

Returning to work, school or being a homemaker is a major problem for many people with traumatic brain injury (TBI). (This *TBI Research Review* does not distinguish between those who did not work at the time of injury and those who did, although important differences characterize these two groups.) The failure to return to productive roles comes at great economic and personal costs to people with TBI, to their families and to society. The costs are great because the number of people with TBI is huge, estimated at more than five million individuals in the U.S.¹

TBI is often an injury of youth, as incidence rates peak between ages 16 and 25², leading to many years of living with disability. This adds to the tremendous cost, which Thurman³ estimates at \$56 billion yearly in the United States. Much of this is due to lost economic productivity. Failure to return to work (RTW) after TBI is the focus of this issue of *TBI Research Review*.

HOW BIG OF A PROBLEM IS POST-TBI FAILURE TO RTW?

Whiteneck and colleagues⁴, analyzing data from the Colorado TBI registry, which includes all people hospitalized with TBI in that state, found that about 50 percent of those who were severely injured failed to RTW at one-year post injury. Twenty percent of those with so-called mild injuries were unemployed. Other studies vary in their estimates. This variation is due to differing definitions of “successful” RTW, how long after injury the outcomes are studied and the severity of injury.

Despite study differences, all evidence points to many people with TBI being unable to return to the vocational roles they had established before injury. This has strong implications at the personal level, where research shows lower subjective well-being⁵ in people who fail to RTW after TBI compared to those who succeed in RTW. Research also shows many people feel they have strong unmet needs in connection with working⁶. At the societal level, lost wages and increased dependence on governmental and other financial support contributes to the huge yearly cost of TBI. Further, employers face the cost of lowered productivity due to unfilled positions and the cost of hiring and training replacement staff.

WHAT DO WE KNOW FROM CURRENT RESEARCH ABOUT RTW AFTER TBI?

A few studies are available that evaluate the effectiveness of efforts to maximize RTW; however, there are many more studies that document the factors *associated with, but not necessarily promoting*, RTW. The results of systematic reviews and other substantive reviews of this literature on RTW⁷⁻¹⁰ are summarized in this *TBI Research Review*. Then we review policy implications for researchers, clinicians and policy makers.

Prognostic Studies

Most reports of research on post-TBI vocational outcomes seek to identify the personal (and, occasionally, the environmental) characteristics that hinder RTW. These research results are potentially useful in pinpointing who needs the most help, but the results seldom demonstrate the specific nature of the needs.

Many studies reviewed⁷⁻¹⁰ suggest what is obvious: that, other things being equal, people with more challenges in functioning after TBI will have more difficulty in RTW. For example, studies find poorer outcomes for those persons who have more severe injuries, experience fatigue, are dependent on others in their activities of daily living, have transportation

challenges, who evidence significant emotional issues and poor neuropsychological functioning, such as problems with memory, sequencing and judgment. Other studies that focus on demographics (such as age, gender and minority status) have generated variable results. In both types of study, however, the correlations between characteristics of the person with TBI (for example, severity of injury or gender) and RTW are quite modest.

In short, while existing research tells us *general characteristics* of people who are less likely to return to productivity, the research does not tell us whether any *specific* person with TBI will succeed or fail. At best, the results of prognostic research can define the conditions/characteristics that should be attended to in developing an array of services to aid RTW. The research results do not, and should not, imply that the person on the negative side of these “predictors” is destined (or even likely) to fail.

Studies Evaluating Service Effectiveness

Effectiveness studies in the past often grossly focused on whether better outcomes were associated with receiving services or not. These “Yes/No” global assessments typically showed that vocational rehabilitation (VR) services help some clients – a not-surprising result. Recent studies that hone in on specific elements or characteristics of service programs have proved to be somewhat more useful.

Before reviewing these findings, some research weaknesses in this area need highlighting, as these weaknesses often undermine the validity of study findings and hinder the comparison of studies focused on the same topic to learn if evidence is consistent across studies:

- While randomized controlled trials (RCT)* comprise the gold standard for judging cause and effect, studies of this type have not been undertaken to evaluate VR services. Thus, because of the *weak methodology* of most of the studies done (non-RCT), one cannot conclude that a service is effective (or ineffective). For example, any positive results could be due to clients simply receiving a service (*any* service), due to receiving more attention than they would otherwise or due to being selected from the most capable people with TBI.
- Comparing studies is difficult when “success” is not *uniformly defined* from study to study. For example,

some studies define success as return to “competitive full-time work;” other studies define it as return to “any productive role at any level.” Alternatively, success may be defined as “maintaining work status” for a specified period.

