1989), is a measure of employment stability calculated by dividing the number of months a client was employed during a particular period by the total number of months he or she could have been employed. This information was collected from the family member or other significant person serving as respondent.

**Supported Employment Information System.** All vocational data were collected using the Supported Employment Information System (SEIS), which consists of nine data collection forms completed by several key staff. The SEIS collects over 200 data elements related to (a) demographic and historical information for the client, including functional limitations; (b) employment outcomes such as wages, work hours, fringe benefits, supervisor ratings, duration of employment, and effects of employment on government and other benefits; and (c) units and types of services provided to each supported employment client.

Forms were completed and submitted by employment specialists on a prescribed schedule. Demographic and historical information was collected once, at the point of referral to the supported employment project. Employment data were collected from the date of first placement and updated at regular intervals throughout the individual's employment history. Service units, in the form of clock hours of client-specific intervention time, were recorded daily.

**Table 2**  
**Occupational Histories (N = 53)**

Employment Variable	Pre-injury (N=44) <sup>1</sup>	Post-injury (N=53)
Percent competitively employed	91.1	35.8
Mean hourly wage	\$5.84	\$3.89
Hours worked weekly	35.9	27.3
Monthly employment ratio <sup>2</sup>	89.18	15.37

<sup>1</sup> Includes only clients injured while of working age (16-65).

<sup>2</sup> The monthly employment ratio is determined by dividing the number of months a client was employed during a period by the number of total months during the period. A ratio of 100 percent indicates continuous employment.

**Medical Evaluation.** All referred clients in the supported employment program are referred for a psychiatric evaluation during which decisions are made regarding the ongoing need for physical and psychosocial rehabilitation. The psychiatrist evaluates the client to determine neurologic status as well as level of independence in activities of daily living. Neuroradiologic examination, seizure management and prophylaxis, and pharmacologic intervention for behavioral, sleep, and appetite disturbance may be required. A number of clients suffer from debilitating headaches which can be managed pharmacologically. Furthermore, rehabilitation services including physical therapy, occupational therapy, and communication skills training are provided by experienced allied health professionals. Therapeutic activities are oriented toward enhanced employability and community living skills.

**Neuropsychological Data.** A set of objective tests is used to understand the client's level of cognitive, psychomotor, and emotional functioning. Selection criteria for the inclusion of tests within our battery included demonstrated predictive validity related to employment (e.g., see Brooks et al., 1987; Ben-Yishay et al., 1987), relevance to functional abilities, and the availability of normative data for uninjured persons as well as persons with brain injury. Traditional neuropsychological tests from the Halstead-Reitan Neuropsychological

Test Battery include the Category Test, Trail Making Test, and Dynamometer Grip Strength. Selected subtests of the Wechsler Adult Intelligence Scale-Revised are used to assess intellectual and memory skills. Functional skills are measured via the Wide Range Achievement Test and the Gray Oral Reading Test-Revised. The Minnesota Multiphasic Personality Inventory (MMPI) is used as a measure of emotional and personal functioning. Test results are considered along with the client's self-report in efforts to establish firm conclusions regarding emotional adjustment.

Preliminary analysis of neuropsychological data suggests that most clients fall below the mean in virtually all areas of academic and cognitive functioning. Clients perform similarly and poorly on many of the tests relative to the noninjured population. Percentile scores on reading and spelling typically average between the 30th and 40th percentile. Most impaired are performances on measures of learning, verbal memory, and motor speed. These findings are consistent with problems observed by employment specialists in the workplace and reported in the literature. Elevated scores on the MMPI are typically most evident on scales 2, 4, and 8. High scores on these scales are often indicative of depression, social isolation, alienation, family conflicts, perceptual disturbances, and disorientation.

### Procedure

**Supported Employment.** Supported employment is defined in the 1986 Amendments to the Rehabilitation Act as "paid work in a variety of settings, particularly regular work sites, especially designed for handicapped individuals: (1) for whom competitive employment has not traditionally occurred, and (2) who, because of their disability, need intensive ongoing support to perform in a work setting" (Federal Register, August 14, 1987, p. 30550). This commitment to periodic job skills reinforcement and other long-term support services distinguishes supported employment from traditional vocational placement models. In addition, supported employment typically involves little or no pre-placement work adjustment or training activities, instead emphasizing training and interventions in natural settings, such as the consumer's home or place of work (Mank, Rhodes, & Bellamy, 1986; Kreutzer & Morton, 1988).

Supported employment has been operationalized in the rehabilitation literature as a number of individual and small group placement models

(Mank et al., 1986; Moon & Griffin, 1988). All of the participants in the current study were placed using the supported competitive employment model described by Wehman and Kregel (1985). This model is distinguished from other supported employment models by (a) individual placement into competitive positions paying at least minimum wage and (b) the provision of job site training and support services by a trained rehabilitation professional often referred to as a job coach or employment specialist.

The program components of supported competitive employment for persons with severe traumatic brain injury have been described in detail in previous articles (Wehman, Kreutzer, West, et al., 1989; Wehman, Kreutzer, & Stonnington, et al., 1988). These components are briefly described below:

1. *A job placement* is made following an extensive ecological analysis of potential work environments and consumer abilities, limitations, and interests. Because the employment specialist provides training at the actual work site, people can be matched to jobs which they are not initially able to perform. The employment specialist will also consider such factors as the availability of transportation, family input and commitment, effects on benefits, and the expectations of the person in assisting him or her to make realistic career choices.
2. *Job-site training and advocacy* efforts are individually determined for each placement. This phase will typically include training in performing job-specific tasks to acceptable levels of quality and quantity. During this phase, the employment specialist might also need to restructure the work environment or adapt tools and equipment to accommodate a client's physical or sensory limitations. Deficits in reasoning, memory, and other cognitive areas might be addressed through the use of compensatory strategies (i.e., checklists or other prompting systems). These strategies have been previously documented and published (Wehman, Kreutzer, Sale, et al., 1989; Kreutzer, Gordon, & Wehman, 1989).

The employment specialist must also attend to the social acclimation of the person into the work setting by stimulating positive workplace interactions and minimizing aberrant or unusual behaviors. During the training phase, the employment specialist would address these behaviors through counseling and training in self-management of behavior. In addition, the employment specialist might discuss

potential problems with the employer and coworkers and establish an array of appropriate responses.

As would be expected, the job-site training period requires a great deal of staff time and involvement. During the initial weeks of employment, the employment specialist will typically remain with the person who has a head injury for 100 percent of his or her scheduled work time. As the person becomes more proficient with the job tasks and social interactions, the employment specialist's presence at the job site is gradually faded.

3. As mentioned previously, *ongoing assessment and support* are distinguishing and indispensable components of supported employment. After the person has achieved competence, the employment specialist will continue to monitor his or her work performance and social adjustment through objective measures and interviews with the worker, employer, coworkers, and family members. The employment specialist's objective is to identify and address any problem areas before they become job-threatening. Intervention will also be needed for incidents which occur outside the work setting which may affect job performance--such as financial or family difficulties, use of alcohol or drugs--and interfere with benefits.

**Funding Coordination and Units of Service.** Supported employment consists of time-limited services (typically funded by the state vocational rehabilitation agency) and extended services (funded by other sources, typically the state mental health/mental retardation/developmental disabilities agencies). The need for funding coordination across time-limited and extended service phases requires the use of uniform units of service for rate-setting and measuring the extent of services provided. In Virginia, where the MCV program was conducted, the unit of service is *clock hours of staff time* which can be tracked to a specific client (Hill, 1988). Time devoted to activities required for the general operation of the program are not tracked or billed. Hourly direct contact rates are calculated to recover personnel costs (direct service, administrative, and support), fringe benefits, occupancy, transportation, and other miscellaneous costs, and are adjusted for approximately 35 percent non-billable time required for the operation of the program. Throughout an individual's supported employment service history, intervention time for activities both on and away from the job site is recorded by direct service staff and submitted

to a data management specialist for review, data entry, and analysis.

**Determining Job Stabilization.** In Virginia the supported employment worker is considered to be stabilized in his or her job when weekly staff intervention time required for job maintenance falls below 20 percent of the person's weekly work hours, at which point funding responsibility is shifted to the extended services funding agency (Hill, 1988). This level of intervention was used as the demarcation point between time-limited and extended service phases. Although policies regarding cooperative funding agreements will vary on a state-by-state basis, our use of this specific level of intervention provides an indication of the relative funding obligations for time-limited and extended service funding agencies.

**Data Verification and Analysis.** A multi-step procedure is employed to insure that information collected by the supported employment project is accurate. First, program staff receive training in supported employment practices and use of the SEIS data collection forms. Submitted forms are reviewed by a data management specialist who checks forms for completeness and consistency with previously submitted forms for the particular individual. An error-checking procedure within the data entry program also identifies inconsistent or out-of-range data. Missing, incomplete, or inconsistent information is corrected prior to entry.

Data from the MCV patient information system and the Supported Employment Information System are analyzed using the SAS computer program (SAS Institute, 1985).

**Staffing of Employment Specialists.** During the time in which these data were collected, the employment specialist staff grew from an initial level of three to a total of twelve. The additional number of staff helped to increase the speed with which new referrals could be placed. All employment specialists except for two, had at least a bachelor's degree. The degrees were in the areas of psychology, rehabilitation, counseling, or adult education. Most staff had limited experience with traumatic brain injury but did have experience in the disability field. A two-week training program, partially clinically based, was put in place for all new staff. After completing this training program, they were assigned to work closely with a more experienced staff person for a period of time before taking on a case independently. Usually this process takes four to six months.

## REHABILITATION OUTCOMES AND PROGRAM COSTS

The data presented in Table 3 indicate that 41 of the 53 persons with severe traumatic brain injury were placed in competitive employment. At the time of this writing 29 persons (70.7%) were still working. A mean of 31.2 hours is worked per week by the 41 placements, with a mean hourly wage of \$4.61. A review of Table 3 indicates most people were placed in warehouse, clerical, and service related positions.

