
VOCATIONAL REHABILITATION, TRAUMATIC BRAIN INJURY AND THE POWER OF NETWORKING

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FOREWORD

People who have experienced a traumatic brain injury (TBI) present a complexity of needs that often formidably challenge traditional service systems. As more people are becoming better informed about TBI and its possible ramifications, service systems are beginning to shift their long-established patterns of service delivery to fit the needs of this population. More non-traditional approaches are being tapped — many of which draw on the power of networking — to provide the linkages and partnerships necessary for the reentry of individuals with TBI into productive roles within home and community.

We developed this publication to aid in this shift toward networking. At the core of this book are the experiences of many individuals working over decades with people who have experienced brain trauma. Several innovative ideas crystallized during the four-year period of funding of TBI-NET (Comprehensive Regional Traumatic Brain Injury Rehabilitation and Prevention Center). Particularly active in developing the ideas and undertaking the research described herein were Rosalind Zuger, Hannah Amitai and Robert Stack (grand rounds model); John O'Neill, Beth Murphy and Susan Mello (vocational rehabilitation follow-up study); Rosalind Zuger (business advisory committee); and Beth Mount (Personal Futures Planning). All associated with TBI-NET are very grateful for their solid contributions to advancing the cause of vocational rehabilitation of individuals who have experienced a brain injury.

TBI-NET linked the resources of ten organizations in New York, New Jersey and Connecticut. In

addition to The Mount Sinai Medical Center, these included Kessler Institute for Rehabilitation (NJ), Hunter College of the City University of New York, International Center for the Disabled (NY), Norwalk Hospital (CT), New York State Department of Health, Human Resources Center (NY), New Jersey Head Injury Association, Connecticut Traumatic Brain Injury Association, New York Head Injury Association and the VR agencies of each respective State. This linking of resources allowed a very creative group of people to develop and carry out activities that would otherwise have been impossible, some of which we describe herein. Both a spirit of great cooperation and the networking of ideas and efforts made these activities possible.

It is the hope of all participants in TBI-NET that people involved in aiding the vocational rehabilitation of individuals with TBI — whether they are employees of state VR agencies, of independent living centers, of inpatient rehabilitation settings or of other organizations, or whether they are nonprofessionals (consumers, family members, friends) — will find these ideas motivating and energizing. Because of the complex set of challenges faced by people with TBI in 'getting a job,' helping them can be tiring and daunting if taken on by only one person or a few. TBI-NET's experience has been that drawing on a network of community resources constitutes a powerful tool. It allows a sharing of responsibility and encourages better outcomes, as it draws on a larger pool of possibilities and knowledge.

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I. OVERVIEW

WHY IS THIS BOOKLET NEEDED?

In this manual, we have tried to pull together in one place diverse insights into the vocational rehabilitation of individuals with TBI. We believe that many resources and innovations can be brought to the complex task of helping people who have experienced brain injuries enter or reenter the world of work. We believe that much is to be gained in our sharing ideas that have worked for us. At minimum, the reading of this manual should help all who work in the vocational rehabilitation arena obtain a few more ideas for their tool kit. We most urgently want to ‘sell’ the idea of networking — a sharing of responsibility, a pooling of resources, a gathering-place for problem solving — as an alternative to the vocational rehabilitation worker’s taking too much on his or her own shoulders when trying to help the person with a brain injury define and reach a vocational goal.

WHAT IS TRAUMATIC BRAIN INJURY (TBI)?

Traumatic brain injury (TBI) refers to damage or destruction of brain tissue due to a blow to the head, such as occurs in an assault, a car accident, a gunshot wound, a fall or the like. The damage associated with the two types of injury that occur (closed head and open head injury) is described below.

In **closed head injury**, damage occurs because the blow to the person’s head whips it forward and back

or from side to side, causing the brain to collide at high velocity with the bony skull in which it is housed. This jarring bruises brain tissue and tears blood vessels, particularly where the inside surface of the skull is rough and uneven; damage occurs at (and sometimes opposite) the point of impact. Thus, specific areas of the brain — most often the frontal and temporal lobes — are damaged because of this harsh shaking/rotating of the gelatinous brain tissue within its jagged casing. This localized damage often can be detected through MRI and CAT scans.

The rapid movement of the brain can also stretch and injure neuronal axons — the long threadlike arms of nerve cells in the brain that link cells to one another and that link various parts of the brain to each other. This diffuse axonal injury interrupts functional communication within and between various brain regions. However, this type of diffuse damage cannot be detected through currently available imaging technology.

In sum, after a closed head injury, damage can occur either in specific brain areas (due to bruising and bleeding) and/or can be diffused throughout the brain (due to stretched or destroyed axons).

Open head injuries, the second type of TBI, occur when the skull is penetrated, for example by a bullet. Damage following open head injuries usually is focal, not diffuse. The effects on the individual’s functioning (see page 2) are likely to be more limited because damage is not spread throughout the brain.

Typically with TBI, loss of consciousness (LOC) occurs — for anywhere from a few minutes to several months. Sometimes LOC does not occur at all, and only a sense of confusion, dizziness or the like signifies the brain’s immediate reaction to trauma.

WHAT ARE THE EFFECTS OF TBI ON THE PERSON'S LIFE?

A wide range of cognitive, physical and behavioral impairments may follow TBI. Basic sensory and motor functions can be affected, as well as the functioning of hormonal, endocrine and other body systems. Cognitively, individuals with TBI may have very subtle to major impairments in their perception, language, attention, concentration, learning and memory. They may also have difficulty in thinking abstractly and in planning/organizing themselves and their worlds. The injury can modify their affective behavior and overt behavioral patterns. In sum, the direct effects of TBI can be complex and diverse within any one individual and will vary greatly from one injured person to the next.

Some individuals who have experienced a TBI are highly aware of these effects; others may be surprisingly unaware, despite feedback from others.

Also, for any specific person the severity of the injury and the resulting direct effects may in no way predict the amount of disruption in his/her life. This follows because each of us draws differentially on differing parts of our brains. A severe frontal injury may have less impact on an agricultural worker's job performance than a so-called 'mild' frontal injury would have on a physicist's work.

An example will be used here to illustrate several of these points:

Joan, a senior in college, was struck by a car and suffered a head injury. Following a few hours LOC and a two-week hospitalization, she was discharged as "recovered." Returning to college, she found that she had to spend an inordinate amount of time

studying to complete her class assignments. After graduation, she attended law school and passed the bar examination. A bright student before injury, afterward Joan succeeded academically by devoting many more hours than most students to studying. She attributed the need for so much homework to her continuing anxiety following the accident.

When she began to work as an attorney, the sequelae of Joan's TBI further manifested themselves, although she did not connect her problems to the injury. She reported that she was having trouble organizing, reading briefs and following conversations; she felt irritable, was hypersensitive to noise and took too much time completing work assignments. She felt her work was too stressful. Her law firm asked her to resign. Joan similarly failed in several subsequent positions with law firms and finally decided to pursue a lower level position outside law while deciding a future course of action. However, during her interviews for positions below her educational qualifications, she reported that she would argue with interviewers — to justify her application. She eventually found a job that she could handle, as a part-time receptionist in a doctor's office.

Realizing, finally, that something was wrong, Joan sought help. Through a series of referrals, she found a neuropsychologist, who discovered that, although her intellectual abilities were intact and her conceptual skills were excellent, she had "cognitive deficits that included decreased speed of visual information processing, visual scanning and impaired verbal memory. These were not severe, but taken together these deficits significantly impeded her career progress." Based on commonly used criteria, her brain injury was considered "mild," camouflaging significant sequelae. She was now reporting that she was feeling constantly angry and out of control; she was having trouble

coping with travel, with crowds and with daily tasks. Cognitive remediation, counseling and vocational rehabilitation were introduced.

While continuing to succeed in her part-time position, she considered this only a short-term plan. It was a dilemma for her to work at a nonprofessional level, which was at odds with her sense of self. This motivated her to explore vocational options. Working with a vocational rehabilitation counselor, she reviewed her areas of interest, and, where additional training was needed, she examined training curricula to decide if they suited her abilities and willingness to commit to course work. She decided, at that point — seven years post-injury — to postpone a career change: to allow her time to receive cognitive remediation and to achieve some successes in a behavioral management program.

Joan continued her remediation over the course of the next two years, but has now stopped. She is still employed in her part-time job, and now has decided to resume her vocational pursuit, with occupational therapy as her chosen profession. She feels she can handle the training, and, if she succeeds, she will find the status and job opportunities she seeks.

This example illustrates points previously made and demonstrates some considerations that are important in vocational rehabilitation of people with TBI:

- o Services are likely to be needed over lengthy periods. People with TBI are commonly not quickly ‘in and out’.

- o The consumer and counselor, in formulating an acceptable plan, need to address pre-injury life style, interests, abilities and goals.

- o Typically, starts and stops, not a nonstop progression, will characterize the course of rehabilitation.

- o For a variety of reasons, the time frame for achieving specific markers during rehabilitation

needs to be kept loose; rigid deadlines are not likely to work to the advantage of the individual with TBI.

- o The need of each consumer of VR services to be empowered to make choices that will become his or her customized rehabilitation plan is multiplied in importance for the person with TBI.

HOW COMMON IS TBI, AND WHO IS THE TYPICAL PERSON WITH TBI?