- Research reports often fail to *describe* adequately the treatment or service being evaluated, so that, if successful, the service is not easily duplicated elsewhere, for lack of program detail that others can “run with”.
- Most studies are unclear about which types of clients fail and which succeed. Studies often do not use statistical methods to *control for the impact of certain characteristics*, such as severity of injury, on the client’s program success. When these methods are not used consistently, comparing results across studies is impossible.
- Most research in this area is conducted with very *small samples*. Frequently, the degree to which the sample studied represents the full TBI population is not discussed. This is important since only a small fraction of people with TBI seeking or wanting to RTW ever receive VR services.
- Studies are difficult to compare as they may include very different types of people. These include small convenience samples that represent everyone with a TBI who has received rehabilitation services at a particular place; registry-based samples that represent everyone with a TBI hospitalized in a particular geographic region during a specific time; all individuals who have managed to find their way into and complete (successfully or not) a VR program during a certain time; people entered into either “arm” of a study of a specific treatment aimed at improving RTW, and other differences. “Success” means very different things in these varying types of samples.

Given these methodological problems, the reviews of research referred to above⁷⁻¹⁰ have found moderate support for some service elements in aiding RTW:

- Providing VR services *early* in the rehabilitation process¹¹⁻¹³
- Creating a supportive work environment¹³
- Providing cognitive skills training¹⁴⁻¹⁵
- Supplying assistive technology and training in its use¹⁶

As for obtaining and maintaining work, supported employment has been found useful^{11,17-20}, although one study²¹ did not find this to be the case.

* An RCT at minimum requires that service recipients are randomly assigned to an experimental treatment or to a control group, such as receiving “the usual” services.

Within the context of state VR agencies, the following elements have been associated with greater probability of RTW:

- On-the-job training²²
- Counseling and guidance²²
- Job placement services^{21,23}
- Creation of a working alliance with the counselor²⁴

O'Neill and colleagues²⁵ compared outcomes of community-based teams within VR offices to the outcomes of typical VR services. They found that the former outperformed the latter in achieving RTW, at equivalent costs.

A recent study²¹ analyzed state VR agency data (that is, RSA-911 data) on 7,366 persons with TBI who ended services in 2004, either successful in RTW or unsuccessful. This study addressed several criticisms enumerated above. To determine the services associated with successful RTW for VR clients with TBI, Catalano and colleagues²¹ used a “data mining” statistical technique (known as CHAID) on the RSA-911 data. The data mining took place based on groups that were homogeneous on several variables, for example gender, age, race, education and co-occurring conditions such as substance abuse or depression. Clients who succeeded in RTW differed strongly from those who failed. The successful clients:

- Had more federal money spent on their services.
- Spent less time receiving services.
- Received on-the-job training, job readiness training, other training, job search assistance, job placement assistance, on-the-job supports, maintenance, rehabilitation technology or other services.

Individuals with the lowest rates of RTW were receiving disability-related benefits and only received services such as assessment and counseling. However, the interpretation of such findings is unclear. For example, if those who only received assessment services had received more services, would there have been any difference in outcomes? Alternatively, did those who were viewed as “destined to fail no matter what” receive minimal services to avoid “wasting” resources? Catalano’s study as well as other studies^{21,23} suggest that “job placement” is effective in RTW. However, is this simply an artifact, since this service is provided only to those who *through other means* have been

prepared for RTW? Despite the drawback in interpretation, because of the large number of records examined, Catalano’s study provides leads about what *may* be helpful in nurturing RTW and generates specific hypotheses for further study.

WHAT CAN WE CONCLUDE FROM CURRENT RESEARCH?

- We know that too many people with TBI fail to RTW. In this context, the Catalano study²¹ reveals a related problem in that relatively few of the many Americans with TBI who have failed in RTW are “graduating” from State-Federal VR services yearly. Thus, VR services are reaching only a small minority of people with TBI who might benefit.
- Each study reviewed suggests that one or more elements of VR services are helpful, mostly because people who are exposed to them “get better.” With few exceptions, the studies often rely on relatively weak pre-post designs, anecdotal approaches or retrospective data mining. The methods prevent us from knowing that positive “change” in vocational status is due to the services provided.
- Prognostic studies have been less than helpful because many are based on small numbers of study participants. The results are all too often obvious or inconsistent across studies because of differing approaches to studying the interrelationships and interdependencies among predictors.
- The body of research shows that our knowledge is clearly inadequate regarding our effectiveness in attempting to help people with TBI in RTW. We also have no clear idea of just what the problem is in successfully promoting RTW. Thus, to define and evaluate potential solutions to the problem of RTW, we first need to better define the problems that interfere with post-TBI RTW.

WHAT ARE THE IMPLICATIONS OF CURRENT RESEARCH?

Implications for Researchers

The first requirement implied by the current state of research in this area is to better define the causes of post-TBI failure to RTW. For example, the Catalano study suggests that financial “disincentives” play a

strong role²¹. If that is correct, we must ask why approaches such as Ticket to Work²⁶ do not work. For example, Do people know of these alternative paths and programs? Although the National Planning Assistance and Outreach Program has provided training and consultation to support better counseling on benefits, Catalano's findings indicate stronger measures are needed. As another example, the prognostic research strongly suggests that people with more cognitive, physical and behavioral challenges succeed less often in RTW. What are the exact reasons for this? Some may say, "The answer is obvious," but to what degree does this problem require "fixing the person" versus "fixing the environment?" It raises the critical question: How can we fit services to the person to achieve success whenever possible? To answer questions like these, we need carefully conceived qualitative studies to better define pathways that people follow in successfully returning to work. And, we need to document how these pathways differ for those who fail to achieve their productivity goals.

