

# Retrospective Assessment of Rehabilitation Outcome After Traumatic Brain Injury: Development and Utility of the Functional Independence Level

**Objective:** To develop a measure suitable for retrospective analysis of qualitative brain injury outcome data, the Functional Independence Level (FIL), and document its reliability, validity, and utility. **Design:** Retrospective analysis of existing records, with inclusion based on availability of records, and quantitative or qualitative documentation of functional status at a minimum of 1.5 years after injury. **Setting:** Statewide acute and postacute rehabilitation facilities, as part of a State Head Injury Program. **Participants:** A total of 338 individuals, with documented moderate to severe traumatic brain injury; primarily males ages 16 to 45. **Main Outcome Measures:** Disability Rating Scale (DRS) at discharge from primary rehabilitation, Living Situation and Functional Independence Level coded from information in postacute rehabilitation reports, at an average of approximately 6 years after injury. **Results:** Inter-rater reliability coefficients for FIL ratings extracted from rehabilitation records, and between retrospective and in vivo assessments were highly significant. DRS scores at discharge from primary rehabilitation predicted a significant amount of variance in FIL scores at an average of 5 years after injury, and DRS scores remained a stable and significant predictor of FIL scores as the time period between discharge from rehabilitation and outcome ratings increased to 10 years after injury. FIL ratings were significantly lower for individuals living in residential facilities than those living with their families, as compared to living alone. **Conclusions:** The FIL is a reliable and useful tool for retrospective and prospective assessments of rehabilitation outcome. Gains made during primary rehabilitation by people with severe traumatic brain injury are generally maintained at long-term follow up. Retrospective ratings using the DRS and FIL can help guide postacute rehabilitation planning within state or regional head injury programs. *Key words:* functional outcome, level of independence, traumatic brain injury, rehabilitation, retrospective archival research

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COORDINATED NATIONAL databases and model systems emphasize reporting and prevention of traumatic brain injury (TBI), as well as long-term outcome issues.<sup>1</sup> The

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TBI Model Systems National Database (TBIMS) provides longitudinal data on brain injury rehabilitation processes and outcomes as defined by the National Institutes of Health's (NIH) Consensus Development Conference on Rehabilitation of Persons with TBI.<sup>2</sup> To this end, the TBIMS addresses the needs outlined by the NIH (such as focusing on the duration, natural history, and life course manifestations of TBI), and has contributed significantly to the literature.<sup>1,3-6</sup> Similarly, statewide TBI surveillance programs attempt to address these needs by tracking TBI data within 15 states. These state programs provide important epidemiological and clinical data from a regional perspective, with particular studies dating back to the early-to-mid 1990s. Unfortunately, the data from these programs are often published in esoteric journals<sup>7,8</sup> or state-provided pamphlets.<sup>9,10</sup>

The paucity of published data from statewide programs is attributable to several factors. First, many regional studies are "snap shots"<sup>11</sup> in that they have limited longitudinal data or very small sample sizes. Second, data from statewide sources may be lost because of sporadic or incomplete collection and transmission. Third, databases require maintenance costs, must deal with changing clinical practices over time, and often lack consistency. Finally, data are collected across medical facilities, and thus lack uniform outcome measures, particularly for functional domains. Such obstacles to data collection and reporting emerge when attempting to measure functional outcomes across an entire state from a multitude of rehabilitation facilities with varying allegiances to outcome scales. However, this form of archival research is critical for hypothesis generation and testing, which ultimately informs treatment planning and lends to the understanding of life-course manifestations of TBI. It is the intention of this article to ad-

dress issues related to long-term assessment of outcome after TBI. In doing so, we discuss the advantages and pitfalls associated with large database research and introduce a scale that we have found suitable for retrospective measurement of outcome.