The incidence of TBI is high, but just how high is not known, primarily for two reasons: (1) many head injuries are not included in official statistics, and (2) definitions of TBI and of disability vary across the respective groups and agencies that track TBI incidence. Estimates have been made as high as three million injuries a year, with 750,000 persons being hospitalized, 100,000 dying and 90,000 left permanently disabled. However, what is clear from any of the estimates of incidence is that many people with injuries do not enter the health care system, because many such injuries are labeled incorrectly or are ignored. We can understand this if we consider that if LOC does not occur or is very brief, the injured person may never go to a hospital or see a doctor. And, with this type of TBI, called ‘minor’ TBI, often the injured person does not tie the dysfunctional consequences of TBI to the injury. No one had told them what to expect even if they did get medical attention. Thus, the individual may have all the symptoms of TBI and not know the cause of his or her symptoms.

The typical person with TBI historically has been depicted as a young male, under the age of 24. The ratio of males to females has been estimated at 4:1. These data may adequately describe people with head injuries who have been hospitalized. How-

ever, newer data based on interviewing people with head injuries living in the community suggest that the ratio of head injured males to females in this group is closer to 3:2. This may be the case partly because females are more likely to receive blows to the head, for example because of domestic violence, that are not viewed as serious enough to send them to the hospital, but the cumulative effects lead eventually to serious consequences in day-to-day functioning.

The significance of this is that many people have experienced a TBI, but they do not necessarily tie problems in living to LOC or TBI. However, where difficulties are found to occur in cognitive, behavioral, affective and social functioning, TBI should be suspected. And, remember that TBI is not rare, it may never have been diagnosed, it may be very debilitating, but it can be diagnosed and worked with. Also to be kept in mind is that myths about the ‘typical’ brain-injured person may prevent us from recognizing actual brain injury when we see it in front of us.

WHAT ARE THE MAJOR BARRIERS TO SUCCESSFUL VOCATIONAL OUTCOME?

For the person with TBI, four types of barriers to vocational success need to be considered: (1) the complexities and characteristics of the injury itself, (2) services — not available or inappropriate if available, (3) restraints within the community and society, and (4) potential loss of benefits associated with vocational placement.

Characteristics of the Injury. Essentially, the challenge for vocational rehabilitation rests with individuals with mild and moderate injuries; those

with severe injuries are often unable to pursue a vocational course at all after injury. The complexities of injury can only be briefly outlined here, but the import for the VR counselor is that, with the person with TBI, a ‘cookbook’ approach will seldom be useful, as it assumes that individuals with TBI are more or less alike. In fact, no two individuals with a brain injury will have had the same history, interests and abilities before injury and will not display the same post-injury deficits or implications for daily living.

For many individuals with moderate TBI, the brain injury leads to reduced functioning; however, areas of strength and interests also define the person, as does his or her social context. In evaluation, goal setting and treatment, the counselor must creatively attend to these complexities. Artistry, as much as experience, will aid the counselor, as will some of the innovative tools and adaptations described herein.

For the person with a mild injury, deficits may be less than with a moderate injury. However, significant difficulties may arise because of the often lengthy lag between injury and the point when the individual recognizes that the injury is the cause of functional problems. Months, sometimes years, go by before the problem is correctly diagnosed and appropriate treatment introduced. By then, a “psychological overlay” may have emerged, as the individual’s difficulties in daily life weave their effects throughout his or her social and vocational worlds.

Services. People with disabilities rely upon the state-federal VR system to help them become employed. Aspects of this system, along with the lack of other services and programs, may inhibit successful vocational outcomes for people with TBI. More specifically:

- o The VR system is a time-limited service

provider that does not meet the long-term needs of many individuals with TBI.

- o Large case loads prevent concentrated delivery of services and discourage the pursuit and adoption of innovative approaches to service.

- o Counselors are not specifically trained to be ‘experts’ in traumatic brain injury and effective approaches to rehabilitation.

- o Delayed referral to VR results in delayed services, but too early a referral may result in a determination of ineligibility for services. Timeliness of referral is fundamental with this disability group.

- o Vocational programs adapted to the special needs of people with TBI are rare. Long-term supported employment programs are also absent within many geographic regions.

Community and Society. Within the individual’s immediate and societal worlds, many barriers to successful vocational outcomes exist, for example, inadequate housing, inaccessible transportation and lack of social supports. Within the service system, no coordinated system of care for community reentry exists. The absence of community resource linkages to provide pre- and post-vocational support is also clearly problematic.

Loss of Benefits. Because some benefits will be withdrawn under certain circumstances when the individual with TBI earns money, the risk of losing benefits can inhibit vocational progress. To minimize this disincentive, the individual must evaluate his or her ‘portfolio’ of benefits to determine what will be affected and what protected, and under what circumstances. For example, Social Security Work Incentive Programs, particularly PASS (Plan to Achieve Self Support) and IRWE (Impairment-Related Work Expenses), have the potential to assist people with disabilities secure a variety of necessary supports to obtain and maintain employ-

ment (e.g., job coaches, transportation, equipment, work-site modifications, training). Knowledge of these incentives and how to help in applying for them is part of the essential arsenal of VR counselors (see Appendix I). Also, in New York State, funds have become available through a TBI-Medicaid waiver to help severely disabled individuals with TBI to receive services in the community, avoiding placement in nursing facilities (see Appendix II).

WHAT DOES THE RECORD SAY ABOUT VOCATIONAL SUCCESS WITH THIS GROUP?

What do we know about the impact of TBI on return to work? Generally, studies have shown that TBI compromises post-injury employment status on many dimensions: Fewer people work post-injury, and those who do work do so for fewer hours, earn less money and enjoy fewer employee benefits.¹⁻⁷

How can one tell if an individual with TBI is a good risk for vocational rehabilitation services? Research cannot tell us who definitely will or will not reach their vocational goals. However, we do know some variables associated with success (but certainly do not guarantee it). For example, many studies^{1-3,6} have found that those with a more substantial career path or higher employment status pre-injury have a greater likelihood of returning to work after injury. However, a study done by O’Neill and colleagues⁵ found the opposite. This inconsistency is probably due to varying subgroups of people with TBI being sampled into respective studies: Because the O’Neill study⁵ selected participants solely from those who had had contact with a

VR agency, they eliminated individuals with TBI who had returned to work post-injury without requiring any formal VR assistance.

Follow-up studies have also shown consistently that severity of injury (based on indicators such as time unconscious or numbers of days hospitalized) and severity of impairment (in terms of mobility, cognitive functioning and behavioral/emotional performance) are inversely related to level of involvement in the labor market. Those 'hardest hit' are least likely to work. One fact that 'softens' this finding is that the amount of time since injury has been found correlated positively with attachment to the labor market;^{2,5} thus, time promotes healing, recovery of psychosocial strengths and consequent return to work — for individuals at all levels of severity.

Two other factors have been consistently shown to be associated with return to work: age and education. Those who are younger and have more education have a greater likelihood of returning to work post injury. One of the better studies² used all of the variables discussed above (e.g., time since injury, education, severity of impairment) in predicting return to work. Administrators may find the formula they developed useful in helping allocate limited resources and services.

What must be kept in mind is that data such as these tell us about tendencies within groups of people. None of this can predict what will happen to any single member of that group. For example, in the O'Neill et al. study⁵ although most of those who had been in coma for a long time did *not* return to work, 12% of these most severely injured people *were* employed at least part-time at follow-up. Thus, if 100 severely injured people presented themselves as candidates for vocational rehabilitation, and, if all of them were rejected as "too risky," this rejection would be wrong, the data suggest, for 12

members of this group.

How well does the state-federal VR system address the vocational rehabilitation needs of people with TBI? The study by O'Neill and his colleagues⁵ provides some sense of "who" the VR system serves. In looking at VR populations in the New York and Connecticut state agencies over three years (1991 - 1993), this study revealed that people with TBI constitute 1.2% and 3.1% of the average caseload in the respective states. Is this good? The rates of acceptance for people with TBI show that, although they were a small percentage of the caseload, they were accepted at a slightly higher rate than the general population of all applicants for VR services. Thus, for example, in New York, 77% of *all* VR applicants were accepted for services, while 83% of those with TBI were accepted.

In terms of numbers rehabilitated, VR agencies are succeeding with only a few people with TBI. Thus, 413 individuals with TBI were closed "rehabilitated" in New York over the three years, with 137 "26 closures" in Connecticut. This is a small number, given estimates of the TBI populations in these states. However, the *rate* of rehabilitation (successful closures vs. all closures) was about the same for individuals with TBI as for all clients. Thus, in New York 57% of individuals with TBI were 26 closures vs. 55% of all clients, while the respective percentages were 44% vs. 40% in Connecticut.

Whether one looks at numbers of people with TBI in the total caseload or numbers rehabilitated, VR agencies in these two states are doing about the same for this disability group as for their total caseloads. Services may not be reaching sufficient numbers, but the data suggest that this is not a matter of discrimination. Instead, it is more likely that insufficient resources within these agencies are at the root of the problem.

When one looks at the impact of VR services on hours worked per week and average earnings, the O'Neill study shows that both of these important indicators increased dramatically for individuals with TBI who were successfully 'closed.' In New York, individuals with TBI who were closed rehabilitated increased their working hours from 3 at referral to 30 at closure. Their earnings increased from \$16 per week to \$174. In Connecticut, hours worked increased from 5 to 30 at closure, with earnings increasing from \$27 to \$201.