Figure 1 shows the mean hours of employment per week by all workers during the first year of supported employment and also the gradual reduction of time which the employment specialist spends on a case. By about the 20th week, persons with most brain injuries reached a point of being stable and independent on the job. Within 40 weeks, very little intervention was required.

Since the initiation of supported employment, the mean monthly employment ratio has been 74.64 percent with 19 clients (46%) achieving ratios of 100 percent continuous employment. This compares favorably with the pre-injury levels reported in Table 2 of 89.18 percent and shows a dramatic improvement over the mean post-injury level of 15.37 percent.

During time-limited services (i.e., mean intervention 20 percent or more of mean hours of work), the mean amount of intervention time totaled 237.8 hours. Persons served in this program required on average approximately 22 weeks of intervention to achieve stabilization. The mean cost of time-limited services was \$6,896.

For those individuals who achieved stabilization, intervention hours ranged from 2 to 593, with corresponding costs ranging from \$58 to \$17,197.

A mean of 1.64 hours per week of post-stabilization intervention was required to maintain people in employment for the first year of extended services. At the \$29 per hour contact rate, the mean weekly cost of follow-along and support was \$47.56. Annualized, the mean cost of time limited services for all people stabilized on their jobs was approximately \$2,476. Individual weekly hours worked and costs did not vary appreciably from these means.

**Table 3**  
**Status of Traumatic Brain Injury Placements**

Client #	Currently Working	Current or Last Job Title	Total # of Times Placed	Current/Last Wage	Current/Last No. Hrs/Wk	Total Months Employed	Reason for Job Separation(s)
1	No	Microfilm Clerk	1	\$5.00	39	28	Transportation problems
2	Yes	Maintenance Worker	1	\$4.15	40	23	NA
3	Yes	Activities Aide	1	\$3.55	20	29	NA
4	No	Child Care Aide	1	\$4.00	17	15	Moved away
5	No	Price Ticket Changer	1	\$4.40	40	13	Arrested for illegal drug use
6	Yes	Office Service Aide	1	\$5.16	30	33	NA
7	Yes <sup>1</sup>	Operations Supervisor	1	\$8.81	40	7	Short-term hospitalization
8	Yes	Groundsman	2	\$5.11	30	11	Residential problems
9	Yes	Lobby Worker	2	\$4.25	25	12	Required continued prompting
10	Yes	Rod and Chain Man	2	\$5.00	40	49	NA
11	No	Internal Auditor	1	\$4.50	40	3	Medical/health problems
12	No	Warehouse Worker	1	\$3.90	30	13	Aberrant behavior
13	Yes	Order Entry Operator	2	\$4.65	28	20	Poor attendance
14	Yes	Salad Prep Worker	2	\$3.90	30	12	Poor social skills
15	No	Maintenance Worker	2	\$4.50	20	7	Did not want to work
16	No	Kennel Helper	1	\$4.50	20	1	Aberrant behavior/return to school
17	Yes	Food Prep Worker	2	\$4.75	25	8	Poor work attitude
18	No	Sales Associate	2	\$3.60	15	7	Insubordinate/aggressive
19	No	Food Prep Worker	2	\$3.45	20	11	Psychiatric/marital problems
20	No	Office Services Aide	1	\$4.93	20	2	Business closed (also too slow)
21	No	Courtesy Clerk	1	\$3.75	18	2	Did not want to work
22	Yes	Office Services Aide	1	\$5.11	20	9	NA
23	Yes	Warehouse Worker	2	\$4.50	40	8	Financial aid interference
24	Yes	Draftsperson	1	\$4.25	40	11	NA
25	Yes	Linen Room Attendant	1	\$4.75	40	9	NA

241



**Table 3 (Continued)**  
**Status of Traumatic Brain Injury Placements**

Client #	Currently Working	Current or Last Job Title	Total # of Times Placed	Current/Last Wage	Current/Last No. Hrs/Wk	Total Months Employed	Reason for Job Separation(s)
26	Yes	Packer	2	\$3.50	285	5	Change in job duties
27	Yes	General Laborer	1	\$4.75	40	7	NA
28	Yes	Shoe Repairman	2	\$5.50	30	6	Economic situation/slow business
29	Yes	Information Officer	1	\$9.14	20	7	NA
30	Yes	Cafe/teria Line Server	1	\$5.00	38	7	NA
31	Yes	Porter	1	\$3.90	18	10	NA
32	Yes	Stock Clerk	2	\$5.50	40	6	Inability to meet production
33	Yes	Linens Room Attendant	1	\$4.00	35	5	NA
34	No	Landscaper	1	\$3.50	40	1	Required continual prompting
35	No	Customer Service Rep	1	\$3.35	40	2	Inappropriate social interactions
36	Yes	Installation Prep Worker	1	\$4.75	40	2	NA
37	Yes	Furniture Refinisher	1	\$3.35	40	3	NA
38	Yes	Groundskeeper	1	\$4.00	40	3	NA
39	Yes	Bus Person	1	\$4.00	40	1	NA
40	Yes	Porter	1	\$5.25	30	1	NA
41	Yes	Office Clerk	1	\$5.00	40	1	NA

Means = \$4.61 31.2 10.0

Currently working, but not in supported employment.

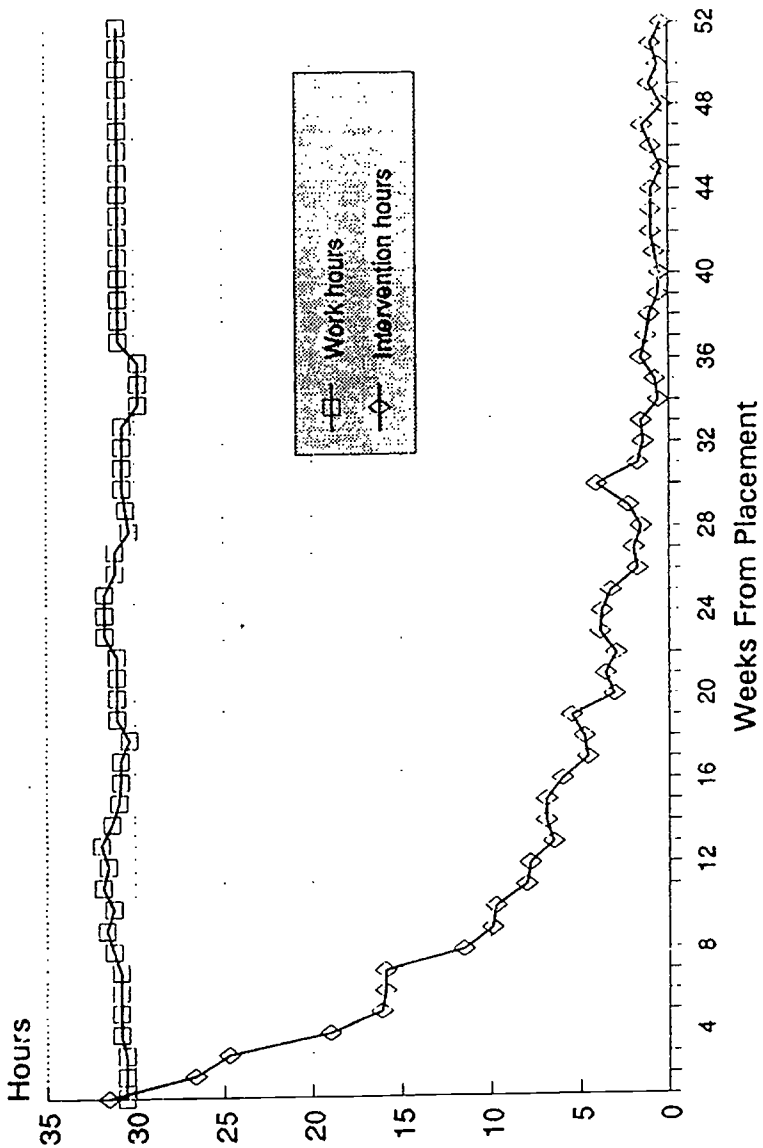


Figure 1  
Mean Hours of Work Per Week and Intervention Hours Per Week  
for Supported Competitive Employment Clients With Traumatic Brain Injuries

## DISCUSSION

The data presented in this prospective study provide reason for cautious optimism concerning the utility of supported employment as a vehicle to enhance the vocational outcomes of persons with traumatic brain injuries. In this descriptive study 41 persons were placed in competitive employment with the help of an on-site employment specialist who provided ongoing support and case management. Approximately 71 percent of these persons continue to work. The majority of this group of people were long-term post-acute cases most of whom are unable to live independently due to the effects of the injury. Many continue to experience serious cognitive problems in areas such as memory, thinking, and reasoning.

It is noteworthy that in only 15 percent of the total possible months during which people could have worked, was there actual employment post-injury. The sharp increase with supportive intervention of up to almost 75 percent of total months working is very encouraging. Clearly, it appears that the majority of these involved in the supported employment process, who were overwhelmingly stable members of the work force pre-injury, were able to compensate for their deficits and resume productive roles.

A comparison of the intervention totals and costs with those reported by Kregel, Hill, and Banks (1988) and Kregel (1989), who analyzed intervention time for individuals in supported employment with different primary disabilities, yields some noteworthy findings. Persons with traumatic brain injury required considerably more intervention time to stabilize in their jobs and to maintain employment than was reported (Kregel et al., 1988) for persons with mental retardation (IQ below 70), the disability group most often associated with supported employment programs. Thus, persons with severe traumatic brain injury generally have required more time, effort, and expenditures to learn and maintain their jobs than have persons in this latter disability group. Second, individuals with traumatic brain injury required proportionally less time in on-site training and advocacy efforts and more in off-site activities than was found for persons with mental retardation, long-term mental illness, physical disabilities, and other disabling conditions (Kregel, 1989).