### **THE PENNSYLVANIA HEAD INJURY PROGRAM AND DATABASE**

The Pennsylvania Head Injury Program (PHIP) emerged from the Commonwealth Head Injury Program (established in 1985), and as a result of the Emergency Medical Services Act. This Act established a Catastrophic Medical and Rehabilitation Fund available to trauma victims *when all alternative financial resources had been exhausted*, and allowed the state to prioritize the distribution of funds for provision of two basic services: comprehensive residential or day rehabilitation and case management services. It is important to note that, as it is a "funder of last resort," many individuals may not have qualified for and thus not have applied to the program. As a result, over the course of 15 years, only a relatively small percentage of individuals with brain injuries in the Commonwealth of Pennsylvania have applied to the PHIP.

The Pennsylvania head injury database was developed in 1995, approximately 10 years after the inception of the program, and has been a resource for retrospectively and prospectively tracking rehabilitation outcomes for individuals enrolled in the PHIP. The database integrates patient information from a variety of sources and serves as a tool for developing sample-based data, which has allowed us to generate and test useful hypotheses, address quality assurance, help guide rehabilitation planning, and inform decisions regarding potential to benefit from services.

### RETROSPECTIVE ANALYSIS OF OUTCOME

A primary emphasis of TBI research in the past two decades has been prediction of the length and nature of the recovery process.<sup>12</sup> Outcome studies generally place survivors of brain injury in categories using rating scales. The Glasgow Coma Scale (GCS),<sup>13</sup> Glasgow Outcome Scale (GOS),<sup>14</sup> Glasgow Outcome Scale Extended (GOS-E),<sup>15</sup> Rancho Los Amigo Levels of Cognitive Functioning Scale (LCFS),<sup>16</sup> Disability Rating Scale (DRS),<sup>17</sup> Functional Independence Measure (FIM),<sup>18</sup> Community Integration Questionnaire (CIQ),<sup>19</sup> and Craig Handicap Assessment and Reporting Technique (CHART)<sup>20</sup> have been used as outcome measures, as has living situation after TBI.<sup>21</sup> Each of these measures has been widely researched, with their respective strengths and weaknesses well-documented.<sup>22-30</sup>

Prospective analysis of long-term rehabilitation outcome allows for real-time tracking and outcome assessment, as well as qualitative and quantitative "experiential" documentation of changes in functional status, living situation, employment status, social relationships, quality of life, and ongoing behavioral sequelae after TBI. Although prospective, multicenter research is certainly desirable, health care professionals or rehabilitation programs may not have the time or funding to engage in such activities. Instead, professionals are often required to rely on clinical "hunches" or program-specific trends to answer questions about how a specific individual might fare several years postinjury. Retrospective research can take the form of chart reviews or individual case studies or analyses for the purposes of guiding rehabilitation planning. Clinical practices and rehabilitation programs have a vast pool of clients served, and inspection of existing records may address many of the critical issues raised by

NIH, while remaining relatively attainable and feasible.

Retrospective analysis of outcome requires review of existing documents containing quantitative, qualitative, or experiential data. In reviewing acute care and rehabilitation hospital admission and discharge summary reports from more than 100 different hospitals in Pennsylvania, we found the GCS to be exclusively documented in acute care trauma centers.<sup>31</sup> These GCS scores documented acute duration of coma, and a "new" GCS was never measured and recorded on rehabilitation intake assessments, except where the individual was emerging from coma. However, *initial* GCS was repeatedly documented in discharge and admission reports throughout an individual's rehabilitation. In spite of the availability of alternate and more appropriate outcome scales, LCFS scores (never intended as an outcome measure<sup>32</sup>) were documented in approximately 50% of the rehabilitation discharge summary reports reviewed, and subsequently were repeated in succeeding admission summary reports. We interpret this not as an endorsement of the GCS or LCFS for outcome assessment, but rather, as either an underuse of functional outcome measures or a lack of documentation. Although use of scales such as the GOS, DRS, FIM, CIQ, or CHART may be prevalent in research or idiosyncratic to specific rehabilitation facilities, appropriate documentation of their use appears nonexistent because none were listed in any one rehabilitation admission or discharge summary report we reviewed.<sup>31</sup>