In looking at the jobs obtained by individuals with TBI in the VR system, O'Neill⁵ found that a large portion of the 26 closures were in clerical/sales or service positions, which reflects employment opportunities in the region. Specifically, 44% of consumers with TBI finding jobs in New York went into these two employment categories, with 60% in Connecticut. Professional/technical/managerial positions also drew large numbers -- 12% of clients with TBI in each state. The study also found that New York State VR counselors more often used sheltered workshops for placements, compared to those in Connecticut (23% vs. 3%). These proportions remained relatively constant over the three years surveyed. However, in both states a trend toward increasing homemaker closures was found. Again, New York had more of this type of closure (8% vs. 3%), but the percentage was increasing in both states from 1991 to 1993.

What specific methods or techniques produce better outcomes within the VR context? Studies show that both the VR planning process itself and the mix of services provided to individuals with TBI can affect outcome. For example, the O'Neill study shows that those individuals with TBI who were more aware of steps in the VR process, particularly being aware of the Individualized Written Rehabilitation Plan, were more likely to be employed after

discharge. Thus, the quality of the individual's involvement with a state VR agency made a difference to the vocational outcome (participants in this part of the study were 77 individuals with TBI who had applied to or availed themselves of VR services in New York or Connecticut in 1992-1993 and were willing to be interviewed). This underscores the need for consumer empowerment through active participation in the VR process, a service direction strengthened in the 1994 Amendments to the Rehabilitation Act of 1973⁸.

Studies have also raised the question of the services or mix of services that work. In sum, vocational interventions (i.e., supported employment⁹⁻¹¹, enhanced vocational placement services¹²) were more successful in helping individuals with TBI return to work than was neuropsychological treatment¹³; the latter may be necessary for some but is likely to be insufficient on its own. Also, in the O'Neill study⁵, those who reported receiving services for productivity while clients of a VR agency were more likely to be engaged in the labor market after being 'closed'.

WHAT APPROACHES CAN BE USED TO ASSIST PEOPLE WITH TBI ACHIEVE THEIR VOCATIONAL GOALS?

Section II (pp. 8 - 12) recommends **adaptations of traditional approaches** used within vocational rehabilitation, to best benefit the population of individuals with TBI. Section III (pp. 12 - 20) describes **innovative methods**, all of which draw upon resources within community networks and speak to the power of networking in helping people with TBI reach vocational goals.

II. OPTIMIZING TRADITIONAL APPROACHES TO TBI

WITHIN TRADITIONAL APPROACHES, WHAT CAN BE USED TO AID VOCATIONAL SUCCESS?

Two areas are important to review when considering the unique needs of people with TBI: assessment and plan development. Clearly, assessment provides the informational springboard for plan development.

WHAT ASSESSMENT APPROACH IS RECOMMENDED?

In assessing the person with TBI, four principles are critical: (1) The characteristics of the *pre-injury person* (e.g., strengths, values, accomplishments, family support) are as important to the functioning of the person after injury as are the effects of injury. (2) Information obtained through formal assessment needs to focus primarily on *functioning* of the individual: What do the results of testing mean in terms of what the person can or cannot do in daily life? (3) The *individual's strengths* as well as problems and deficits need to be defined. (4)

Characteristics of situations (e.g., the person's home, workplace and neighborhood) affect the individual's functioning and are typically crucial factors that can 'make or break' any attempts to reach vocational goals. These 'truths' about people with TBI lead to the primary recommendations about assessment discussed below.

WHERE SHOULD ASSESSMENT START?

Assessment begins with the vocational intake interview. The detailed information gathering essential to plan development requires one or more sessions with the injured person and family members. This process provides an opportunity to begin establishing rapport with the injured individual and those who play key roles in his or her life.

As people with TBI do remember 'who they were' pre-injury, information about their life before injury is as important as knowing their current status. Probing questions covering the following aspects of the individual, both pre-injury and post-injury, will provide the beginning of an information base upon which plan development will rest:

- o Cultural background
- o Personality
- o Interests
- o Vocational status
- o Awareness of the effects of injury
- o Emotional strengths/problems
- o Behavioral strengths/problems
- o Expectations
- o Alcohol/drug use.

Family members provide information complementing that obtained from the individual with TBI. In interviewing family members, the following topics

are important to cover:

- o Family constellation and supports
- o Family roles altered post-injury
- o Family understanding of the sequelae
- o Family perspective on issues that arise in vocational planning
- o Family expectations for the injured person, both pre- and post-injury.

HOW DOES NEURO-PSYCHOLOGICAL ASSESSMENT FIT INTO VOCATIONAL REHABILITATION?

The neuropsychological assessment serves as a key building block in developing a plan for an individual with TBI. It provides information regarding the person's abilities in the following areas:

- o Sensory and motor function
- o Language
- o Memory and learning
- o Speed of thinking
- o Perception
- o Planning and organization
- o Attention and concentration
- o General intellectual functioning

The neuropsychologist analyzes performance and function based on actual tasks performed and reports the cognitive, meta-cognitive and behavioral patterns observed. In this analysis, the neuropsychologist avoids a focus on summed scores, such as intelligence and memory quotients, but instead emphasizes function. The neuropsychologist also provides descriptions of the individual's behavioral characteristics, insight and adjustment.

Besides administering standardized tests, the neuropsychologist gathers information on the individual's background and interviews the person and family to learn how each views the current situation and their goals/hopes for the future. This knowledge is essential in building a vocational plan that will motivate the person with TBI and enlist adequate family support.

Ideally the assessment should take place over more than one session, to allow observations at different times of day and on different days. Multiple observations expose characteristic changes in fatigue and mood; they also suggest implications about the individual's application of strategies to cope with cognitive or other difficulties, outside the structured testing environment.

The vocational counselor must play a key role in insuring that the neuropsychological assessment process provides information that is relevant. In seeking such an assessment, the counselor should not assume that the psychologist will provide a report that 'fits the bill.' All too often such reports focus on documentation of what has been lost or retained, but without tying this to daily life functioning. The vocational counselor cannot assume a reactive stance, but must actively pose a series of vocationally relevant questions for the neuropsychologist to address within the assessment. For example, the following questions might be explicitly posed:

- o How well does the person learn and remember?
- o Under what circumstances is information best learned?
- o How well does the person concentrate?
- o Is performance maintained consistently? If not, what factors seem to affect performance?
- o Are environmental modifications recommended — to compensate for sensory or motor

losses or for cognitive or affective problems?

- o Is it likely that this person will form cooperative working and social relationships? Communicate effectively? Accurately perceive the intentions of others? Manage behavior?
- o Will modifications be needed in work/study schedules to alleviate fatigue?
- o Is the person able to carry out strategies?
- o Does the person accurately monitor his or her performance? Does she or he spontaneously use compensatory strategies?

As often as needed, the neuropsychologist and counselor should consult each other about compensatory strategies, problem solving and supports.

Appendix III provides a checklist aimed at helping neuropsychologists write reports in functional terms. Appendix IV suggests tests for inclusion in the neuropsychological assessment of persons with TBI.

HOW DOES SITUATIONAL ASSESSMENT FIT INTO THE PICTURE?

A situational assessment is one in which the person being assessed is placed within a work setting to evaluate his or her ability to carry out a job in which he or she has expressed interest. For example, if one is trying to assess the individual's ability to wait tables or to be a bank teller, a situational assessment would evaluate the person's comprehensive performance in an appropriate setting.

The traditional approach to assessment measures aptitude and achievement but, being removed from real life situations, does not evaluate the ability to apply skills in real work situations. Traditional

approaches are lacking in the potential for measuring behavioral and cognitive abilities, self-awareness, capacity for adapting to novel situations and the generalizability of skills. On the other hand, situational assessments are preferred for individuals with TBI because they occur in actual work settings and allow more accurate observation of many traits especially important to successful vocational outcomes:

- o Ability to perform job-related tasks
- o Consistency in carry-over and follow-through
- o Interpersonal skills
- o Response to supervision
- o Impulsivity/distractibility
- o Irritability and its etiology
- o Efficacy of strategies and interventions introduced to help with functional performance and/or to alleviate problems
- o Environmental issues, e.g., noise levels, density of staffing in the work area.

As with all assessments, the emphasis in situational assessments should be placed on the individual's strengths, abilities and problem-solving skills. A well-formulated assessment will generate a meaningful 'by-product,' i.e., the chances are optimized for the individual to experience success, more self-awareness and even the enhancement of self-confidence, while coping positively with a series of situational assessment experiences.

Such assessment should be made as relevant as possible for the individual with TBI, in terms of work setting, tasks tested and the general environment. Usually more than one assessment is necessary to achieve a comprehensive evaluation. As an ongoing process, situational assessments can be used to monitor the continuing effectiveness of strategies and the emergence of new problems, and also encourage proactive problem solving.

HOW SHOULD PLAN DEVELOPMENT/IMPLEMENTATION BE ADAPTED FOR PEOPLE WITH TBI?

Three ideas are key: (1) empowerment, (2) inclusion and (3) redefinition.

By “empowerment” we mean that the individual with TBI gains more by using, and being encouraged to use, his or her power — to choose, to act and to set goals. For example, TBI survivors sometimes have a mind-set that, from the counselor’s point of view, impedes the process of vocational rehabilitation and turns what should be a cooperative partnership between counselor and consumer into an adversarial relationship. This consumer views his or her post-injury world as not being very different from that prior to injury: “My functioning will soon go back to what it was like before, and few, if any, problems will occur upon return to work.” These beliefs may suggest to the counselor an inability to perceive the present situation clearly and may lead the person with the brain injury to resist suggestions from the counselor who challenges them.