These findings must be viewed in light of three major factors:

1. In our program design, employment specialists also function as case managers, job developers, off-site trainers, and counselors. These functions are frequently filled by support personnel within the existing service systems for persons with mental illness, mental retardation, and other developmental disabilities. For individuals with traumatic brain injury, off-site and post-stabilization interventions are often critical to the employment process and, as Kregel (1989) has demonstrated, require a proportionally greater amount of staff time than do persons with other primary disabling conditions. Thus, the reported intervention time and costs of service may be inflated by the absence of a similar comprehensive system of services for persons with traumatic brain injury.
2. Disproportionate amounts of intervention in activities away from the job might also be related to the relative absence of structure in the home or community at large as compared to the workplace and to the deficits in judgment and self-regulation of individuals with brain injury.
3. Interpretation of these results must also take into consideration the relatively recent application of this rehabilitative strategy to persons with traumatic brain injury and the early inexperience of project staff with this unique population.

The costs for providing supported employment to persons with severe traumatic brain injury must be considered within the context of costs for other rehabilitative services for this group, information which is extremely limited. McMordie and Barker (1988) reported that annual costs for specialized head injury programs averaged \$25,779. This finding, although from a limited sample ( $n = 16$ ) and with extreme ranges (\$1,500 - \$80,000), suggests that costs for supported employment are well in line with other rehabilitative efforts.

As with the Kregel et al. study (1988), considerable variations in intervention totals and costs were found. This finding should discourage provider or funding agencies from setting caps on the amount of services individuals may receive based upon mean amounts of intervention. Many of the individuals in the MCV program who required the most amounts of intervention time were also the most successful at maintaining employment.

Based on the participants' mean wages and work hours, we can

project that clients' earnings will exceed program costs after approximately 58 weeks of supported employment services. In terms of payback to taxpayers, we can project that, at current minimum levels of federal income taxation and Social Security payments (including employer contributions), client contributions from supported employment will provide a net positive gain to taxpayers after approximately 2.5 years. These estimates, however, do not include savings from alternative programs, contributions from family members who were also free to return to work, or other costs and benefits of employment, nor are these figures discounted. More in-depth benefit/cost information and comparisons are needed for supported employment and other return-to-work methodologies for persons with traumatic brain injury and for the personal and social costs of *not* returning to work as well.

This report represents one of the first to present a sizable number of clients for ongoing vocational intervention. As indicated in Table 2, this group of referred clients as an aggregate clearly showed poor post-injury recovery in independent living and the ability to return to work. Supported employment clearly appears to have been a factor in aiding this group of clients back to work. The employment specialist plays a major role in this process as the one who arranges the placement, provides training and counseling at the job site, and then carries out long-term case management services to enhance retention. There are two obvious methodological limitations with this report: the first is the lack of a control group to compare these results. As of this writing a contrast group of similar clients is in the process of being developed. However, a randomized experimental control group design was not possible since clients locally refused to enter a nonservice group option.

The second limitation is the subject selection bias which is inherent when employment specialists identify which clients are to be placed. There were 12 persons who were not placed at the time of this writing due to (a) the severity of their disability or (in greater likelihood), (b) their refusal to consider certain employment opportunities which were located on their behalf. For the most part these persons have shown greater neurophysical problems and cognitive slowness as contributing factors to lack of job placements. They remain on the waiting list for eventual placement.

A common thread running through all client separations from jobs in Table 3 is that of psychiatric, substance abuse, psychological, or social adjustment problems which impair work habits and interfere with a

steady work history. Presentation of serious behavioral and psychiatric problems has been consistently documented in long-term post-acute patients (Eames, 1988; Prigatano, O'Brien, & Klonoff, 1988) as has substance abuse (Brooks et al., 1989). The question remains, however, What rehabilitation interventions are optimal to help in the return-to-work process? With a supported employment model, interventions are provided for these problems while the person is employed. In an effort to maintain meaningful work activity, unfortunately, even the best efforts do not always work successfully. Hopefully, the additional allocation of resources for psychosocial problems and issues affecting employability will enhance vocational outcomes.

Our clinical activities and research efforts are moving in the direction of identifying a "profile" of those clients who are traumatically brain injured whom supported employment can help, similar to the work of Fraser (1988). What we still do not know are what are characteristics of those who place more easily than others, who retain more easily than others, and what support services are the most critical. We also need to know which persons cost less in terms of job coach intervention hours. A number of the persons placed into jobs have been employed only recently and much longer term data will be necessary before meaningful analyses in this area can be undertaken.

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## *Chapter 10*

### **DEVELOPING FUNDING POLICY IN THE PUBLIC SECTOR WHEN RESOURCES ARE UNCERTAIN AND WHERE COMPETITION IS KEEN**

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## INTRODUCTION

Traumatic brain injury (TBI) has grown dramatically in the past 25 years as a source of functional impairment and disability to people whose lives were saved, largely as the result of faster and better emergency treatment at the scene of an accident or injury, more rapid and safer transport to specialized treatment facilities, and much improved methods of medical treatment. Traumatic brain injury involves "damage to the brain, temporary or permanent, that results when the head is hit, strikes a stationary object, or is shaken violently (as in some whiplash injuries)" (Corthell & Tooman, 1985). Brain penetration as well as loss of consciousness may or may not occur. Not included in the definition of traumatic brain injury is brain damage caused by genetic abnormalities, in utero nutritional and biochemical deficits, birth trauma, blockage or bursting of a blood vessel (stroke), tumors, or degenerative processes associated with substance abuse or Alzheimer's disease. Traumatic brain injury is acquired in the course of normal development, occurs suddenly and unexpectedly, and immediately produces varying and often multiple functional deficits because of diffuse brain damage. In consequence, traumatic brain injury affects many aspects of the person's life.

Estimates of the annual incidence of traumatic brain injury vary widely, largely because of differences in data collection methods. Estimates vary from a high of 600 per 100,000 population (Kraus, 1980) to a low of 69.8 per 100,000 (Hensley, 1988). Statistics based on counts of hospital discharges overstate true incidence; since many people with traumatic brain injury are doubly and triply counted as they enter and are discharged from more than one hospital in the course of the year. What is more, not every head injury leads to significant functional impairment or long-term disability.

While methodologically diverse and lacking in precision, studies of the incidence of traumatic brain injury indicate that males are roughly twice as likely as females to sustain traumatic brain injury, and the highest incidence occurs in the 15-24 year age group. Most studies (e.g., Cooper et al., 1983; Axelrod, 1986) report incidence 30 to 70 percent higher among black and Hispanic minorities compared to the white population, although one study (Kalsbeek, McLaurin, Harris, & Miller, 1980) has reported 10 percent lower incidence among the black population compared to the white population. Socioeconomic class differences largely go unreported. Although minority status may be construed as a good proxy for lower socioeconomic class, the

relationship between lower class and minority status is confounded and may account for the higher rates of traumatic brain injury reported among minorities.

Especially noteworthy are the emotional problems and behavioral disorders which exact a heavy toll on families, friends, and neighbors who often have difficulty recognizing the person with traumatic brain injury as the same person they knew before the injury. Family members typically complain about the person with the head injury's slowness of thinking, loss of memory, lack of energy, impatience, loss of temper, aggression, depression, and lability of mood. These subjective complaints about the "changed personality" of the person with traumatic brain injury tend to intensify over time (Brooks, Campsie, Symington, et al., 1986; Livingston & Brooks, 1988).

Family members often exhibit high levels of depression and anxiety resulting from coming to grips with the reality of head injury. Several studies (Rosenbaum & Najenson, 1976; Oddy, Humphrey, & Uttley, 1978; Livingston, Brooks, & Bond, 1985; Livingston & Brooks, 1988) document depression in the range likely to require psychiatric treatment among 39 percent of relatives in the first month post-injury; by six months post-injury 20 percent still remained in this range of depression. Similarly, levels of anxiety likely to require psychiatric treatment were reported soon after injury in 40 percent of relatives of people with severe injuries and in 19 percent of relatives of people with minor injuries.

Evidence of social dysfunction, as manifested by friction, poor interpersonal relationships, or marital or sexual difficulties, tends to emerge six months and later after the injury. In terms of severity, greater family disturbances tend to occur in families where the person with a traumatic brain injury lives with parents than when the person lives with a spouse (Oddy, Humphrey, & Uttley, 1978). The degree of adverse personality change manifested by the person with a head injury usually defines the meaning of "severity." More than 50 percent of the psychosocial dysfunction in relatives at 3, 6, and 12 months post-injury can be predicted by the level of symptomatic complaints in the head injured person with a traumatic brain injury--especially those of a non-physical character (Livingston, 1987).

In this chapter several issues are addressed bearing on the financing of services to people with traumatic brain injury and their families, including the economic consequences of traumatic brain injury, features

of the impairment/disability that are shared by other disability groups as well as common needs, and the merits of pursuing a reform strategy that incorporates traumatic brain injury into existing programs in contrast to one that seeks to create a new comprehensive categorical program specifically designed to meet the special needs of people with traumatic brain injury and their families.

### THE ECONOMIC CONSEQUENCES

The economic consequences of traumatic brain injury for individuals, families, and society are enormous. One study (Lehmkuhl & Wagner, 1988) analyzed charges billed for services provided to two young adult males who suffered severe traumatic brain injury as the result of motor vehicle accidents. The total bill for one patient amounted to \$170,000 for a 30-month period, and for the other it was \$234,000 over an 11-month span. Another study (Deutsch, undated) estimated the total lifetime cost of care for a hypothetical individual with severe head injury. The estimate included acute medical care, acute and extended rehabilitation, and residential care for the remainder of life. The total lifetime cost of care came to \$4.6 million. Costs tend to vary with the severity of the injury. A Maryland study (MacKenzie, et al., 1987) estimated the average *first year* costs of caring for people with different traumatic brain injury severity levels. Average first-year costs for minor head injuries were \$8,416; \$23,708 for low moderate injuries; \$56,858 for high moderate injuries; and \$105,570 for severe injuries. Clearly, few families can afford costs of this magnitude unless they are covered by adequate private medical insurance or are eligible for Medicare or Medicaid.

The direct and indirect costs of the impairments and disabilities arising from traumatic brain injury impact heavily on society. Without specifying the year of estimate, a federal Interagency Head Injury Task Force (1989) estimated that the total direct and indirect costs of medical treatment, rehabilitative and support services, and lost income approach \$25 billion annually.