### RATIONALE

In the absence of a commonly documented outcome measure, we sought to adopt an existing scale for the purpose of retrospective assessment of rehabilitation outcome. With well-established psychometric

properties, many of the previously listed scales would be likely candidates for extracting information from discipline-specific reports common to rehabilitation hospital discharge summaries and case manager progress reports. However, detailed quantitative information is notably absent from postacute rehabilitation reports, such as monthly case manager reports 10 years after injury. This, in turn, prohibits completion of outcome measure subscales (e.g., "How many times a month do you shop outside the home," as required in the CIQ, or "In a typical day, how many hours are you out of bed," as required in the CHART). Although quantitative measures may be well-suited for current or prospective assessment of functional abilities after TBI, we believe more qualitative measures may be better suited for retrospective assessments. However, ordinal scales such as LFCS or GOS-E do not specifically address functional independence or changes during recovery<sup>32</sup> or require a structured interview.<sup>15</sup> Thus retrospective analysis of long-term rehabilitation outcome would require development of a scale appropriate for extraction of qualitative information from rehabilitation records. In a pilot study,<sup>31</sup> we were able to retrospectively document long-term outcome scores (extracted from postacute rehabilitation and other such reports) for only 69% of participants using a quantitative scale (DRS), versus 96% using an ordinal, categorical scale, as described in the following section.

## **PURPOSE**

The purposes of this study were:

1. to develop a measure for retrospective analysis of outcome, the Functional Independence Level (FIL), and document its validity and reliability;
2. to determine the relationship between long-term rehabilitation outcome, as

measured by the FIL, and well established measures of injury severity and rehabilitation outcome;

3. to assess the temporal stability of those factors predictive of FIL as the time between discharge from primary rehabilitation and outcome measurement increased; and
4. to determine the relationship between FIL ratings and independence in living as measured by after-injury living situation.

## **METHODS**

### **Participants**

Participants were 595 individuals domiciled in the Commonwealth of Pennsylvania (at the time of injury) who sustained a TBI and applied to the PHIP.

### **Inclusion criteria**

Inclusion in the study required the presence of acute care and rehabilitation hospital records in individuals' charts. All participants met the diagnosis of brain injury, defined as: "an insult to the brain, not of a degenerative or congenital nature, but caused by an external physical force that may produce a diminished or altered state of consciousness, which results in impairment of cognitive abilities or physical functioning."<sup>33(p.1)</sup> For this study, documentation of functional ability at least 1.5 years after injury was also required. This interval was selected because the greatest gains in recovery and impact of therapeutic interventions after TBI occur from the first 3 to 6 months,<sup>34</sup> to the first year,<sup>35</sup> to a year or more after injury.<sup>34</sup>

Individuals were excluded from the study if they did not meet the above-listed inclusion criteria, if they were younger than 16 years of age, if there was evidence of more than one brain injury or of preexisting conditions (e.g., congenital or hereditary birth defects, birth trauma/asphyxia neonatorum, organic or

degenerative brain disorders, cerebral vascular disorders).

### **Demographics**

There were 338 participants who met inclusion criteria. Demographic variables and comparisons between inclusion and exclusion groups are provided in Table 1. Participants in the study were predominantly male, at a somewhat higher ratio (4:1) than the 2:1 to 3:1 traditionally reported in the literature<sup>36,37</sup> and the 3:1 ratio in the "exclusion group." Significant between-group differences were noted on motor vehicle-related causes of injury, with significantly fewer motor vehicle occupants and more pedestrians in the "exclusion group."<sup>37</sup> These differences may be explained, in part, by the exclusion of individuals under the age of 16 (i.e., fewer motor vehicle drivers, more pedestrians). Individuals in the "inclusion group" scored significantly worse on measures of severity of injury, such as GCS and LOC, because the "exclusion group" also included individuals who did not show unequivocal evidence of having sustained a brain injury. Between-group differences were also noted on the length of time after injury that outcome measures were recorded. As this was a factor for inclusion in the study, the "exclusion group" comprised individuals who had not yet reached 1.5 years postinjury and individuals for whom outcome scores could not be determined.