We advise counselors in this situation to acknowledge what the individual is experiencing and give the person power to pursue a goal, even one that the counselor may feel is unrealistic. Yielding the right to veto what seems out-of-bounds, the counselor will encourage the growth of the individual. Choice and empowerment allow movement forward and encourage the consumer to develop new self-perceptions based on post-injury realities.

By “inclusion” we refer here to the family, whose support is crucially important for the vocational

rehabilitation success of their family member — achieving it and maintaining it. Therefore, the counselor should make sure not only that the family understands the whole process, but also concurs with the individual rehabilitation plan to be carried out.

Most important in encouraging their sustained involvement is keeping the family informed, in both face-to-face meetings and in writing. The counselor should provide regular updates on progress and problems via conferences that include the consumer, family members, the counselor and others essential to plan implementation. Further, when written reports are shared with the consumer and family members, they are better able to absorb information, which they can review at their leisure. Such information also provides a written ‘history’ of the consumer’s progress.

Having said this, we should also add that, at times, counselors may experience family involvement as intrusive. Nevertheless, it is essential for the counselor and other team members to understand and acknowledge the stress on the family. Regular communication, explanation and negotiation are essential to the process and encourage the family to play strong and positive roles in the consumer’s attempts to seek a meaningful vocational role.

By “redefinition” we refer to the need to modify expectations. For example, redefining expectations regarding rates of progress and time frames for reaching goals is responsive to the decreased level of tolerance, fatigue and inconsistent pacing found in many individuals with TBI. For many people with TBI, “progress” must be redefined so that smaller increments are integrated into the measurement scheme, which allows positive reinforcements to be given more often. This redefinition of “gain” allows the person with TBI a positive experience as

she or he continues to progress. Similarly, we may need to redefine time frames — in several ways. For example, in plan development, many consumers may require shorter planning sessions over longer periods of time. These redefinitions, in sum, are reasonable adaptations, to encourage the consumer’s involvement in planning and to optimize the positive experiences of plan implementation.

III. INNOVATIONS: THE POWER OF NETWORKS AND NETWORKING

In the previous section, many suggestions were made about adapting techniques within the current framework to assist individuals with TBI achieve vocational success. This section focuses on adopting *new* techniques — looking beyond the consumer-counselor-family triad. All of the innovative techniques discussed below have in common their drawing on community *networks* — to better address the complex issues of vocational rehabilitation for individuals with TBI.

WHY ARE NETWORKS IMPORTANT?

A person with TBI who is reentering the community usually has highly complex needs (e.g., housing, transportation, benefits, socialization, as well as vocational planning) that must be identified and addressed. Because the vocational rehabilitation counselor is often the sole professional remaining in the picture when the physician and therapists are no longer constants for the consumer, the counselor often takes on both the role of “constant” and the job of plan coordination, putting all the pieces in place

to activate and advance vocational plans.

This is where networks and networking comes in. A network can be defined as an open fabric or structure joined at regular intervals. Unlike a pile of loose unconnected threads, a network forms a strong tool because of its connectedness. The counselor/coordinator obviously will benefit from making use of such a tool to address the complex demands of the coordinator's role. Networking promotes the sharing and rotation of responsibilities, as needs dictate, thereby preventing counselor 'overload'.

The goal of the plan must be to empower the person. To maximize power, the consumer must maximize his or her resources. "Empowering" requires, therefore, tapping into community networks, helping the consumer connect with resources that will aid him or her in reaching goals. The word "empowerment" includes within it "me," "we," and "power": Power lies in both the individual "me" and in connecting to the "we" that can provide tools for achieving vocational success. Networks maximally empower, as they are the antithesis of fragmented, uncoordinated efforts, which many individuals with TBI find debilitating.

WHAT ROLE DOES THE COUNSELOR PLAY VIS-À-VIS NETWORKS?

The counselor's role is to analyze and identify existing community supportive networks and settings that will serve a specific purpose — helping create and nurture a network that is suitable as a specific tool. Because a network is made of specific interconnected elements, the counselor's job is to identify the elements essential to the task at hand, which may be a specific consumer or a group.

This is a very creative and challenging job. However, when achieved, creation of a network will make the counselor's job much easier: the burden no longer sits squarely on the counselor's shoulders. By bringing a variety of agencies and groups into the "we" of empowerment, the counselor distributes responsibility to those who can help directly. The counselor is still the coordinator, but now has developed a valuable tool — a "circle of friends" with whom to work.

The vocational counselor is the person with the overall view of the fabric or network. Various people or programs will assume dominant roles at different times, while the counselor monitors progress and facilitates movement toward independence. As one part of the network nears completion of its task, the counselor should be assembling resources to address the next phase.

In the development of a network, it is important to include non-traditional resources. True community reentry means getting away from 'special' programs and segregated facilities. Generic community resources can provide specific training and support, with the additional benefit of peer interaction. For example, one innovative counselor was working with a woman who needed assistance with budgeting and banking. The counselor reached out to the community and found a YWCA that offered a money management course for female heads of households. The woman with TBI not only received the skills training she needed, but also had the opportunity to meet and learn from other women engaged in enhancing personal empowerment.

Networks sometimes form easily, building on the commitment of family or friends. The vocational rehabilitation counselor can maintain the enthusiasm of the members by continually asking what the person needs and the tasks necessary to meet that

need. Participation is most effective when people have defined roles and specific expectations.

The counselor is responsible for providing the technical assistance that network members need to accomplish their roles. For example, if a network member has agreed to accompany the person with TBI to make contacts with community agencies, that member might need information from the counselor regarding the person's verbal skills or fatigue level. Another network member working on improving executive skills may need education regarding the use of memory books or tape recorders by individuals with TBI. Thus, the network members look to the vocational counselor to provide information necessary to fulfill their roles.

Establishing and maintaining a community support network involves time, planning and creative energy. A viable network empowers the person with TBI and enhances the work and commitment of the vocational rehabilitation counselor.

WHAT ARE SOME INNOVATIVE WAYS OF USING/CREATING NETWORKS?

We discuss three innovations at length below: (1) business advisory committees, (2) grand rounds and (3) Personal Futures Planning. Each innovation requires the counselor (and agency administrators) to make a commitment to building network structures that will exist long after the needs of one individual with TBI have been met. Once the structure is in place, it obviously can be used to address the needs of large groups of persons with TBI (and persons with other disabilities who also have complex needs best addressed through networking).

WHAT IS A BUSINESS ADVISORY COMMITTEE, AND HOW CAN IT BE HELPFUL?

Rehabilitation counselors need strong linkages specifically with community business leaders who can help them find appropriate employment for consumers. One approach to establishing this network is through developing a business advisory committee.

The use of these committees has become popular and effective when properly established and employed, enhancing the vocational and placement components of the rehabilitation process. Comprised of local business representatives, a committee can make inroads into community arenas that are not directly available to agency personnel. That is, the committee members have access to decision-makers in local corporations, and to business clubs and organizations.

They can assume many roles — as advisors, advocates and educators, thereby helping the agency and individuals with TBI, as well as informing and educating employers about people with disabilities.

Some committees, in addition to the efforts of individual members, produce a newsletter to publicize the existence of the committee to the business community, conveying information and introducing qualified candidates for employment.

Whatever the path taken, the results are threefold: jobs, jobs and jobs.

HOW CAN A VOCATIONAL REHABILITATION AGENCY ESTABLISH A BUSINESS ADVISORY GROUP?

The first step in forming a committee is to select a chairperson who can attract and motivate members. All members should be at a decision-making level in their companies. The chairperson and members should be recruited from diverse sources, each of which has potential for offering employment, e.g., manufacturers, universities, hotels and other local businesses with moderate to large working forces.

Initially, working under the guidance of the chairperson, it is advisable to assemble only a few business executives to form the core of the committee. Over time the membership can be increased gradually, but with membership limitations — so that the committee stays manageable and every member has an important role to play.

At the outset, the core committee should establish the frequency and time of meetings (e.g., breakfast meetings once a month). Then it should develop a mission statement and action plan that addresses its priorities. For example, since members need suitable ‘tools’ to do their job, the first order of business may focus on assessing the needs of respective members for information, e.g., information about TBI and its impact, knowledge of how vocational rehabilitation works and profiles of program ‘graduates’ whom the committee will assist. The action plan should define how this information is to be imparted to committee members. The plan also should state how the committee will expand awareness within the business community about its goals and its work. Finally, a process for planning the committee’s program needs to be established, as

does the agenda for the first few meetings of the full committee.

Active and meaningful participation by each member of the committee is crucial to its success. Concrete projects in which members can be involved include:

- o Identifying and contacting employers in a defined geographic region,
- o Recruiting corporate personnel to develop a mock interview team,
- o Developing situational assessment sites as the need arises, and
- o Becoming directly involved with vocational rehabilitation staff and job candidates to help with job preparation and placement.

Because of the busy schedules of members, an additional key to a successful committee is to keep meetings short and focused, which requires fostering both concise discussions and presentations of job candidates.

WHAT IS "GRAND ROUNDS" AND HOW IS IT PART OF NETWORKING?