The enormous costs associated with traumatic brain injury preclude all but a very few persons from covering these costs out of pocket. Consequently, adequate medical care can be provided only if the costs of care are socialized through insurance systems, tax-supported public programs, or private philanthropy. Many insurance plans, however, place maximum limits on their liability so that in catastrophic instances,

such as often occurs with traumatic brain injury, the funds available from the insurance company fall short of the amount needed to pay the entire medical bill. Further, a significant percentage of Americans are not covered by private medical insurance. In some cases, their employers do not offer it.

## TWELVE FAMILIES

In order to reach some understanding of the types of impairments that result from traumatic brain injury and the kinds of services that individuals and families use and seek, the characteristics and experience of 12 families in Western New York State who have elected to care for their family at home are presented. No claim is made for the representativeness of the sample. Drawn from the membership of one traumatic brain injury advocacy organization, the families agreed to respond to a mail survey in return for a \$20 payment. Considering the amount and sensitivity of the information asked for, the completeness of the response to all items of the survey questionnaire was exceptional. Of the 15 completed questionnaires, three (20 percent) were discarded because they failed to meet the strict definition of traumatic brain injury that were employed. One was a case of carbon monoxide poisoning; the other two involved brain tumors.

As shown by Table 1, the 12 families lived in households containing an average of 2.2 people in addition to the caregiver, ranging from one to four additional people. Caregivers were predominantly female, married or widowed, and middle aged. The average age of the caregivers was 55 years, ranging from 37 to 72 years. Most were high school graduates or had attended but did not complete college. There were slightly more Catholics than Protestants in the sample. All but one caregiver was white. Two-thirds were caring for a son; two cared for a husband; one cared for a wife; and one cared for a daughter.

The caregivers were highly committed to maintaining the person with a traumatic brain injury at home, feeling that it was better for the head-injured person and for family life. Consistent with this, they tended to believe that caring for a family member with a head injury was compatible with living a normal community life and being accepted by friends and neighbors. However, they acknowledged that caring for a person with a traumatic brain injury disrupted their work and social lives and their ability to plan ahead.

**Table 1**  
**Twelve Families: Characteristics**

		Percentage or Mean	Range
Household size (less caregiver)		2.2	1-4
<b>CAREGIVER</b>			
Age		55	37-72
Gender:	Female	72.7	
	Male	27.3	
Marital Status:	Single	8.3	
	Married	50.0	
	Widowed	33.3	
	Divorced	8.3	
Education:	High School	50	
	Some college	25	
	Bachelor's degree	8.3	
	Master's degree	8.3	
	Doctoral degree	8.3	
Religion:	Protestant	33.3	
	Catholic	41.7	
	No religion	8.3	
	Other	16.6	
Race:	White	91.7	
	Black	8.3	
Head injured/caregiver relationship:			
	Son	66.7	
	Daughter	8.3	
	Wife	8.3	
	Husband	16.7	



**Table 1 (Continued)**  
**Twelve Families: Characteristics**

	Percentage or Mean	Range
<b>FAMILY COHERENCE (maximum score in percent)</b>		
Commitment	70.3	50.0 - 100.0
Fit	66.2	50.0 - 81.3
Predictability	45.8	25.0 - 100.0
<b>HEAD INJURED MEMBER</b>		
Current age	33.8	24-56
Gender:		
Male	83.3	
Female	16.7	
Age at injury	27.0	17.5 - 49.9
Days unconscious	48.4	4 - 152
Years since injury	7.2	5.2 - 17.8

The family members who had the traumatic brain injury were relatively old, averaging 33.8 years. All but two were male. They were also injured at a relatively older age--27 years on average. All but one was injured in an automobile accident. As indicated by an average of 48.4 days of post-trauma unconsciousness, all had suffered severe head injuries. The lapse of an average of 7.2 years since injury is evidence that the families have grown used to the vicissitudes of caring for a person with a head injury.

As shown by Table 2, the families were largely middle-class with an average gross income of \$43,002 per year. The bulk of this income was derived from salaries and wages, followed by SSDI, court settlements, SSI, pensions, and investments and/or trust fund proceeds. Clearly, for the family with a traumatic brain injury member, their relatively high levels of income and assets preclude easy access by other family

members to income and/or means-tested public benefits.

**Table 2**  
**Twelve Families: Income and Sources**

Income Sources	Members Receiving	Mean	Range
Annual Gross Income	---	\$43,002	16,400 - 78,000
Salaries & Wages	10	18,058	1,000 - 45,000
SSDI	7	6,998	5,300 - 9,900
SSI	4	3,080	2,500 - 4,320
Pension	5	8,731	1,000 - 21,000
Court Settlement	2	30,750	20,000 - 41,500
Investments/Trust	2	10,000	5,000 - 15,000
Other Source	1	10,000	NA

As shown by Table 3, the families have had to contend with a large number of physical, cognitive, and behavioral problems of the person with a head injury since the injury occurred. The people with head injury averaged 6.7 physical problems since injury, 5.1 cognitive problems, and 6.3 behavioral problems. The percentages reported for each kind of problem give an idea of the amount of stress that these families have had to contend with in the course of 7.2 years on average since the head injury.

As indicated by Table 4, the severity of the initial head injury and sequelae in most cases required sequential treatment in an emergency room, an acute care hospital, both inpatient and outpatient rehabilitation programs, and in a doctor's office.

Table 5 provides detailed information about service utilization among the 12 families during the past 12 months. It also gives an idea of the possible extent of unmet need by indicating what percentage of the families would have used various kinds of services if they had known about their availability. Only two people with head injuries had been hospitalized during the past 12 months--one case paid for by Medicaid and the other by private insurance.

**Table 3**  
**Twelve Families: Problems Experienced Since Injury**

PHYSICAL	Percent	PHYSICAL	Percent
Chewing and swallowing	41.7	Tube feedings	41.7
Blackout spells	16.7	Breathing problems	25.0
Walking	91.7	Tracheotomy	50.0
Seizures	41.7	Ventilator	25.0
Dizziness	25.0	Tiredness	83.3
Vision	0.0	Insomnia	50.0
Hearing	25.0	Bowel problems	16.7
Speech	58.3	Bladder problems	33.3
Headaches	25.0	Moving slowly	83.3
Pain	41.7	Paralysis	25.0
Upset stomach	8.3	Other physical problems	16.7

Number of problems: Mean = 6.7, Range = 2-10

COGNITIVE	Percent	COGNITIVE	Percent
Memory	100.0	Learning	58.3
Reading	66.7	Making choices	66.7
Attention	83.3	Speech or talking	66.7
Understanding	58.3	Other cognitive problems	8.3

Number of problems: Mean = 5.1, Range = 2-7

BEHAVIORAL	Percent	BEHAVIORAL	Percent
Restlessness	41.7	Uncontrolled laughter	16.7
Nervousness	25.0	Uncontrolled crying	16.7
Frustration	91.7	Stealing	0.0
Impatience	58.3	Fearfulness	25.0
Tantrums	41.7	Nightmares	25.0
Swearing	33.3	Screaming	16.7
Sexual acting out	8.3	Hurting self	8.3
Aggressiveness	25.0	Throwing things	0.0
Irritability	41.7	Threatening	25.0
Depression	58.3	Hitting others	8.3
Anger	50.0	Other problems	8.3

Number of problems: Mean = 6.3, Range = 2-14

**Table 4**  
**Twelve Families: Services Received After Head Injury**

Type	Percent	Type	Percent
Emergency room	91.7	Outpatient rehabilitation	75.0
Acute care hospital	100.0	Doctor's office	66.7
Inpatient rehabilitation	100.0	Other	16.7

**Table 5**  
**Twelve Families: Service Utilization During Past 12 Months**

Type of Coverage	Percent Used	Percent Would Have Used if Known/Available
<b>Inpatient</b>		
Medicare	0.0	0.0
No-fault insurance	0.0	0.0
Medicaid	8.3	16.7
Private insurance	8.3	0.0
Self-paid	0.0	0.0
<b>Outpatient</b>		
Medicare	0.0	25.0
Medicaid	8.3	16.7
No-fault insurance	0.0	0.0
Private insurance	16.7	0.0
Self-paid	0.0	8.3
<b>Physician</b>		
Medicare	16.7	8.3
Medicaid	16.7	8.3
No-fault insurance	16.7	0.0
Private insurance	0.0	0.0
Self-paid	8.3	0.0
<b>Mental Hospital</b>	16.7	0.0
<b>Outpatient Mental Health</b>	25.0	16.7
<b>Individual Counseling</b>	33.3	33.3

**Table 5 (Continued)**  
**Twelve Families: Service Utilization During Past 12 Months**

Type of Coverage	Percent Used	Percent Would Have Used if Known/Available
Family Counseling	8.3	41.7
Marital Counseling	8.3	25.0
Counseling for Sibling	8.3	8.3
Financial Counseling	8.3	33.3
Support Group	83.3	0.0
Home Aide	16.7	8.3
Housekeeper	8.3	25.0
In-Home Respite	0.0	16.7
Out-of-Home Respite	8.3	8.3
Legal	8.3	33.3
Special Education	8.3	25.0
Vocational Rehabilitation	16.7	25.0
Transportation	16.7	41.7
Group Home	0.0	16.7
Foster Home	0.0	8.3
Skilled Nursing Facility	0.0	0.0
Health-Related Facility	0.0	0.0
Disability Information	8.3	41.7
Information About Service Availability	0.0	0.0
Other Services	8.3	16.7

Outpatient services were used by three individuals--one case paid for by Medicaid and two others by private insurance. Most people with head injuries were seen by a physician during the past 12 months. Medicare, Medicaid, and no-fault insurance were the principal sources of payment for physician services.

The most frequently used services were support groups, individual counseling, and outpatient mental health services. Less frequently used services were home aides, mental hospital services, vocational rehabilitation, and transportation. Family counseling, marital counseling, counseling for a sibling, financial counseling, a housekeeper, out-of-home respite, legal services, special education, and disability information

were used by but one individual each. Some services - in-home respite, group home, foster home, skilled nursing facility, health-related facilities, and information about service availability - were not used at all. Knowledge, availability, affordability, and need are possible reasons for use and non-use of services.