Three-fourths of participants obtained a GCS of 8 or below, with a mean GCS score of 5.4, and a median loss of consciousness of 3 weeks. Thus the sample is most representative of a severe brain injury population.

### **Measures**

Injury severity, hospitalization, and outcome variables were recorded directly from participants' emergency room, acute care, and rehabilitation hospital medical records. Measures included: GCS ratings, duration of

loss of consciousness (LOC), acute care hospital and primary rehabilitation hospital length of stay, DRS scores at discharge from primary rehabilitation, and FIL scores at last measured outcome (i.e., at the time of the most recent report in the individual's chart, as described below). Duration of LOC was considered to be the period from the date of the injury to the time the individual first responded to command.<sup>38</sup> This was coded as 0 (no coma), 1 (<20 minutes), 2 (<24 hours), 3 (<1 week), 4 (7-20 days), 5 (21-34 days), 6 (35-56 days), or 7 (coma lasting > 8 weeks).

### **THE FUNCTIONAL INDEPENDENCE LEVEL**

The FIL (Table 2) is a 10-point ordinal scale we developed for retrospective documentation of functional ability, integrating cognitive and physical limitations, and their effects on activities of daily living, basic living skills, and employability.

Members of a transdisciplinary rehabilitation team (neuropsychology intern, neurobehavioral specialist, resident physiatrist, social worker, and rehabilitation nurse) provided input for initial scale development. Initially, a list of functional abilities often compromised by TBI was generated by team members, along a continuum of independence (i.e., completely dependent to completely independent). From this list, critical functional abilities were defined in the following areas: ability to respond and communicate, ability to communicate self needs, ability to direct or assist in self-care, ability to initiate and complete activities of daily living and basic living skills with or without assistance, ability to participate in vocational activities, ability to be left alone versus the need for supervision, ability to monitor personal safety, and the ability to monitor one's behavior or exhibit judgment.

Team members then generated scale items (or levels), based on the critical need areas

**Table 1.** Demographic data for all subjects and subjects meeting inclusion criteria

	All subjects (N = 595)		Included (N = 338)		Not included (N = 257)		Test of significance
Gender							
Male	456	76.9%	276	81.6%	182	70.7%	$\chi^2(1) = 9.73$
Female	137	23.1%	62	18.4%	75	29.3%	$P = .002$
Age at injury	28.43 (12)*		29.16 (10.6)*		28.51 (13.9)*		$F(1, 596) = 0.25$ $P = .62$
Cause							
MVA	287	49.2%	178	52.7%	115	44.7%	$\chi^2(1) = 16.6$
Pedestrian	83	17.8%	35	10.4%	47	18.3%	$P = .002$
Motorcycle/ATV	64	11.0%	44	13.0%	17	6.6%	
Fall	45	7.7%	24	7.1%	20	7.8%	$\chi^2(1) = 3.78$
Assault	41	7.0%	26	7.7%	19	7.4%	$P = .46$
Gunshot wound	29	5.0%	13	3.8%	15	5.8%	
Other	34	5.9%	18	5.4%	17	6.6%	
Length of LOC							
None	35	5.9%	2	0.6%	35	13.6%	U-test
<20 minutes	53	8.9%	19	5.6%	41	16.0%	$P = .001$
<24 hours	26	4.4%	14	4.1%	11	4.3%	
<1 week	80	13.4%	41	12.1%	34	13.2%	
1 to 2.9 weeks	129	21.7%	77	22.8%	48	18.7%	
3 to 4.9 weeks	78	13.1%	54	16.0%	22	8.6%	
5 to 8 weeks	64	10.8%	44	13.0%	18	7.0%	
>8 weeks	59	9.9%	46	13.6%	12	4.7%	
Unknown	71	11.9%	41	12.1%	36	14.0%	
GCS in ER	6.15	(3.8)*	5.4	(3.1)*	7.18	(4.5)*	$I(1, 506) = 27.8$ $P = .001$
3 to 5	306	52.5%	193	57.1%	102	39.7%	
6 to 8	116	19.9%	63	18.6%	50	19.5%	
9 to 12	28	4.8%	17	5.0%	10	3.9%	
13 to 15	56	9.6%	21	6.2%	50	19.5%	
Unknown	77	13.2%	44	13.0%	45	17.5%	
Years post at outcome <sup>†</sup>	4.3	(3.3)*	5.6	(2.9)*	2.4	(2.9)*	$F(1, 558) = 165.7$ $P = .001$
<1.5	120	20.2%	0	0.0%	120	46.7%	
1.5-3.49	115	19.3%	85	25.1%	30	11.7%	
3.5-5.49	120	20.2%	102	30.2%	18	7.0%	
5.5-7.49	95	16.0%	76	20.5%	19	7.4%	
7.5+	93	15.6%	75	22.2%	18	7.0%	
Unknown	52	8.7%	0	0.0%	52	20.2%	