Within the medical model, physicians and other professionals use grand rounds for teaching and problem solving. Although formats vary, typically a grand rounds is a gathering that focuses discussion on unique and problematic cases, in which the opinions of experts across a spectrum of medical specialties are invited, as part of a debate on reaching a definitive diagnosis and/or prescribing a course of treatment.

This model, with modifications, ideally suits the challenges of vocational rehabilitation of people

with TBI. The vocational counselor or agency administrator can adopt the grand rounds model as a means to brainstorm with colleagues, build community understanding of and involvement with specific individuals with TBI, update knowledge and creatively focus rehabilitation efforts drawing on community resources.

With the aim of advancing the vocational rehabilitation of one or more specific individuals with TBI on the counselor's/agency's caseload, the vocational counselor/administrator initiates a grand rounds by: (1) shaping the format to meet specific needs, (2) selecting cases that are particularly challenging, and (3) inviting participants from the agency and community-based resources, who may contribute to rehabilitation planning or who may benefit from the information shared. Resource teams with expertise in the vocational rehabilitation of people with TBI (e.g., neuropsychologists, VR specialists) may be useful to include in the initial grand rounds sessions, to help build 'TBI expertise' within the community and within the agency.

As a dynamic approach to outreach and education, the grand rounds model provides an opportunity to strengthen already existing partnerships between counselors and organizations. It also helps initiate and develop long-term relationships among community-based resources whose understanding and support of individuals with TBI are essential for successful community reentry. We recommend this forum: (1) to focus the efforts of counselors, facilitate problem solving and define plans of action; and (2) to provide entree to the community, providing a focused arena for informing people about TBI and providing a novel method of network-building.

WHAT HAS BEEN THE EXPERIENCE OF TBI-NET IN IMPLEMENTING GRAND ROUNDS?

TBI-NET pioneered the use of the grand rounds model in vocational rehabilitation, primarily serving as consultants to designated VR offices. For each grand rounds undertaken, a VR office selected one or more current cases -- individuals with TBI who were problematic to the counselors coordinating vocational rehabilitation efforts. The date and time of each grand rounds session were set to optimize the number of counselors and supervisors able to attend, and to maximize the participation of invited representatives of community-based organizations. A typical mix of invitees might represent the local police, Social Security office, psychiatric outpatient program, school, college, local 'Y' and other community resources and agencies.

A few weeks before the scheduled grand rounds, the VR office sent all case documentation to the TBI-NET's technical assistance team, which included a neuropsychologist, a vocational rehabilitation specialist and a community resource consultant. The team reviewed the demographics, education, work history, pre- and post-injury life style, circumstances of the injury, neuropsychological report, the VR plan, actions taken and their outcomes, and the presumed external and personal barriers to further progress.

Each grand rounds meeting began with the VR counselor and the technical assistance team's VR specialist presenting the background of the selected case. Then the neuropsychologist reviewed the neuropsychological report that had been part of the case file, explained the tests administered and inter-

preted the results. Functional meaning of the results was emphasized whenever this had been neglected. The neuropsychologist recommended additional testing if the evaluation fell short of optimal. The VR specialist then reviewed the treatment plan, identifying the steps taken and probing reasons for these actions. In exploring the process, the VR specialist discussed options, raised questions, validated actions taken and made further recommendations. Throughout these sessions, all attendees were encouraged to participate and the adaptations of 'usual' VR procedures to fit individuals with TBI (described on pp. 8 - 12) were reviewed.

Examples of grand rounds presentations may help exemplify this approach to networking:

Len experienced a TBI as a result of a motor vehicle accident while driving intoxicated. This occurred shortly after his starting college as an accounting major. The accident left him with weakness on the left side of his body and slow labored speech. He uses a wheelchair to get around. Following discharge from a rehabilitation program, he attempted to return to school with support from VR. Len attended a liberal arts program for three semesters, but experienced difficulties keeping up with the course work, leading to his withdrawal from the school. After relocating to another state, he attended a computer training program for people with disabilities and again had difficulties with the material and had to drop out. He then found a routine job sorting clothes with a nonprofit organization and stayed with that job for two years.

When he returned to New York, he reopened his case with the State VR agency and expressed interest in accounting or bookkeeping. A neuropsychological assessment was recommended. The report was comprehensive and functionally oriented, revealing, for example, his ability to organize material,

excellent attention and concentration, good arithmetic skills, good overall verbal ability (though reading skills were impaired), average abstract reasoning skills, deficits in visual motor functioning, slowed visual motor speed, some social inappropriateness and poor judgment. The neuropsychologist concluded that "Len's expressed interest in bookkeeping coincides with the results of the testing; this choice is well suited to his general verbal strengths and particularly his facility in manipulating numbers. However, time pressure should be minimized."

This neuropsychological report was very helpful, providing vocationally relevant, functional information, which the counselor could easily use. (This contrasts sharply with a report by a neuropsychologist on another individual, Liz, a young woman with severe TBI, in which the psychologist suggested that, because of the woman's interests in social issues and the outdoors, "employment such as redeveloping Kuwait or providing relief to weather-torn Ethiopia would be appropriate.") Although he had already failed a computer course, the counselor decided to place Len in another such course rather than a bookkeeping training program. He similarly failed this one, and unfortunately was retained in the program long after staff had concluded that computer programming would not be a feasible goal.

At the grand rounds, participants raised questions about this course of action — Why this type of training, when a similar program had been tried already? The discussion revealed that Len had even offered to work extra time, to meet the demands of the bookkeeping training. The suggestion was made that he might originally have benefitted, and still would, from a 'place-and-train' situation in bookkeeping.

In another grand rounds, the young woman mentioned above — Liz — was discussed. The counselor said that he and others had urged Liz repeatedly (to no effect) to explore benefits at her local Social Security office. This discussion led one community agency present at the meeting to offer to accompany her to the local Social Security office to help her with SSA procedures. Representatives of another agency recommended a variety of social and recreational programs available in the community. Here, networking through grand rounds enabled counselors to reach out for and obtain support, to share responsibility with others and to obtain up-to-date information on community resources available to this and to other consumers.

Another grand rounds focused on Henry, a young married man who had a motor cycle accident as a result of which he experienced a TBI. Shortly thereafter his wife divorced him; and he obtained rights to visit his daughter. His high level of anxiety, both before and after visiting days, about whether he could entertain his daughter led to a loss of concentration and began interfering with his vocational rehabilitation. During the grand rounds session, a community participant suggested his joining the local chapter of Parents Without Partners, to provide him a social program and a network for both him and his child. He subsequently pursued this suggestion, to good effect.

WHAT IS PERSONAL FUTURES PLANNING AND HOW IS IT PART OF NETWORKING?

Personal Futures Planning (PFP) is a set of values and tools that can be used by vocational counselors

in assisting people with TBI find a new direction in life and organize a personal network that provides both emotional and practical support to the person with the injury. The PFP approach encourages us to look at the focal individual broadly, avoiding narrow thinking that may unnecessarily limit his or her attempts to reach vocational and other goals. PFP assumes that vocational goals (like any goal) are defined, achieved and retained within a broad context: the individual — with many interests, abilities, values and motivations — living within a world of family, friends and the wider community.

PFP helps persons regain their sense of self after injury by renewing their understanding of their gifts and potential. It restores a vision for their life, adapted to fit new challenges and realities of living with the aftermath of injury. PFP helps counselors, too. It provides tools that help shape goals that are more likely to be successfully addressed, as they are part of a larger personal vision. The tools also generate personal networks to help the counselor in his or her role of aiding individuals with TBI achieve their vision, including, but not limited to, their vocational vision.

What is PFP? It is an approach to planning for the future that avoids treating the person with a head injury as a “case,” to assess and fix. It avoids fragmenting further the individual whose life may have already been fragmented by injury. What PFP does do is encourage the counselor and person with TBI to focus on creating a vision and an action plan to address all areas of life important to the individual with TBI: work, education, community work, recreation, relationships, health and well-being.

PFP begins by developing an in-depth description of the interests, gifts, personal preferences and hopes of the focal person. The profile also identifies strengths and opportunities in the social network of

the individual with TBI. The profile is developed through interviews with the focal person and others who know the person well. A central element of PFP is the building of a “circle of support” — friends, family members, community residents and others interested in the welfare of the focal individual. The circle of support and the individual with TBI work together to develop not only the profile of capacities and hopes but also, in the next step, a vision for the future — a vision of how the focal person can contribute positively in diverse areas of his life. Both the opportunities within the neighborhood/community and the focal person’s profile of preferences and strengths are primary contributors to the vision.

From the vision, a specific action plan is developed, the application of which depends not only on the focal person’s activities but also on the continuing support and problem-solving of the circle of support. An example of PFP in action will help convey the potential of this approach for the vocational counselor:

Charles is an eloquent, bright and compassionate man who has been seeking a focus for his life since his head injury, which occurred over 20 years ago. Before his accident, he was in college, headed for graduate or law school. An ambitious person, Charles was interested in economics, politics, social justice and teaching.

Following his accident and a long recovery process, his periods of unemployment were punctuated with a variety of jobs that fell into two extremes: they were either menial and unchallenging or they required very high-level information processing and organizational skills. At either end of the spectrum, these jobs ended, leaving Charles with a sense of failure and disappointment. Throughout this period, Charles assumed a central role in managing

his home, raising his children and supporting his wife in her work. He was active in his church, and in the TBI self-advocacy community, where he discovered and participated in Personal Futures Planning.