The types of services that would have been used most frequently if the families had known of their availability include Medicare or Medicaid reimbursed outpatient services, family counseling, individual counseling, marital counseling, financial counseling, housekeeper services, legal services, special education, transportation, vocational rehabilitation, and disability information. Less frequently mentioned services that would have been used if their availability had been known include Medicare or Medicaid reimbursed physician services, counseling for a sibling, a home aide, in-home respite, out-of-home respite, group home care, and foster home care. Interestingly, none of the families mentioned that they had obtained information during the past 12 months about the availability of services, nor did they indicate that such information would have been sought if they had known of a source for such information.

What can we infer from the pattern of service utilization during the past 12 months? How clearly do the indicators of possible unmet need argue for specific kinds of service expansion? The most urgent need appears to be for family counseling, transportation, and disability information, followed by individual counseling, financial counseling, legal services, special education, vocational rehabilitation, and marital counseling. Three families are interested in finding a suitable group or foster home placement for their family member with a traumatic brain injury. This probably reflects the diminished capacity of the caregiver in these families to continue to provide care much longer. The wear and tear of caring for a severely impaired family member coupled with the advancing age of this cohort of older caregivers will probably at some point make out-of-home placement a necessity.

The modest means of most of these middle-class families do not permit unsubsidized access to the additional services they would have used even if they had known of their availability. If middle-class families go unserved to the extent of these 12 families, how much more constrained must be the circumstances of lower-class families? Finally, it must be said that the services that are being used and are sought after by the 12 families are very much the same as those used and sought after by families caring for members with severe disabilities other than

traumatic brain injury. The similarity in service needs lends support to the following arguments for a generic rather than a categorical approach to financing and service systems reform.

### State Legislation

When individuals and families cannot protect themselves from catastrophe, there is good reason for the state to intervene in order to minimize the externalized costs to the rest of society. These costs ripple throughout society and assume a variety of forms. Among them are (a) the need for other family members to quit or reduce work in order to care for the person, (b) the breakdown of marriages, and (c) the loss of educational opportunities for siblings or children, as the case may be. The ripple effect of reduced earnings leads inevitably to a reduction in aggregate savings that adversely affects the long-term growth of the economy. Also at stake is the enormous, albeit intangible, value that is placed on life itself and all of the factors that influence its enjoyment, including good health, intellect, and emotional stability.

How might state legislation help ease the burden of traumatic brain injury on individuals and families? At this juncture, a small but growing number of states have passed legislation to assist individuals and families to cope with traumatic brain injury.

As outlined in Table 6, the menu of possible state legislation encompasses narrow, intermediate, and broad interventions. Starting with the narrow and limited, such states as Florida, Georgia, Iowa, Maine, Maryland, Missouri, Pennsylvania, Rhode Island, and West Virginia have passed legislation to establish central registries of traumatic spinal cord or brain injuries. These statutes usually require that the agency operating the central registry refer affected individuals to appropriate public or private agencies where rehabilitation services may be obtained, subject to the substantial eligibility and budget constraints that these agencies impose on access to services under existing state and federal laws. At a minimum, a central registry will document the size and dimensionality of the traumatic brain injury problem and provide the basis for later improvements in the public policies that govern the response to the problem. Lacking a central registry and the objective evidence it can provide, a state must depend solely on the representations of special interest groups or look to other states for guidance about the size of the problem and its possible abatement through various service options.

**Table 6**  
**State Legislative Initiatives For Traumatic Brain Injured Persons By Scope/Activity**

SCOPE/ACTIVITY	STATE	CODE CITATION (YEAR)
<b>NARROW</b>		
Create central registry	FL	Social Welfare Sec. 413.611-413.612 (1987)
	GA	Health Sec. 31-18-1 - 31-18-3 (1985)
	IA	Social Welfare Sec. 225C.22 (1986, 1988)
	ME	Human Services Sec. 3086-3087 (1987)
	MD	Health Sec. 20-108 (1984, 1986)
	MO	Public Health & Welfare Sec. 192.735-192.745 (1986)
	PA	Emergency Medical Services Act, P.L. 164, No. 45, Sec. 5(b) (4) & (14) (1985)
	RI	Human Services Sec. 42-12-8.1 (1985)
	WV	Rehabilitation Services Sec. 18-10A-15 (1985)
	<b>INTERMEDIATE</b>	
Recognize traumatic brain injury as distinct disability for funding purposes	CA	Welfare & Institutions Sec. 14132.8 (1985)
	GA	Health Sec. 31-18-4 (1985)
	FL	Social Welfare Sec. 413.611 (1987)
	IA	Social Welfare Sec. 225C.23 (1988)
	IN	Education Sec. 20-1-6A (1979)
	IL	Schools Sec. 14-1.03a (1972)



**Table 6 (Continued)**  
**State Legislative Initiatives For Traumatic Brain Injured Persons By Scope/Activity**

SCOPE/ACTIVITY	STATE	CODE CITATION (YEAR)
<b>INTERMEDIATE (Continued)</b>		
Recognize traumatic brain injury as distinct disability for funding purposes	MD ME NJ RI	Health Sec. 20-108 (1984, 1986) Health Services Sec. 3088 (1987) Higher Education Sec. 18A:72H-3 (1985) Human Services Sec. 42-12-8 (1986)
Funding of special demonstration projects	CA	Welfare & Institutions Sec. 5564.2-5564.7 (1988)
Create special trust fund by special levy or use of moving vehicle fines	FL PA PA	Social Welfare Sec. 413.613 (1988) Vehicles Sec. 1761-1769 (1984; repealed 1989) Emergency Medical Services Act, P.L. 164, No. 45, Sec. 14(e) (1985)
<b>BROAD</b>		
Create new system of care	CA MA ME PA	Welfare & Institutions Sec. 4330-4349.6 (1988) Rehabilitation Commission Sec. 107 CMR 73.00-73.13 (1985) Human Services Sec. 3088 (1987) Emergency Medical Services Act, P.L. 164, No. 45, Sec. 14(e) (1985)

255

Taking an intermediate position, California has initiated demonstration projects in the search for post-acute care service options that can handle various aspects of the traumatic brain injury problem. The New York State legislature passed similar legislation in the 1989-90 regular sessions, only to witness its veto by Governor Cuomo. Other states, including California, Georgia, Florida, Maryland, Iowa, Indiana, Illinois, Maryland, Maine, New Jersey, and Rhode Island have recognized traumatic brain injury as a distinct disability to be served by state agencies, again subject to whatever eligibility and budget constraints prevail under existing state and federal laws. Florida has gone one step further by creating an "impaired drivers and speeders trust fund" to siphon off a portion of the fines imposed on violators of motor vehicle law in order to pay for the acute care, rehabilitation, transitional living, and equipment necessary for the activities of daily living of people with head injuries.

On a more ambitious plane, California, Massachusetts, Maine, and Pennsylvania have enacted legislation that is meant to create a new "system of care" for people with traumatic brain injury and their families along with a budget to go with it. Massachusetts established a statewide head injury program (SHIP) with an initial appropriation of \$2.1 million and the broad mandate to "address the needs of Massachusetts residents, of any age, who have sustained a traumatic, externally caused head injury resulting in severe physical, cognitive and/or behavioral deficit" (Kamen, 1988, p. 10).

Even though there was to be cooperation with other public and private human service agencies, the Massachusetts program was swamped by 20-25 new referrals each month, totalling more than 600 referrals in two years. One month after its commencement, the new program had to institute an order of selection system with three priority levels: Class I for people considered a threat to themselves or others and requiring 24-hour-a-day structured supervised living to gain behavioral control; Class II for people needing comprehensive rehabilitation services to function more independently in the community but not meeting Class I criteria; and Class III for people needing ongoing rehabilitation services to maintain appropriate functioning in the community but not meeting Class I or II criteria.

The SHIP program has developed plans for a better future and begun to implement them, including one 16-bed secure inpatient neurobehavioral unit, four-day care programs to serve people living at

home or in a community residence, two community-based housing programs with 24-hour supervision, and 16 case managers. Only five case managers have been hired due to budget constraints. These five case managers carry an active caseload of 150 regular clients and 1,000 crisis-oriented cases, who have been given instructions to call the case manager in case of emergency. According to our sources, no further expansion is possible until Massachusetts solves its current fiscal problems.

The Massachusetts statute has created a dilemma for people with traumatic brain injury and their families. By law, the SHIP program *cannot* provide any services that are obtainable elsewhere. However, other Massachusetts agencies, such as the Department of Mental Health, have taken the position that they will not serve people with traumatic brain injury because the SHIP program was created to serve them (Ferris, 1989).

California presents an interesting contrast to Massachusetts in defining a new system of care for people with traumatic brain injury. Entitled the "Comprehensive Act for Families and Caregivers of Brain-Impaired Adults," the California statute openly acknowledges the state's past history of discrimination against adults with brain damage or degenerative brain disease. While accepting responsibility for people under age 18 who were "developmentally disabled," California had not assumed responsibility for similarly situated people over the age of 18, thereby causing "severe financial liability and physical and mental strain on brain-impaired people, their families, and caregivers" (Noble, Conley, Laski, & Noble, 1990).

Unlike the Massachusetts statute which limits coverage to traumatic brain injury, California covers all individuals with brain damage regardless of cause. Thus, "brain damage" is covered regardless of its possible origins in Alzheimer's disease, multi-infarct disease, Pick's disease, Krutzfeldt-Jakob's disease, epilepsy, multiple sclerosis, Parkinson's disease, amyotrophic lateral sclerosis (ALS), or Huntington's disease; cerebrovascular accidents, whether or not involving cerebral hemorrhage, aneurysm, or embolism; post-traumatic, postanoxic, and post-infectious damage caused by coma, accidental skull and closed head injuries, loss of oxygen, and infections such as encephalitis, herpes simplex, and tuberculosis; and permanent brain damage caused by tumors, hydrocephalus, abscesses, seizures, substance toxicity, and other disorders.