\*Mean (standard deviation).

<sup>†</sup>Years post injury when outcome measures were recorded.

MVA = motor vehicle accidents (includes drivers and passengers); pedestrian = MVA pedestrians (includes bicyclists hit by automobiles); GCS in ER = Glasgow Coma Scale Score at presentation to emergency room.

**Table 2.** Functional independence level

Dependent for self-care	Level 1:	No response to stimuli. Movements, actions, responses are reflexive. Completely dependent for all aspects of self care.
	Level 2:	Response modality identified; response rate inconsistent. Cannot communicate needs. Completely dependent for all aspects of self care.
	Level 3:	Response modality identified; response rate is consistent. Can communicate via response modality. Can direct self care.
Can assist with self-care	Level 4:	Able to respond and communicate. Able to direct and assist with self care. Unable to initiate tasks without cues. Requires supervision for safety/judgment.
	Level 5:	Able to respond and communicate. Able to direct and assist with self care. Initiates tasks, able to complete tasks with assistance. Requires supervision for safety/judgment.
	Level 6:	Able to respond and communicate. Inconsistently able to complete self-care/activities of daily living (ADLs) independently. Unable to link tasks without cues/assistance. Able to participate in basic living skills with assistance. Requires supervision for safety/judgment.
Independent for self-care	Level 7:	Able to respond and communicate Able to complete self-care/ADLs independently Able to participate in basic living skills with supervision May require supervision for safety/judgment.
	Level 8:	Able to communicate, complete and link self-care/ADLs. Able to initiate basic living skills; requires part-time supervision. Able to be left alone for extended periods of time. Requires part-time supervision for structuring daily activity pattern. Candidate for sheltered employment.
	Level 9:	Able to communicate, complete and link self-care/ADLs. Able to live independently and independently perform basic living skills May require part-time supervision for "fine tuning" and organization. Candidate for competitive employment.
	Level 10:	Able to live independently. Candidate for competitive employment.

**Instructions for raters:**

The FIL is a 10-point rating scale of an individual's current level of functional independence, with an emphasis on how much daily supervision they require. Choose the category/ranking that best represents the individual's current functional level. If specific behaviors are represented in more than one level, choose that level that best represents the amount of daily supervision required. If you are unable to discriminate between levels, then choose the lower level used to describe that individual's level of functioning.

described previously, with each level describing a particular individual at some point in the recovery process. After all possible levels were generated, they were ranked ordinally, with obvious overlapping levels omitted. Then, starting at the lowest level of functioning (those most dependent), final FIL descriptors were defined, in the context of the needs of the individual at that level, and the responsibilities of the rehabilitation professional or caregiver in meeting those needs. In this final step, ambiguous levels were merged, with the resultant scale comprising 10 ordinal categories, each describing a hierarchical ability not uniquely met by the previous level.