A support circle was developed, including his wife and several friends/colleagues from the TBI network. Working with a skilled facilitator and his support circle, Charles examined his past and present interests and dreams, his job successes and failures, and his personal and community-oriented interests and involvements. Through this process, which involved several individual and support circle meetings, Charles developed a vision and action plan. His ideas and the responses from his group were recorded on large sheets of chart paper, which helped clarify the themes in his life and his ideas about the future. The results of this process incorporated his strong interests in helping and teaching others and his commitment to pursue higher education.

Charles began working as a personal assistant in a large human service agency, providing both personal care and life skills instruction to people with developmental disabilities. He has been promoted once and received an award for his commitment to the people served within this agency. He plans to continue his education by enrolling in an MSW program. Charles is also planning to apply for other jobs within this agency that will further his interests in teaching and leading others.

In his own words, he reports, “Following my accident, society seemed to say to me, ‘Drop out of life, take your medication and maybe we can find you a job in a file room somewhere.’ PFP helped clear the psychosocial logjam that inhibited the flow of my personal development.”

The principles of PFP can be learned in a variety of ways. *Person-Centered Planning: Finding Directions for Change Using Personal Futures Planning* provides a basic introduction to PFP. A variety of other publications, including one being developed that modifies the general PFP approach for use with people with TBI (see Appendix VI), are also available.

APPENDIX I: SOCIAL SECURITY WORK INCENTIVES

“Work incentives” refer to a variety of programs that provide strong encouragement for people who are receiving public funds to enter the labor market for the first time or return to work after being out of the labor market due to disability. The work incentives developed within the Social Security Administration (SSA) are those often most important for people with disabilities. Many SSA work incentive programs are designed to help individuals with TBI or other disabilities to make the transition to full- or part-time employment. Work incentive programs accomplish this by providing short-term financial support enabling the individual to work, in order to reduce his/her long-term draw on public funds. We describe two of the most important programs below.

PASS: PLAN FOR ACHIEVING SELF-SUPPORT

Mike, a person with a head injury, receives \$200 monthly in SSDI and \$227 in SSI benefits. He would like to learn a skill so that he can get a job, but the training program he has in mind costs \$150 per month, which he cannot afford and still meet his living expenses. To overcome this ‘impossible’

situation, he makes use of a Social Security work incentive, known as Plan for Achieving Self-Support, or PASS. The impossible becomes possible for Mike because through PASS, the \$150 a month from SSDI he uses for tuition no longer ‘counts’ in determining the amount of his SSI benefit, and, thus, this latter benefit increases substantially under PASS. Mike’s benefits with the PASS allow him to meet his basic needs and he has funds to pay for job training.

PASS, in essence, is a ‘deal’ Social Security makes with the individual with a disability. The deal is that the person will use some of his or her funds (e.g., SSDI, earnings, Workers’ Compensation benefits, insurance benefits, lawsuit settlements, inheritance, gifts) to reach a vocational goal, and Social Security will exclude these funds in deciding the person’s eligibility for SSI and in calculating the amount of his or her monthly SSI benefits.

PASS is extremely flexible and useful. PASS funds may be used in acquiring new skills to get a job or in starting a business. PASS is useful in many types of situations. For example, it will allow an individual like Mike, who already is on SSI, to use his funds to pay for expenses necessary in getting back to work and simultaneously increase SSI benefits to make up the shortfall from paying tuition. It will allow another person initially applying for SSI to hold onto savings or other funds (rather than having to spend them down) as long as they are used as part of a PASS plan to get back to work. PASS is also useful for the individual on SSDI who *cannot* get SSI. She or he can file a PASS plan that invests all or part of SSDI benefits in work-related expenses, making him or her then eligible for applying for SSI benefits to live on. This also makes the person Medicaid eligible — often the most important benefit to a person with a disability.

The individual with a disability must develop the

PASS plan in writing and have it approved by the local Social Security office. The PASS must include a detailed explanation and justification of the goal to be achieved. For example, a person would have to show evidence of training and experience in computer programming to obtain approval for a PASS to open a computer programming service. Another person who wants to enroll in a training program would need to show, for example, that she or he meets all criteria to enter the program, has an interest in doing work of that type and that positions are likely to be available after training.

The plan also must detail the proposed expenses that will be involved in reaching the goal (for example, office rent, phone and equipment for starting a business; or tools to be purchased and tuition required in a training program). Additionally, the plan also must show that the person can meet personal expenses (for example, rent, food, electricity, transportation) after setting aside a specified amount of money monthly for vocational purposes.

A final component of the plan is setting a timetable for the PASS. The maximum time allowable is three years, unless a training program is involved, in which case the PASS may be extended for a fourth year.

Once SSA approves the plan, the money saved must be kept in a separate bank account designated solely for PASS savings and expenditures. SSA may ask for an accounting at any time, at which point the money planned to be saved must be in the account, or receipts for expenses incurred must be available. For example, if the PASS says that \$1,000 will be saved during the first four months of PASS, that amount should be in the account and/or receipts should be available reflecting allowable purchases covering the difference between planned savings and those in the bank account.

What is the first step? The individual interested in PASS should request information from a nearby Social Security field office. The SSA suggests that applicants obtain help in developing the PASS (for example, from vocational rehabilitation agencies or an independent living center) or use the work incentives specialist at the SSA office.

IRWE: IMPAIRMENT-RELATED WORK EXPENSES

This work incentive program, known as IRWE, is potentially useful to those receiving SSI and/or SSDI benefits. IRWE is the most flexible and long-lasting of the work incentive programs of the Social Security Administration: IRWE benefits can be claimed for the individual's entire working life.

Impairment-related work expenses refer to costs that an individual with a disability incurs in order to work. In calculating how much of the SSI or SSDI benefit payment the individual will retain after return to work, these costs are deducted from the person's earned income. If, for example, the person is entering the work force, the IRWE deductions allow more SSI and SSDI benefits to be retained — as long as the individual does not exceed the Substantial Gainful Activity Level defined by SSA.

IRWE expenses must meet strict criteria: only those expenses that the individual pays (and will not be reimbursed for), that are work related and that are directly impairment related. Examples include adaptive equipment, mobility aids, personal care costs, medical costs related to disability, and transportation costs related to disability. Personal care costs provide an example of the complex principles that define whether an expense is an IRWE: Personal

care costs associated with getting ready for work *do* count as part of IRWE, but payments for personal care after work or on weekends *do not* count. SSA guidelines (see below) summarize what can and cannot be included as a part of IRWE.

The individual receiving SSDI or SSI who is planning to return to work applies for the IRWE work incentive by notifying the SSA's local office of his or her intent to work and attaching an itemized list of IRWE expenses with the letter. Receipts and other documentation may be required by SSA to verify any or all of the expenses being claimed.

Additional Resources: Call the local field office of SSA and request the *Red Book on Work Incentives*, also known as SSA Publication No. 64-030. This is the official SSA guide, intended for public distribution, and includes detailed information on PASS, IRWE and several other SSA work incentive programs. *Working While Disabled*, SSA Publication No. 05-11017, is also very useful.

This text is adapted from: (1) *The ACCESS Guide to Federal Work Incentives*, written by John Woodward of the CIL of North Florida, in Tallahassee; the *Guide* was published by the CIL and sponsored by the Division of Vocational Rehabilitation of Florida; and, (2) *Working While Disabled*, SSA Publication No. 05-11017, August 1991, Social Security Administration. We also want to thank consumer advocate Alayne Kuffner for her helpful suggestions and editorial review.

APPENDIX II: MEDICAID WAIVER FOR HOME AND COMMUNITY- BASED SERVICES FOR INDIVIDUALS WITH TBI (NEW YORK STATE)

The Home and Community-Based Services (HCBS) waiver for individuals with TBI is a program sponsored in New York by the Department of Health (DOH). The purpose of this waiver is to fund the services and supports that individuals with TBI need to live in the community rather than in a nursing facility. Historically, the Medicaid system funded only institutional care, but with the arrival of the HCBS waiver, an individual is now able to use Medicaid funding to live in the community of choice, in a situation of choice.

All existing services provided under the regular Medicaid program and under other publicly funded services (e.g., VESID) are available to the recipient of a waiver. It is expected that with the waiver

services, the participant will be able to maintain his/her health and welfare, remain in the community and increase his/her independence and self-reliance. Waiver services include:

- o Service coordination
- o Structured day programs
- o Training in independent living skills
- o Substance abuse programs
- o Home and community support services
- o Community integration counseling
- o Environmental modifications
- o Vehicle modifications
- o Intensive behavioral programs
- o Respite care
- o Medical equipment and supplies
- o Transportation

Who is eligible? All of the following criteria must be met:

- o The individual with TBI must have been injured after the age of 18 and before age 65.
- o The individual with TBI must currently be in a nursing facility or have been evaluated as needing a nursing facility level of care.
- o The residence must be identified in which the waiver participant will be living when receiving services; the residence must meet the individual's safety and health needs.
- o The waiver applicant must have an approved service plan that fits within regional HCBS waiver budgetary caps. (The fact that the cap is regional allows more flexibility than if individual caps were mandated; however, as the number of service plans within a region increases, the flexibility decreases.)

What is the process for applying for the waiver?