Unlike the Massachusetts statute which focuses on the individual with traumatic brain injury, California explicitly targets the caregiver for technical assistance and training in order to better serve the client. Pursuant to the support of caregivers, the California statute establishes a statewide resources consultant to develop respite care training materials for distribution to appropriate state agencies. It makes provision for regional resource centers to "ensure an array of appropriate programs and services for brain-injured adults" with high priority to be placed on "utilizing community resources in creating opportunities for families to maintain a brain-impaired adult at home when possible and in other community-based alternatives when necessary."

Unlike Massachusetts, California requires that all state departments with resources applicable to individuals with disabilities also make them available to people with traumatic brain injury, listing the entire array of state human services agencies with the expectation that all will make their contribution to the cause. For example, Medi-Cal reimburses providers of case management services throughout California (Goldfarb, 1989). Responsibility for administering the entire program is lodged in the Department of Mental Hygiene with the expectation that 90 percent of funds appropriated for the contractual regional resource centers will be spent on direct services, including:

1. Information, advice, and referral and family support services, such as
  - a. Information and counseling about diagnostic procedures and resources
  - b. Long-term care planning and consultation
  - c. Legal and financial resources, consultation, and representation
  - d. Mental health interventions
  - e. Caregiving techniques
2. Respite care services, such as
  - a. In-home care
  - b. Adult day health and social day care services
  - c. Foster and group care
  - d. Temporary placement in a community or health facility
  - e. Transportation
3. Training and education programs for the brain-impaired adults, caregivers, other family members, and service providers

### Generic vs. Categorical Coverage

Existing state legislation can be viewed as essentially pursuing one of two distinct strategies: either incorporating people with traumatic brain injury into existing programs or creating a new comprehensive categorical program specifically designed to meet the special needs of people with traumatic brain injury and their families. The first strategy of incorporation is being pursued by the states that have passed legislation to recognize traumatic brain injury as a qualifying disability for purposes of providing services within existing state programs subject to whatever eligibility and budget constraints may prevail. Massachusetts is the prototype for the strategy of creating a new comprehensive categorical program. California is pursuing a mixed strategy of simultaneously creating a new program to encompass a broad range of conditions that produce similar deficits and requiring all relevant state agencies to do their part in meeting the needs of the statutorily defined target population.

At this juncture, which strategy is best? Should advocacy organizations pursue the strategy of creating distinct new programs with their own state budget line, or does advantage lie in entering broad coalitions to gain acceptance of traumatic brain injury as falling within the scope of many of the existing programs? For the want of a better term, we label the latter strategy as "generic" because it tends to broaden the clientele of existing programs.

To illustrate how the generic strategy works, consider how the federal developmental disabilities legislation shifted over the years away from the original categorical target population of people with mental retardation, cerebral palsy, epilepsy, and related conditions. The current federal statute incorporates a purely functional definition of the eligible population, subject to an age limitation of 22 years for the onset of the disability.

While conceptually appealing, there is need to consider the politics of pursuing a generic strategy. Competition for scarce resources and the desire of constituencies for identity and autonomy make pursuit of the generic strategy difficult. An example of this is ongoing competition among the mental retardation, cerebral palsy, epilepsy, and autism constituencies for service and research dollars.

There is increasing public awareness of how fragmentation and

inefficiency in the health care and social service system in the U.S. cost the nation billions of dollars of unnecessary expenditures that could be better used in filling the terrible gaps in service coverage (Dentzer, 1990). Pursuing a strategy of obtaining generic coverages for conditions that produce similar deficits and require similar services may become more feasible if the federal government and the states begin to revamp the health care system along the lines suggested by the Congressional Bipartisan Commission on Comprehensive Health Care.

As noted elsewhere (Noble, Conley, Laski, & Noble, 1990), existing public and private arrangements for financing medical and other services seldom support equitable distribution of existing resources, particularly in the case of traumatic brain injury and other catastrophic disability where third-party financial support is always essential. The availability and coverage of private health insurance, the work-relatedness of an injury, the availability and coverage of liability insurance, the arbitrary two-year waiting period for Medicare coverage, the age of onset, the place of residence, and the availability or lack of skilled advocacy, all lead to different results for individuals with similar incomes and wealth.

Continuing to pursue a categorical strategy to better meet the needs of individuals with traumatic brain injury and their families will simply perpetuate a ponderous and increasingly expensive system. For this reason, we argue for the generic strategy of incorporating traumatic brain injury into existing service programs as an eligible condition. Despite the generic nature of these programs, the universal use of individualized service plans enables the unique and varying service needs of clients to be identified and appropriately served.

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# *Chapter 11*

## **PUBLIC POLICY FOR PERSONS WITH TRAUMATIC BRAIN INJURY<sup>1</sup>**

Summarized by  
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**Daniel C. McAlees, Ph.D.**

The preceding chapters have attempted to define strategies and techniques to achieve increased inclusion of persons with traumatic brain injuries in employment and in their communities. Each author has presented an important approach or offered the reader a better understanding of what an individual goes through following brain injury and during their rehabilitation. Each of these authors, however, only offered instances and examples of what can be. The strategies and suggestions they propose are parts of a larger spectrum of comprehensive rehabilitation services. In no way did they intend to or have they offered a program of rehabilitation available and applicable to all individuals who sustain brain injuries. That is the province of public policy and an area which continues to draw upon the energies and attention of advocates, families, professionals, and legislators at federal, state, and community levels.

Peter Griswold, State Director of the Michigan Rehabilitation Agency, in his comments, on how public policy is developed, to the 1991 Clearwater Conference stated that:

"Rehabilitation services to persons with traumatic brain injury have expanded rapidly in the private sector, but those offered by public rehabilitation programs are often inadequate. Legislation in many states requires comprehensive rehabilitation services to injured individuals (e.g., under Workers' Compensation, in automobile insurance coverage), yet there is a notable lack of public policy to fund rehabilitation services for individuals not covered by the loose web of insurance programs."

"While the process of developing a national public policy is long and arduous, it begins with a realization [among a part of the American public] or a precipitating factor [e.g., recognition of the extreme cost to taxpayers] around which to guide, drive, or focus all subsequent efforts. The process requires strategic planning, broadly representative coalition building, and long-term collaboration among those demanding and those likely to be part of the processes which come about once public policy is achieved (1991)."

This chapter is included to present a summary of issues which emerged as a result of collaborative planning and decision-making among a broad cross-section of consumers, families, and concerned significant others and professionals. The 1990 "Pathways Meeting" was sponsored

by the National Head Injury Foundation and the President's Committee on Employment of Persons With Disabilities to assess needs, concerns, and issues and to define strategic actions that should be taken to achieve a national policy for rehabilitation of persons with traumatic brain injury.

Seven topical areas around which the Pathways Meeting achieved consensus were (a) personnel training; (b) advocacy; (c) policy, legislation, and financial disincentives; (d) assistive technology; (e) employers; (f) testing and evaluation; and (g) attitudes. The editors suggest that the foci, issues, and actions recommended are as relevant today as elements within a cohesive public policy for persons with traumatic disabilities as they were when the group met in New Orleans.

### Personnel Training

**Focus:** Methods, level, philosophy, content and structure of both pre-service and in-service professional training activities. The assumption is made that improvement in both the quality and quantity of community re-entry needs of persons who have sustained traumatic brain injury can be realized by better addressing skill and knowledge needs through professional personnel preparation programs. This includes examination of the effectiveness of preparation and coordination of all levels of educators, rehabilitation professionals, program planners, and others involved with persons who have sustained traumatic brain injury and who are entering or re-entering employment.

**Issue 1. Coordinate training resource development, evaluation and dissemination in the area of traumatic brain injury.**  
Actions needed to address this issue include:

- A. The Department of Education or their designee creating a mechanism to effectively use the existing and future personnel preparation resources which exist in the various public sector agencies. Agencies to be included in this coordination and documentation activity include the National Institute on Disability and Rehabilitation Research, The Rehabilitation Services Administration, Office of Special Education Programs, National Institute of Health, the Rehabilitation and Training Centers and the Regional Rehabilitation Continuing Education Programs. In order for this to occur, language should be added to the Rehabilitation Act during this reauthorization cycle to mandate the

establishment of a coordinating body. The National Head Injury Foundation should take the lead in having this occur;

- B. The National Head Injury Foundation taking the lead in providing coordination and dissemination for training resource development in the private sector. This will provide more effective utilization of existing and future personnel preparation resources. In order to facilitate this occurring the National Head Injury Foundation should develop grant proposals to obtain funds to establish this function within their national office; and
- C. In conjunction with the action to be taken by the National Head Injury Foundation to coordinate private sector training resources, the National Head Injury Foundation should work with the National Rehabilitation Information Clearinghouse and the National Clearinghouse on Training Materials on Rehabilitation to improve the efforts directed at managing Traumatic Brain Injury Training Resources.

**Issue 2. Incorporate traumatic brain injury specific training in pre-service and in-service training programs of education, rehabilitation providers, and related fields.** In order to accomplish this, the National Head Injury Foundation should develop a transdisciplinary task force to develop a traumatic brain injury curriculum. Further, this task force would work with appropriate college and university personnel to recommend and implement pilot projects to introduce traumatic brain injury curriculum into university and college settings.

**Issue 3. Develop standards for professional competency for all professionals serving persons who have sustained traumatic brain injury.** The National Head Injury Foundation should develop specialty task forces to approach Council on Rehabilitation Education, Commission on Rehabilitation Certification, and other accrediting, licensing and certification bodies to recommend and promote the inclusion of training standards for individual who will serve persons who have sustained traumatic brain injury. Further, these task forces would work with the various accreditation and certification bodies to develop traumatic brain injury

sub-specialties in their accreditation or certification programs.

## **Advocacy**

**Focus:** The role of individuals, family members, and advocacy organizations working to improve employment opportunities, and preparation for employment and the empowerment of individuals who sustained traumatic brain injury.