The FIL is intended to be a measure of current level of functional independence, so emphasis is placed on an individual's specific functional abilities and how much daily supervision they require. In the case in which an individual displays functional abilities described by two or more categorical levels, the level assigned is the one that best describes the amount of daily supervision required to care for that individual. If the rater is unable to discriminate between levels, then the lower level is used. For example, an individual with the ability to independently complete self-care routines may be rated at a level of 7, 8, 9, or 10. In this case, the individual's need for supervision or assistance with basic living skills or vocational activities would differentiate between scale levels. This straightforward scoring criterion allows the FIL to be easily administered by most experienced rehabilitation personnel, regardless of discipline.

### **Living situation**

After injury, individuals with brain injuries are more likely to live with parents or in supervised facilities and less likely to live with spouses or friends.<sup>21,39</sup> Although these categories do not directly address level of independence, changes in living situation

(from preinjury status) likely represent decreased independence. Discrepancies have been noted in ratings of independence between self-ratings by individuals with brain injury and the opinions of their family members or significant others. Whereas individuals with brain injuries were more likely to report that they could support themselves independently, their family members were more likely to report that they required 24-hour supervision or a skilled nursing facility-like setting.<sup>39</sup>

For this study, living situation was determined from case manager reports or progress reports from residential facilities, and was defined as follows: "alone," "with family" or "other," which includes individuals living in residential facilities, rehabilitation facilities, or skilled nursing facilities. We recognize that these categorical groupings do not directly reflect independence (i.e., individuals could live with their family and receive considerable support or live independently).

### **Coding of injury severity, hospitalization, and outcome variables**

Information was obtained from PHIP files comprising the following sources: (1) PHIP application, (2) acute care emergency room records and discharge summary, (3) rehabilitation hospital admission and summary, (4) therapy reports from acute care or rehabilitation hospitals (when available), (5) neuropsychological evaluations (when available), (6) admission/discharge reports from any "other" facility, such as skilled nursing facility, psychiatric hospital, or residential facility, and (7) case manager reports.

Extraction of information from PHIP charts was performed by two independent raters, and coding of DRS scores and FIL scores was completed at two different times. DRS ratings at discharge from primary rehabilitation were extracted from rehabilitation discharge summary reports and summary reports upon admission to secondary rehabilitation facilities.

FIL scores were coded based on postacute rehabilitation reports, such as progress reports from residential facilities, neuropsychological evaluations, or PHIP case manager reports. DRS scores at discharge from rehabilitation were not used in the determination of FIL scores.

### Analyses

Bivariate correlation coefficients were calculated to establish inter-rater reliability, Spearman's rank-order correlation coefficients were calculated for FIL scores (ordinal data), and Pearson's product-moment correlation coefficients were calculated for DRS scores (interval data).

In identifying group differences between those participants included in and excluded from the study, measures comprised of interval and ratio level data (age, GCS, years after injury at outcome) were analyzed with one-way analysis of variance (ANOVA). Nominal data (gender, cause of injury) were analyzed with chi-square analysis, and ordinal data (LOC) were analyzed with the Mann-Whitney *U* test. Analysis of variance was conducted on FIL scores between independent groups coded by living situation with post hoc Scheffé analysis.

Stepwise multiple regression was performed to identify predictive factors for FIL. Skewed predictor variables (number of days in acute care, number of days in primary rehabilitation) or noncontinuous predictor variables (GCS upon presentation to the emergency room, duration of LOC) were adjusted through logarithmic transformation. All variables were significantly correlated with the dependent variable and showed intercorrelation, with coefficients ranging from .23 to .58; these bivariate coefficients (as a measure of multicollinearity) remained below .70.<sup>40</sup> To control for potential reduction in the predictive power of the regression equations

(shrinkage), the ratio of subjects-to-predictors in the main regression analyses was at least 15:1,<sup>41</sup> and adjusted  $r^2$  coefficients were used as a more conservative estimate of explained variance. Default values for the probabilities of "F-to-enter" (.05) and "F-to-remove" (.10) remained constant for all of the regression analyses. Mahalanobis' and Cook's distance were used to check for, and remove the effects of, any outliers.