In the first step, the individual with TBI must decide to live in the community, not in a nursing facility. The individual then will meet with his/her Regional Resource Development Specialist (RRDS), who is

contracted to provide this service by the DOH, and who will explain the waiver program and provide a list of approved service coordinators. The individual with TBI must then choose a service coordinator (see below) to help in developing the documentation needed as part of the waiver application. The individual with TBI, the service coordinator and other individuals, as needed, then develop the service plan, which is submitted to the RRDS for review. Notification of the decision about the application will then be sent to the applicant and service coordinator.

A provider manual describing services available and processes for accessing services may be obtained by contacting the **NYS DOH** (518) 474-6580.

APPENDIX III: CHECKLIST FOR WRITING NEUROPSYCH- OLOGICAL REPORTS IN FUNCTIONAL TERMS FOR VOCATIONAL REHABILITA- TION

A neuropsychological report describing the strengths and limitations of the individual with TBI, in functional and vocationally relevant terms, is often a key item in developing a vocational rehabilitation plan. The Checklist for Writing Neuropsychological Reports in Functional Terms for Vocational Rehabilitation is a procedure designed to facilitate communication between counselors and psychologists. It was developed at the Southwest Regional Brain Injury Rehabilitation and Prevention Center in Houston, and was authored by Mary Ellen Young, Joyce Eisner-Leverenz, Linda Ewing-Cobbs and Walter High.

I. COGNITIVE OBSERVATIONS

A. Attention and Concentration

1. HOW LONG CAN THE INDIVIDUAL FOCUS ON A TASK?
 < 5 min. 5-30 min. 30-60 min.
 longer (specify # of hours)
2. DOES THE INDIVIDUAL NEED BREAKS?
 usually sometimes rarely
3. DOES THE INDIVIDUAL MAKE IMPULSIVE ERRORS?
 usually sometimes rarely
4. IS THE INDIVIDUAL DISTRACTABLE?
 usually sometimes rarely
IF USUALLY OR SOMETIMES DISTRACTABLE, IS THE SOURCE OF THE DISTRACTION:
 external internal both?
5. IS THE INDIVIDUAL AT INCREASED RISK IN JOBS INVOLVING SPECIFIC HAZARDOUS CONDITIONS SUCH AS:
MOVING EQUIPMENT? yes no
ELECTRICAL SHOCK? yes no
HEIGHTS? yes no
HAZARDOUS MATERIALS? yes no
SECURITY / POLICE DUTY? yes no

B. Approach to Task and Problem-Solving Skills

1. CAN THE INDIVIDUAL USE AN ORGANIZED APPROACH TO TASKS?
 usually sometimes rarely
 with prompts without prompts
2. CAN THE INDIVIDUAL RECOGNIZE ERRORS?
 usually sometimes rarely
 with prompts without prompts

3. CAN THE INDIVIDUAL CORRECT ERRORS?
 usually sometimes rarely
 with prompts without prompts
4. CAN THE INDIVIDUAL ACCEPT AND USE FEED-BACK?
 usually sometimes rarely
5. CAN THE INDIVIDUAL GENERATE PROBLEM-SOLVING STRATEGIES?
 usually sometimes rarely
 with prompts without prompts
6. CAN THE INDIVIDUAL CHANGE HIS OR HER APPROACH WHEN INEFFECTIVE?
 usually sometimes rarely
 with prompts without prompts

C. Memory

1. DOES THE INDIVIDUAL HAVE ANY PROBLEMS REMEMBERING EVENTS THAT OCCURRED OR PERSONS WHOM THEY KNEW PRIOR TO INJURY?
 yes no
 IF YES, INDICATE IF THE INDIVIDUAL HAS PROBLEMS REMEMBERING:
 MINUTES BEFORE INJURY? yes no
 HOURS BEFORE INJURY? yes no
 THE DAY BEFORE INJURY? yes no
 THE WEEK BEFORE INJURY? yes no
 THE MONTH BEFORE INJURY? yes no
2. ... ANY PROBLEMS REMEMBERING CURRENT EVENTS/PERSONS?
 yes no
 IF YES, INDICATE IF THE INDIVIDUAL HAS PROBLEMS REMEMBERING THINGS THAT HAPPENED:
 IN THE LAST MINUTE? yes no
 IN THE LAST HOUR? yes no
 IN THE LAST DAY? yes no
 IN THE LAST WEEK? yes no
 IN THE LAST MONTH? yes no

3. ... ANY PROBLEMS REMEMBERING ONE- OR TWO-STEP DIRECTIONS?
 yes no

IF YES, INDICATE IF THE INDIVIDUAL HAS PROBLEMS REMEMBERING:

- FOR A MINUTE? yes no
 FOR AN HOUR? yes no
 FOR A DAY? yes no
 FOR A WEEK? yes no
 FOR A MONTH? yes no

4. ... ANY PROBLEMS REMEMBERING MORE COMPLICATED DIRECTIONS?
 yes no

IF YES, INDICATE IF THE INDIVIDUAL HAS PROBLEMS REMEMBERING:

- FOR A MINUTE? yes no
 FOR AN HOUR? yes no
 FOR A DAY? yes no
 FOR A WEEK? yes no
 FOR A MONTH? yes no

5. ARE THE INDIVIDUAL'S MEMORY PROBLEMS: (check all that apply):
 GLOBAL? VISUAL? VERBAL?

6. DOES THE INDIVIDUAL USE MEMORY AIDS?
 usually sometimes rarely
 with prompts without prompts

7. DOES THE INDIVIDUAL ASK FOR CLARIFICATION AND REPETITION OF DIRECTIONS?
 usually sometimes rarely

8. DOES THE INDIVIDUAL HAVE MORE SUBTLE PROBLEMS REMEMBERING NEW INFORMATION THAT AFFECT HIS OR HER ABILITY TO DO MORE COMPLEX JOBS OR TASKS?
 yes no

D. Insight

1. DOES THE INDIVIDUAL OVERESTIMATE HIS OR HER PHYSICAL CAPACITIES?
 usually sometimes rarely
2. DOES THE INDIVIDUAL OVERESTIMATE HIS OR HER MEMORY ABILITIES?
 usually sometimes rarely
3. DOES THE INDIVIDUAL OVERESTIMATE OTHER COGNITIVE ABILITIES?
 usually sometimes rarely
4. DOES THE INDIVIDUAL UNDERESTIMATE BEHAVIORAL CHANGES?
 usually sometimes rarely

II. WORKER TRAIT FACTORS

A. Functional Reasoning Level (check one)

- 0 Does not use common sense, cannot follow simple instructions
- 1 Uses common sense, follows 1-2 step instructions in tasks with no variability
- 2 Uses common sense, follows simple written and oral instructions, minimal variability in tasks
- 3 Uses common sense, interprets instructions in written or diagram form, deals with several concrete variables
- 4 Solves practical problems within preexisting structures, deals with several concrete variables with limited standardization, interprets directions in all modalities
- 5 Defines problems, collects data, establishes facts, draws valid conclusions, interprets extensive

instructions in any format, deals with both abstract and concrete variables

- 6 Applies logical or scientific thinking to solve a wide range of abstract problems, may involve formulas and equations

B. Physical Capacities / Sensory Modalities

1. STATUS OF MOTOR SYSTEM? (check all that apply)

hemiparesis right left
 hemiplegia right left
 paraplegia
 quadriplegia
 ataxia
 apraxia

2. PROBLEMS NOTED IN VISUAL ACUITY?
 yes no

3. PROBLEMS NOTED IN PERCEPTION?
VISUAL SCANNING? yes no
FORM PERCEPTION? yes no
CLERICAL PERCEPTION? yes no

4. VISUAL FIELDS INTACT?
 yes no
IF NO, SPECIFY:

5. DOES INDIVIDUAL HAVE INATTENTION TO VISUAL FIELD (VISUAL NEGLECT)?
 yes no
IF YES, right left
 subtle apparent

6. PROBLEMS WITH HEARING?
 yes no

7. PROBLEMS WITH SENSATION/TOUCH?
 yes no

8. PROBLEMS WITH SENSE OF SMELL OR TASTE?
 yes no

C. Language Skills

1. RECEPTIVE: UNDERSTANDS SIMPLE 1-2 STEP VERBAL INSTRUCTIONS?
 usually sometimes rarely

2. EXPRESSIVE:
 EXPRESSES BASIC NEEDS (E.G., FOOD, WATER, TOILETING)?
 usually sometimes rarely

- EXPRESSES MORE COMPLEX IDEAS (E.G., SOCIAL RELATIONSHIPS, ABSTRACT CONCEPTS)?
 usually sometimes rarely

FOR THE NEXT SECTIONS (C-3 through E-3),
 CIRCLE THE APPLICABLE RATING BASED
 ON THE FOLLOWING SCALE, WHERE AP-
 PROPRIATE:

- 1 = TOP 10% OF GENERAL POPULATION
 2 = TOP THIRD OF GENERAL POPULATION
 (EXCLUSIVE OF TOP 10%)
 3 = MIDDLE THIRD OF GENERAL
 POPULATION
 4 = BOTTOM THIRD OF GENERAL
 POPULATION (EXCLUSIVE OF
 BOTTOM 10%)
 5 = BOTTOM 10% OF GENERAL
 POPULATION