- Issue 1. Increase advocacy for employment by persons who have sustained traumatic brain injury.** They need to take a more active leadership role in advocating for employment. The Survivors Council of the National Head Injury Foundation should take the lead in defining the issues to be addressed regarding employment. In order for this to occur, additional funds will need to be directed to the Council from the Foundation. The Council will need to assume more of a leadership role in the Foundation and the Foundation should work to prepare members of the Survivors Council for this leadership. The method for developing leadership among persons with traumatic brain injury would be to utilize the current survivor organization structure that accents sharing leadership and survivor based advocacy. This model must be replicated within each of the state organizations.
- Issue 2. Persons with brain injury need training on how to advocate for employment.** In order to prepare persons with brain injury to assume this role, support will be needed from families, professionals and other advocacy groups. Forums to train individuals with brain injury on how to advocate must be developed and/or strengthened.
- Issue 3. Training in advocacy.** The groups who impact, and the employment preparation and entry or re-entry into employment of persons who have sustained traumatic brain injury, need to be better identified. They also need to be defined in terms of needs for, and ability to provide training in effective advocacy. Training could assist in their development of awareness, knowledge, and specific skills to effectively advocate for individual needs and effect

systematic change; and thus promote employment for persons who have experienced traumatic brain injury. This concept of advocacy needs to be directed to the following:

- A. Persons with brain injury
- B. Employers, large and small
- C. Family and significant others
- D. Professional community, including medical, general rehabilitation specialties, social service, and vocational rehabilitation practitioners and administrators of public and private facilities
- E. Decision makers in federal, state, county, and city government
- F. Other disability groups and organizations (i.e. the independent living movement)
- G. Funding sources (both public and private)
- H. General public

**Issue 4. Direct advocacy efforts for persons who have sustained traumatic brain injury must be directed toward insuring access to employment.** Steps which must be taken are:

- A. Advocate for equal protection of everyone under the legal and regulatory system;
- B. Advocate for sufficient financial resources for every level of vocational need including, social, housing, transportation, and attendant care; and
- C. Conduct research and demonstrations into alternative models of employment to determine the most effective methods of employing persons with brain injuries.

**Issue 5. Increase emphasis, education, and research on prevention of traumatic brain injury.** Educational programs with the employment community and the general public regarding the consequences of and prevention modalities must be enhanced.

### **Policy, Legislation and Financial Disincentives**

**Focus:** Review applicable community, state and federal legislative mandates and public/private funding stipulations which impact on the effective delivery of community reintegration training and vocational rehabilitation for adults who have sustained traumatic brain injury.

**Issue 1. Inconsistencies among public agencies and states regarding the inclusion and treatment of persons who have sustained traumatic brain injury.** Agencies operate under different definitions, obligations, and objectives and do not undertake efforts needed to eliminate the differences. The Rehabilitation Services Administration should monitor compliance with disability codes under the existing coding systems in order to establish the incidence and prevalence of traumatic brain injury. This would provide the needed data base to determine what exists and assist in what must be changed. Legislative steps must be taken at the state and federal levels to establish traumatic brain injury as a category of disability with a common definition that is accepted and used by all states, federal agencies, and third party payers to ensure consistent eligibility criteria and treatment.

**Issue 2. Lack of guidance for development of cohesive service delivery systems.** There is a lack of evaluative research, uniform measurement systems, and coordination to determine a systematic, cohesive service delivery system for persons who have sustained traumatic brain injury. An agency must be identified to coordinate and gather existing studies, direct additional research, and evaluate programs and treatment modalities in order to synthesize and share findings. This then can lead to a definition of appropriate services and service providers within a consumer driven system of care.

**Issue 3. Major disincentives for community re-entry and employment.** Current policies and legislation in the areas

of Rehabilitation, Job Training, Social Security, Public Aid, Worker's Compensation and Medical and Disability Insurance have created major disincentives for persons who have sustained a brain injury. The National Head Injury Foundation working in concert with other organizations for and by persons with disabilities must develop and lobby for changes in existing legislation or new legislation which regulates rehabilitation, job training, social security, and medical and disability insurance, so that these disincentives can be eliminated.

**Issue 4. Uncoordinated and incompatible legislation.** Current local, state, and federal legislation which impacts on the employment preparation and entry or re-entry into employment and/or community life of persons who have sustained traumatic brain injury is not coordinated, or in some instances incompatible. For that matter, much of the legislation does not include persons who have sustained traumatic brain injury. In order to eliminate duplication, maximize resources, strengthen service delivery, simplify bureaucratic procedures, and ensure sequential programming opportunities, legislation entitling services must include all disability groups and mandate inter and intra-agency coordination of services. The National Head Injury Foundation working with other advocacy organizations and congressional leadership must take necessary action to see that this is accomplished.

**Issue 5. Restricted or denied access to essential services.** Many current private medical, disability, and other insurance practices have effectively restricted or denied essential services to persons who have experienced traumatic brain injury. Federal and state governments working with the leadership of the National Head Injury Foundation must undertake comprehensive evaluation of existing insurance practices, so that unfair and discriminatory policies can be eliminated and equitable changes can occur. This could very well lead to the establishment of a national catastrophic insurance policy.



## **Assistive Technology**

**Focus.** The utilization of assistive technology devices, services, and strategies as a means of supporting and facilitating the employment of people who have experienced traumatic brain injury. Many individuals with traumatic brain injury, once thought to be too disabled to work, are now finding employment opportunities because of the advances in technology and the products which have been developed. The key question was "what needs to be done in order to improve awareness, access, training and availability of assistive technology to individuals with traumatic brain injury, the professionals who work with them and the employers who hire them"?

**Issue 1. Expand assistive technology concepts and funding.** Concepts and funding are needed which address psychosocial, educational, cognitive, and behavioral needs of persons who have sustained traumatic brain injury. Current definitions, laws, and research regarding assistive technology only addresses hardware and devices. To address this concern it was recommended that a coalition of private enterprise, advocacy organizations, and federal government personnel be formed to develop a new conceptual framework regarding assistive technology which include the needs of persons who have sustained traumatic brain injury. This new framework would then be applied to legislation and funding in the area of assistive technology. This will also lead to vocational consultants and employers working together to perform job analysis, job restructuring, and creation of new jobs which can be performed by persons who have experienced traumatic brain injury. Another outcome of this process would be the recognition that the provision of therapeutic interventions are a necessary part of work site vocational training.

**Issue 2. Inadequate knowledge of assistive technology.** There is inadequate knowledge among professionals, consumers, family members, reimbursement sources, coworkers, educators, legislators, and employers regarding the full range of assistive devices and strategies and technological services, the resources to obtain these, and the methods of application in the workplace. There is an immediate need for high-quality education, training, and communication regarding the

functional utility of assistive technology in the work place and training arena.

The National Head Injury Foundation should undertake a mass media campaign to provide education on this subject to all publics. Further, the National Head Injury Foundation must advocate for more federal dollars to be provided to the National Institute on Disability and Rehabilitation Research and the Rehabilitation Services Administration to develop and evaluate assistive technology, devices, and services. In addition, the National Head Injury Foundation must develop and seek funding for a pilot-model system for the use of assistive technology in employment of persons with traumatic head injury.

**Issue 3. Development of a comprehensive information resource on technology.** There is a need to develop a comprehensive system for information on delivery of assistive technology, services, and devices. The National Head Injury Foundation in conjunction with private-public enterprise must develop a nationwide resource directory of assistive technology and recommend a system of delivery. These efforts should be done through utilizing existing dissemination systems such as the Job Accommodation Network.

**Issue 4. Adequate funding for needed assistive technology.** There is a need to procure adequate funding for assistive technology, services and devices for integration of persons who have sustained traumatic brain injury into gainful employment. Strategies which must be undertaken to accomplish this include:

- A. Legislative bodies need to implement changes in the Social Security Administration delivery systems in regards to work disincentives for persons with traumatic brain injury. Allowable expenses under Medicaid and Medicare need to be expanded to include funding for assistive technology, services, and devices;
- B. Regulations to implement Title I, Employment, of The Americans With Disabilities Act need to include specific

recommendations regarding the use of assistive devices, technology, and services as part of reasonable accommodations; and

- C. The Rehabilitation Service Administration working with the National Head Injury Foundation and the National Institute on Disability and Rehabilitation Research must support and/or establish Research and Training Centers whose mission would be the development of a "menu" of incentives for employers, and strategies for employing persons with traumatic brain injury.

### Employers

**Focus:** The needs, obligations, and perspectives of employers regarding the employment of persons with disabilities. Consideration was also given to the role persons with traumatic brain injury must play in their own employment programs.

**Issue 1. General lack of understanding by many employers, and the general public about the employment potential of persons who have sustained traumatic brain injury.** Many do not understand the provision of the newly passed Americans With Disabilities Act. The result has been that corporate America has not come forth with a commitment to hire persons who have sustained traumatic brain injury. A concerted, coordinated effort must be undertaken by persons with traumatic brain injury, family members, service providers and disability organizations to work with employers and the general public to gain commitment to hire qualified persons who have sustained traumatic brain injury. Strategies to be utilized include:

- A. Provide workshops and educational forums for employers regarding the employment of persons with traumatic brain injury. These workshops should be held at conferences attended by employers (i.e. Chamber of Commerce meetings, President's Committee on Employment of People with Disabilities Annual Meeting, Governor's Committee meetings);
- B. Develop a public relations campaign to educate employers

regarding the benefits of hiring qualified persons who have sustained traumatic brain injury and on the provisions of the Americans with Disabilities Act. The public relations campaign would use multi-media, personal contacts with business by service providers, and employers who have successfully hired persons with traumatic brain injury, training, information on the use of financial incentives for hiring, and would work with the local Chambers of Commerce.