## RESULTS

### Scale psychometrics

Retrospective comparisons showed the FIL to have good inter-rater reliability ( $r = .80$  to  $.90$ ; effective reliability<sup>42</sup> =  $.92$  to  $.96$ ). Where both FIL and DRS scores could be extracted from existing records as long-term outcome measures, concurrent validation between retrospective FIL and DRS outcome ratings was highly significant ( $r = .88$ ).

Prospective FIL and DRS ratings by PHIP case managers and retrospective FIL and DRS chart-review ratings were analyzed for 22 participants. Correlation analysis yielded effective inter-rater reliability ratings of  $.86$  for the FIL and  $.90$  for the DRS.

### Relationship between FIL and measures of brain injury severity and rehabilitation outcome

Predictor variables (GCS in the emergency room, duration of LOC, number of days in acute care, number of days in primary rehabilitation, DRS at discharge from primary rehabilitation [DRSatDC], years after injury at time of outcome measurement) were regressed on the level of independence, as measured by the FIL.

Stepwise regression analysis identified the optimal combination of DRSatDC and "days in acute care" variables as having significant predictive value [ $F(2,205) = 125$ ;  $P < .0001$ ],

**Table 3.** Relationship between long-term FIL ratings and measures of injury severity and rehabilitation outcome

Correlations among variables and descriptive statistics									
Measure	FIL	Acute	GCS	LOC	DRSatDC	Yr pos	Rehab1	M	SD
FIL	—							6.8	1.9
Acute	-.420	—						1.6	0.3
GCS	.301	-.391	—					0.7	0.2
LOC	-.271	.399	-.575	—				0.6	0.2
DRSatDC	-.719	.351	-.334	.343	—			10.6	5.6
Yr post	-.123	.252	-.175	.169	.098	—		5.8	2.8
Rehab1	-.304	.363	-.332	.454	.251	.327	—	2.0	0.4
Regression analysis results:									
Measure:	$\beta$		t		P				
DRSatDC	-.65		-13.02		.001				
Acute	-.19		-3.82		.001				
Regression equation:									
FIL = (-.22 * DRSatDC) + (1.21 * acute) + 11 (constant)									

Acute = length of acute care admission (logarithmic transformation); GCS = Glasgow Coma Scale in emergency room (logarithmic transformation); LOC = length of loss of consciousness (logarithmic transformation); DRSatDC = Disability Rating Scale score at discharge from primary rehabilitation; Yr post = years after injury at outcome measurement; Rehab1 = length of primary rehabilitation hospital length of stay (logarithmic transformation).

resulting in a multiple correlation of .74 and accounting for 55% of the total variance in FIL scores. Alone, DRS at discharge from primary rehabilitation accounted for 52% of this variance. Beta weights and univariate t-tests for the predictor variables are provided in Table 3.

We randomly assigned individuals to two independent groups to determine the split-half reliability of the sample. Two stepwise multiple regression analyses yielded nearly identical results; DRSatDC accounted for 51% and 52% of the variance in FIL ratings.

To test the predictive ability of DRSatDC (on FIL ratings) as years after injury increased, individuals were divided into four indepen-

dent groups on the basis of years after injury at the time of their FIL rating: 1.5 to 3.49, 3.5 to 5.49, 5.5 to 7.49, and 7.5 to 14 years after injury. This grouping conveniently represented 2-year intervals and yielded equally distributed groups. Four stepwise multiple regression analyses were performed to predict FIL, controlling for number of years after injury. Predictor variables related to initial injury severity (days in acute care, days in primary rehabilitation, GCS ratings in ER) and postrehabilitation status (DRSatDC) were regressed on FIL scores to track the stability of the predictive power of the DRSatDC as the time between DRSatDC and FIL ratings increased. Again, predictor variables that

**Table 4.** Relationship between long-term FIL ratings and measures of injury severity and rehabilitation outcome, as a function of years after injury