C. Language Skills, continued

3. READING RECOGNITION 1 2 3 4 5
 4. READING COMPREHENSION 1 2 3 4 5
 5. WRITTEN SPELLING 1 2 3 4 5

D. Math Skills

1. CALCULATION 1 2 3 4 5

2. NUMERICAL REASONING 1 2 3 4 5

E. Motor Execution

1. EYE-HAND COORDINATION 1 2 3 4 5

2. FINGER DEXTERITY:
 LEFT HAND 1 2 3 4 5
 RIGHT HAND 1 2 3 4 5
 BOTH 1 2 3 4 5

3. MANUAL DEXTERITY:
 LEFT HAND 1 2 3 4 5
 RIGHT HAND 1 2 3 4 5
 BOTH 1 2 3 4 5

4. IF THE ABOVE RATINGS ARE BELOW AVERAGE, IS
 THIS DUE TO:
 SLOWNESS? yes no
 INACCURACY? yes no

5. REACTION TIME: UPPER EXTREMITIES
 impaired not impaired

III. BEHAVIORAL OBSERVATIONS

- A. APPROPRIATE SOCIAL INTERACTIONS?
 usually sometimes rarely

- B. APPROPRIATE FRUSTRATION TOLERANCE?
 usually sometimes rarely

- C. APPROPRIATE DRESS?
 usually sometimes rarely

- D. APPROPRIATE HYGIENE?
 usually sometimes rarely

- E. PUNCTUAL (APPOINTMENTS/RETURNING FROM
 BREAKS)?
 usually sometimes rarely

F. DEPENDABLE, E.G., APPOINTMENTS SCHEDULED/
KEPT?

usually sometimes rarely

G. ANNOYING HABITS?

usually sometimes rarely

H. DISINHIBITION?

VERBAL?

usually sometimes rarely

PHYSICAL?

usually sometimes rarely

SEXUAL?

usually sometimes rarely

IV. RECOMMENDATIONS

A. RECOMMEND RETURN TO PRE-INJURY JOB?

yes no unable to judge NA

IF YES, ESTIMATE TIME TO RETURN TO WORK:

B. IS FURTHER RECOVERY EXPECTED?

yes no

IF YES, OVER WHAT TIME PERIOD?

C. IS FURTHER REHABILITATION RECOMMENDED?

yes no

IF YES, CHECK ALL THAT ARE RECOMMENDED:

- medical consultation
- occupational therapy consultation
- physical therapy consultation
- psychological services
- psychiatric services
- case management / social services
- independent living evaluation
- speech / language therapy
- educational services
- driving evaluation

vocational assessment

vocational counseling

cognitive training

behavioral training

work adjustment services

therapeutic recreation services

supported employment / job coaching
services

substance abuse screening / treatment

D. IS COUNSELING RECOMMENDED?

yes no

IF YES, CHECK TYPE:

individual

marital

family

E. SUPERVISION NEEDED IN COMPETITIVE JOB FOR:

BEHAVIOR PROBLEMS? yes no

COGNITIVE DIFFICULTIES? yes no

PHYSICAL LIMITATIONS? yes no

OTHER? yes no

APPENDIX IV: SUGGESTED NEUROPSYCH- OLOGICAL TESTS FOR EACH AREA OF FUNCTIONING

This list was developed at the Southwest Regional Brain Injury Rehabilitation and Prevention Center in Houston, by M. E. Young, J. Eisner-Leverenz, L. Ewing-Cobbs and W. High. Modifications and additions were made by the staff of TBI-NET.

ATTENTION / CONCENTRATION / PROCESSING SPEED

1. Behavioral observations
2. Immediate Auditory Attention Span, of the Wechsler Memory Scale-Revised (WMS-R): measures immediate memory for verbal material
3. Visual Attention Span (WMS-R): measures immediate memory for nonverbal material
4. Attention Concentration Index Score (WMS-R): overall performance in this domain
5. Paced Auditory Serial Addition Test (PASAT): measures sustained attention
6. Digit Cancellation: measures speed and accuracy of visual scanning as well as impulsivity
7. Visual and Auditory Vigilance Tasks:

8. Trails A : attention and processing speed
9. Visual Matching and Cross Out subtests, of the Woodcock-Johnson Test of Cognitive Ability (W-JTCA)
10. GFW Test of Auditory Selective Attention

PROBLEM SOLVING

1. Wisconsin Card Sorting Test (WCS): measures abstraction abilities
2. Category Test: similar to WCS
3. Similarities, of the Wechsler Adult Intelligence Scale-Revised (WAIS-R): measures simple verbal abstract reasoning
4. Proverb Interpretation (WAIS-R, Comprehension): measures verbal abstraction/ comprehension
5. Block Design and Object Assembly (WAIS-R): measures visual/spatial problem solving or construction
6. Comprehension and Picture Arrangement (WAIS-R): measures social judgment

MEMORY

1. Wechsler Memory Scale-Revised (WMS-R): measures verbal and nonverbal memory/ learning
2. Buschke Memory Scale - Revised: measures verbal learning
3. Rey-Auditory Verbal Learning: similar to Test 2
4. California Verbal Learning Test: similar to Test 2
5. Rey-Osterieth Complex Figure: measures visual memory
6. Benton Visual Retention Test: measures immediate visual memory
7. Warrington Recognition Memory Test: measures verbal and nonverbal encoding
8. Kimura Figures: measures visual memory
9. Rivermead Test: measures memory in

-
- context of functional activities
10. Visual Memory, Sentence Repetition, and Auditory-Visual Learning (W-JTCA)

INSIGHT

1. Behavioral observations
2. Interview
3. Neurobehavioral Rating Scale: quantifies observations of behavior and emotion

FUNCTIONAL REASONING

1. WAIS-R: measures verbal and nonverbal performance
2. Shipley: measures abstraction
3. Raven's Progressive Matrices: measures nonverbal reasoning
4. Test of Non-Verbal Intelligence: measures nonverbal reasoning
5. Mini Mental Status Examination (MMSE): measures basic cognitive functioning (appropriate for individuals more impaired)
6. Peabody Picture Vocabulary Test: verbal intelligence

SENSORY

1. Visual Acuity Screen: part of a neurological examination, as are Tests 2, 3 and 8
2. Visual Fields Screen
3. Visual Hemispatial Extinction Screen
4. Line Bisection: tests visual perception, as do Tests 5 - 7
5. Benton Form Discrimination
6. Benton Facial Recognition
7. Benton Judgement of Line Orientation
8. Hearing Screen
9. Tactile Form Perception: tests somatosensory perception, as do Tests 10 - 12
10. Finger Localization
11. Graphasthesia
12. Stereognosis
13. Visual Cancellation

LANGUAGE

1. Multilingual Aphasia Examination: Tests 1-4 constitute a comprehensive battery for aphasia
2. Boston Diagnostic Aphasia Examination
3. Western Aphasia Battery
4. Neurosensory Center Examination for Aphasia

WRITTEN LANGUAGE

1. WRAT-R (Reading and Spelling)
2. Reading Comprehension (PIAT): individual achievement test
3. Reading Comprehension (W-JTCA)
4. Gray Oral Reading Test

MATH

1. Arithmetic subtest (WRAT-R)
2. Arithmetic subtest (WAIS-R): measures mental computation abilities
3. Math subtest (W-JTCA): measures comprehension of math concepts

EXECUTIVE FUNCTIONS

1. Digit-Symbol: measures executive skills and the ability to shift set
2. Symbol-Digit Modalities Test (SDMT): similar to Digit-Symbol
3. Trails B: rapid alternating set shifting
4. Category Test and WCS: set shifting and inference
5. Reading comprehension (many tests are available): inference
6. Watson-Glaser Clinical Thinking Appraisal: inference, inductive and deductive reasoning, assessment of logical argument
7. Tower of Hanoi and Tinker Toy Test: trial-and-error thinking, generalization of learning, inductive reasoning
8. Concept Formation (W-JTCA)

APPENDIX V: RESOURCES

1. Independent Living Centers

A directory of ILCs in New York State is available from:

Ny State Independent Living Council
111 Washington Avenue, Suite 101
Albany, NY 12210
888 4NYSILC, 518 427-1060
www.nysilc.org

2. State and National Head Injury Associations

Brain Injury Association of America
703 236-6000
www.biausa.org

Connecticut Brain Injury Association
860 721-8111

New Jersey Head Injury Association
732 738-1002
800 669-4323

Brain Injury Association of New York State
518 459-7911

3. Hospital-Based Traumatic Brain Injury Programs

Mount Sinai School of Medicine, NY, NY
212 659-9372

Kessler Institute for Rehabilitation, West Orange, NJ
973 414-4723

Norwalk Hospital, Norwalk, CT
203 852-2038

Gaylord Hospital, Wallingford, CT
203 284-2800

4. Vocational Rehabilitation Agencies

New York State Vocational and Educational Services for Individuals with Disabilities
518 473-7213

New Jersey Division of Vocational Services
609 292-5987

Connecticut Bureau of Rehabilitation Services
800 537-2549

5. Other Programs

National Center for Disability Services, Albertson, Long Island, NY
516 747-5400

Transitions of Long Island, Inc., Manhasset, Long Island, NY
631 365-4335

6. Publications on Work Incentives

Call SSA (800 772-1213) and request the *Red Book on Work Incentives*, also known as SSA Publication No. 64-030. *Working While Disabled*, SSA Publication No. 05-10095, is also useful.

APPENDIX VI: REFERENCES, BIBLIOGRAPHY AND PFP PUBLICATIONS

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