**Issue 2. Self-confidence and empowerment.** There is a need to educate persons who have sustained traumatic brain injury regarding the employment responsibilities and the provision of the Americans with Disabilities Act. Many individuals with traumatic brain injury lack self-confidence. They must be educated to see themselves as functioning members of the work force. Educators, rehabilitation professionals, job counselors, and family members must foster the concept of self-employment. Persons who have sustained traumatic brain injury must see themselves as responsible, contributing members of society. Strategies recommended to assist in the self-empowerment of individuals who have sustained traumatic brain injury are:

- A. Develop and/or expand mentoring programs for and by persons who have sustained traumatic brain injury. State and local funds need to be sought in conjunction with applications for grants and solicitation of private funds to make these programs widely available; and
- B. Provide information and educational programs to persons with traumatic brain injury regarding their rights, responsibilities and remedies in employment under the provision of the Americans with Disabilities Act.

**Issue 3. There is a need to form early partnerships between persons with traumatic brain injury, employers, and service providers in the re-entry, advocacy and empowerment process.** This process will enable myths and preconceptions regarding the employability of persons who have sustained traumatic brain injury to be destroyed. The goal of putting "disability" into a more realistic

perspective can be accomplished, but will require many steps be taken, on the part of persons with traumatic brain injury seeking employment, the professionals who assist, and the employment community. Steps to be taken by rehabilitation professionals and others are:

- A. Work with company human resource and management personnel to establish training programs for their staffs and others in the company;
- B. Make better use of existing job networks, Chambers of Commerce, Rotaries, Private Industry Councils, and identify persons within companies who can be utilized in partnership building in order to establish a commitment to hire persons with disabilities throughout companies; and
- C. Work with employers to expand opportunities for on-the-job training sites for persons who have sustained a traumatic brain injury.

**Issue 4. Confronting stereotypes of employers, family members, and service providers.** Persons with traumatic brain injury often are hindered from returning to or entering employment due to the stereotypical views held by employers, over-protective family members, and service providers. Too often, these stereotypes discourage persons from risk-taking or putting themselves in a position where success is not guaranteed. To combat this phenomena, the following actions must be taken:

- A. Provide information and encourage individuals with traumatic brain injury to participate in support groups;
- B. Place emphasis on training and awareness programs for employers regarding the employability of persons with traumatic brain injury; and
- C. Develop and implement a massive public relations campaign which shows people with brain injury in visible employment positions and illustrates their potential. This would include billboards, TV (i.e. shows, documentaries, and public service announcements), and radio (i.e., talk shows,

community services announcements).

**Issue 5. Reciprocal relationship between employment and community living.** There was a real concern that employment is viewed myopically. Employment does not exist in a vacuum and the issue of employment for persons who have sustained traumatic brain injury must be viewed in tandem with issues of transportation, housing, and a barrier-free work environment. To address this, the conference attendees and publics must form alliances with other pro-active advocacy organizations to insure current accessibility laws are enforced, that employers and the general public are informed regarding the provisions of the Americans With Disabilities Act and that a massive education program is undertaken regarding this issue.

### Testing and Evaluation

**Focus:** Critically review all testing and evaluation procedures which are used to measure the competencies, achievements and potentials of individuals who have sustained traumatic brain injury in the areas of pre-work education and training programs.

**Issue 1. Limitations of current approaches.** The current systems utilized for testing and evaluation of persons who have sustained traumatic brain injury do not adequately provide realistic assessments of the employment potential of this population. An assessment protocol and/or methodology must be developed which is flexible (i.e., individualized in terms of time, instruments, and professional involved) and comprehensive. This system must be balanced between standardized and functional assessment evaluations. Key to good evaluation practice is tailoring the evaluation to the needs of the individual, rather than to the needs of the service delivery system. If the needed changes are to take place the following must occur:

- A. The National Head Injury Foundation must establish a multidisciplinary task force whose task would be to identify and classify areas, within and across medical, psychological, educational, and vocational assessment which should be utilized in the assessment protocol. Further, this task force

would identify and clarify existing assessment instruments and systematic observation techniques (including situational assessment, observation and work tasks) which could be used to measure the essential factors determined to be needed in the assessment protocol; and

- B. The information and the protocol recommended would be presented to rehabilitation counselors, evaluators and agencies for their utilization in developing an individual assessment package for each individual with traumatic brain injury with whom they work.

**Issue 2. Improve knowledge base of rehabilitation professionals.** There is a need to improve training, education, and the knowledge base of rehabilitation, education, and training professionals who conduct and utilize testing and evaluation procedures both at the pre-service and in-service levels. These individuals need to be professionally prepared in the latest techniques, processes and procedures.

The National Head Injury Foundation's Task Force recommended in Issue 1 the need to share the information and products developed from the actions taken with advocacy groups and personnel responsible for the development of pre-service and in-service training. This then will lead to new and appropriate methods being incorporated into all appropriate pre-service and in-service training programs.

**Issue 3. Validation of effective assessment approaches.** There is a great need to design and implement research programs to validate assessment protocol and methodology utilized in the area of traumatic brain injury. This research must be directed toward determining the effectiveness of the current process and provide direction for the development of new tools and methodology. Funding from the National Institute of Health and similar agencies should be earmarked for this research. In addition, funding should be provided for outcome studies to demonstrate effectiveness resulting in the creation of a nationwide data base.

## Public Attitudes

**Focus:** Consideration of philosophies and perceptions of all publics who affect, and have the potential to impact upon the employment preparation and entry or re-entry into community living and employment of people who have sustained traumatic brain injury. This includes the attitudes of professionals, family members, potential employers, clinicians, and persons with traumatic brain injury.

- Issue 1. Unrealistic expectations and long-term realities of brain injury.** Society (i.e., insurance and other benefit programs, clinicians, service providers, persons who have experienced traumatic brain injury, and families) tend to focus on instant solutions and fixable problems instead of on realistic needs and long-term supports for the total integration of persons with traumatic brain injury into the fiber of society. Steps must be taken to correct this problem so that a better understanding is generated among purchasers of insurance, insurance companies, state agencies, medical and rehabilitation professionals, persons who have experienced traumatic brain injury, families, and caregivers. The actions needed include:
- A. Broad based educational programs by the National Head Injury Foundation and its state associations to inform through the mass media, the general public regarding the causes of traumatic brain injury, the scope of the traumatic brain injury rehabilitation recovery process, the cost of the rehabilitation process and its cost benefits, and the need for creativity in the rehabilitation process;
  - B. Advocacy by the National Head Injury Foundation and its state association for professional organizations (i.e., American Psychological Association, National Rehabilitation Counseling Association, American Rehabilitation Counseling Association, American Speech and Hearing Association) to work collaboratively so that subject matter on traumatic brain injury is included in the professional training curriculum of the professionals they represent; and
  - C. The National Head Injury Foundation working with publishers of special populations' books to have them



distribute these publications in regular book stores. Thus making the information and resources they contain readily accessible to the general public.

**Issue 2. Consumer direction of their rehabilitation.** Currently, there exists a very paternalistic attitude toward service delivery for persons with traumatic brain injury. Too often, service is provided for and to the person with traumatic brain injury instead of with them. The various publics that work with persons who have sustained traumatic brain injury (i.e. rehabilitation professionals, provider organizations, accreditation and licensing organization, caregivers, traumatic centers, and acute rehabilitation facilities) must take steps to include persons with traumatic brain injury in policy and program discussions. This includes

- A. Accreditation and licensing bodies mandating "real" involvement of persons who have sustained traumatic brain injury and families in the accreditation process and development of accreditation policies and practices;
- B. Empowering individuals who have experienced traumatic brain injury and their families through provision of information on options, consumer rights and support for their choices; and
- C. Providing information and education to trauma centers and acute rehabilitation centers regarding service options. Further, the National Head Injury Foundation and state associations need to conduct empowerment conferences, develop resource information (i.e., service options, relevant applicable laws), and lobby the Joint Commission on Accreditation of Healthcare Organizations to provide information to families, caregivers, and persons who have sustained traumatic brain injury regarding service options, public entitlements, and supports.

**Issue 3. Decrease compartmentalization of services necessary for success.** In order for persons with traumatic brain injury to prepare adequately and be successful in entering or re-entering the world of work, they must work and interact with many professionals in the educational, training,

rehabilitation and medical fields. Currently clinical services are too compartmentalized, not functionally based and do not have an outcome focus. This greatly hinders the ability of persons with traumatic brain injury to profit fully from services provided. Steps need to be taken by the National Head Injury Foundation and the state organizations to work with professional organizations to improve their service delivery and make it more functionally based. All programs must be coordinated so that they focus on outcome indicators which include quality of life, integration, job retention, and career development. Additionally, the National Head Injury Foundation and the state associations need to develop professional training opportunities which focus on the attitudes of professionals regarding persons with traumatic brain injury and not on clinical techniques. Research must be undertaken which focuses on outcomes that result in collaborative delivery systems versus more traditional systems.

In summary, issues and action steps are described for achieving a more comprehensive public policy. The thoughts and concerns expressed in the preceding pages represent what was intended to represent a blueprint for facilitating changes in public policy and the practice of rehabilitation and community integration of persons who have sustained a brain trauma injury. Although this "Blueprint for Action" was developed many months prior to the publication of this book, the National Head Injury Foundation and the President's Committee on Employment of Persons With Disabilities continue to encourage changes in the directions laid out by the working group which conceived the ideals and provided the impetus for social change. The sponsors of the meeting are hopeful that everyone who reads this document will reflect and react to the statements and that each participant and other private and public entities will participate in the implementation of the action steps.

#### REFERENCE

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- <sup>1</sup> The editors based this chapter on the summary provided from the President's Committee Paper prepared by Faith S. Kirk and George Zitnay from the "Pathways to Employment" meeting held on November 13, 1990. Editing of their summary does not materially alter the conclusions or recommendations. Seventy individuals representing the various publics who impact on the community re-entry and employment of persons who have sustained traumatic brain injury gathered at the New Orleans Hilton and Tower Hotel, New Orleans, Louisiana to better define a plan of action so that these citizens may readily access the business community to enter or re-enter the world of work. This day-long meeting, entitled "Pathways to Employment," was co-sponsored by the National Head Injury Foundation and the President's Committee on Employment of People With Disabilities.



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292