Once we more precisely define "the problem," specific interventions and services to address various parts of the problem need to be developed and evaluated. Clearly, we need a range of approaches to such analysis. In the end, though, we need to back up initial explorations with stronger research designs, including randomized controlled trials (RCTs). In addition, we must not stop with the yes or no answers of an RCT, but also determine the characteristics of those for whom a specific intervention is useful and why it fails those who do not achieve their productivity goals. Additionally, we need to undertake research that will pinpoint the elements that comprise the "active ingredients" of successful treatments²⁷. If we can identify the critical elements, we can better document the program intervention in detailed manuals for easier duplication of successful interventions by others. In short, research needs to create new, more effective tools for service providers. We also need to better evaluate existing tools and try to explain why certain tools fail certain people and what might work better.

Implications for Service Providers

The body of research reviewed does not offer a strong basis for "evidence-based practice" in post-TBI vocational rehabilitation. However, study results do offer some interim "hypotheses" about what helps people after TBI in RTW. The ideas and directions that find "moderate support" in research reviews⁷⁻¹⁰

provide potential directions for service providers in providing appropriate VR services. Catalano and colleagues²¹ note, for example, that although on-the-job training was strongly associated with RTW, most post-TBI VR clients did not receive this service. Until better research reveals which clients are unlikely to benefit, the hypothesis should be that "on-the-job training works."

Service providers across venues should collaborate with the research community to develop new approaches to services for people with TBI and to provide the latter greater access to treatment settings so that better evidence can be developed. This is perhaps an even more important implication of the lack of a sufficient evidence base for post-TBI VR practice. Although this proactive stance by providers is likely to come from administrative and supervisory levels, we need to bring front-line workers into the partnership from the get-go, so that they are more likely to embrace the facility's or agency's participation in research and adoption of positive results.

Implications for Policy Makers

Strong improvements in public policy are needed with respect to funding VR services to better address the many people with TBI who are not participating in productive activity and who are not accessing the State-Federal VR system. To provide strong advocacy for this stance, individuals with TBI or family members of persons with TBI should be included in the composition of independent commissions and advisory bodies within the public VR system.

Several lines of research suggest that we need to consider carefully what we view as "success" with respect to RTW. First, full-time competitive work at the same level as before injury may be an inappropriate goal for many or most people post TBI. Second, full-time work of any type may be less satisfying than part-time work^{5,28}. Most important, "achieving personal productivity goals" may be a more appropriate definition of success since it accounts for variations due to individual preferences, values and circumstances. This may mean a variety of "outcomes" are incorporated into the "successful" end of the continuum as we redefine success concerning meeting personal goals. For example, working as a volunteer in a disability advocacy organization, working part-time in one's old job, or being self-employed may prove most satisfying. Flexibility in defining "success" should be

built into policy that regulates VR funding; more research is needed to document further how success is defined.²⁹

In addition to the results of systematic research, we can draw on testimony from people with TBI and their support network, who with strong voices have communicated their challenges and needs in a variety of venues, including local and national brain injury associations. For example, testimonials from Ohio citizens who had access to TBI specialty counselors indicate their counselors set more realistic RTW goals based on the individual's strengths, were persistent in exploring options, used creative approaches to funding higher education, and identified natural supports in the workplace. This type of input pointing to a promising practice needs to be followed up with systematic research, as suggested above, and funding support for states who are willing to evaluate such practices.

Consumer voices also suggest that inadequate treatment, inadequate rehabilitation and failure to fully prepare the individual and employer contribute to the lack of successful RTW after TBI. Early and repeated job failures add insult to (brain) injury, causing further emotional and psychological harm. Supported employment of sufficient intensity and duration, with the use of job coaches, on-the-job compensatory strategies and work hardening

experiences, with ongoing follow up and adaptation, should be the standard until such practices are proven *unsuccessful* in RTW. Moreover, it is crucial that standards be developed for determination of readiness for VR following medical rehabilitation, since employers are not prepared to provide all the supports and services needed to support RTW following TBI, particularly when the individual has not received appropriate and sufficient medical and vocational rehabilitation.

Most importantly, policy makers must rectify the paucity of research focused on evaluating methods to help people successfully RTW after TBI. Consumer voices tell us repeatedly that the traditional VR approach of seeking out jobs, filling out applications, modifying a work setting and placing the candidate doesn't work for individuals with TBI. Neither do attempts to return individuals to their previous work environments where their performance is scrutinized by those who are most familiar with their pre-injury skills.

Freud defined the elements in human lives necessary for well-being as work and love. People with TBI clearly are in need of stronger support in helping return them to a standpoint from which they can again participate in both of these defining aspects of a life lived well.

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