	1.5 to 3.5 (yr) (N = 54)		3.5 to 5.5 (yr) (N = 66)		5.5 to 7.5 (yr) (N = 52)		7.5 to 14 (yr) (N = 55)	
	Mult. r/adj. r <sup>2</sup>		Mult. r/adj. r <sup>2</sup>		Mult. r/adj. r <sup>2</sup>		Mult. r/adj. r <sup>2</sup>	
DRSatDC	.75	.55	.72	.52	.66	.43	.75	.55
Acute	.04	.06	—	—	—	—	.03	.04
Rehab1	—	—	.02	.03	.04	.04	—	—
	$\beta/t/P$		$\beta/t/P$		$\beta/t/P$		$\beta/t/P$	
DRSatDC	-.66/-7.4/.001		-.67/-7.7/.001		-.18/-6.2/.000		-.70/-7.9/.001	
Acute	-.27/-3.0/.004		—		—		-.22/-2.5/.01	
DRSatDC	—		-.19/-2.2/.03		-.86/-2.3/.03		—	
	Mean/SD		Mean/SD		Mean/SD		Mean/SD	
DRSatDC	10.7/6.0		9.7/5.1		10.2/5.6		11.7/5.9	
Acute days	1.5/.32		—		—		1.7/.26	
Rehab1 days	—		2.0/.35		2.0/.45		—	
FIL	6.9/2.6		7.1/2.0		6.8/1.7		6.4/1.8	

DRSatDC = Disability Rating Scale score at discharge from primary rehabilitation; Acute = acute care hospital length of stay (logarithmic transformation); Rehab1 = primary rehabilitation hospital length of stay (logarithmic transformation);  $\beta$  = beta;  $t$  =  $t$ -value;  $P$  =  $P$  value; FIL = Functional Independence Level.

were highly skewed (number of days in acute care, number of days in primary rehabilitation) or noncontinuous (GCS upon presentation to the emergency room, duration of LOC) were adjusted through logarithmic transformation. For these regression analyses to include the same "block" of predictor variables, LOC and years after injury at time of outcome measurement were removed as a predictor variable; as a result, subject-to-predictor ratios never dropped below the recommended 15:1 level.

The amount of unique variance in FIL scores explained by DRSatDC by year after injury is presented in Table 4. The combination of DRSatDC and number of days in acute care, for groups of individuals rated at 1.5 to 3.49 years after injury, accounted for 61% of the variance in FIL ratings. As the time between DRSatDC and outcome ratings in-

creased, only DRSatDC predicted a significant amount of variance in FIL ratings. This would suggest that the relationship between functional ability at discharge from rehabilitation (DRS ratings) and long-term outcome (FIL ratings) does not change over time.

#### Functional independence level and living situation

FIL ratings were analyzed as a function of postinjury living situation. The majority of subjects ultimately resided in residential facilities (41.8%) or with their families (47.7%), and only a small percentage lived alone (10.4%). ANOVA revealed a significant effect of living situation on FIL [ $F(2,334) = 27.62$ ;  $P < .001$ ]. Post hoc Scheffé analyses revealed that all three living situation groups differed significantly on mean FIL ratings: [alone (8.5) > with family (7.0) > in facility (5.9)].

## DISCUSSION

There is currently no standard, universally administered and documented long-term rehabilitation outcome measure. To collect retrospective rehabilitation outcome data, we developed the FIL, a measure that is easy to understand and score, irrespective of rehabilitation discipline. Using this scale, we extracted qualitative information commonly found in long-term postrehabilitation progress reports from a variety of sources to describe functional outcome. We found the FIL to have good inter-rater reliability and high concurrent validity with long-term DRS outcome ratings. Results show a high level of agreement between retrospective (chart review) and prospective (in-person) ratings of functional ability using the FIL and DRS. The considerable frequency with which we were able to extract valid and reliable ratings from long-term progress reports is a testament to the utility and applicability of the FIL to retrospective studies. In the PHIP records, there are no documented functional outcome measures in rehabilitation progress reports, rehabilitation discharge summaries, or case manager reports. Using the FIL as a functional outcome measure allowed us to reliably extract estimated scores for significantly more cases (96% versus 69%) than would have been possible using the DRS as an outcome measure.<sup>31</sup> Making retrospective determinations using scales of quantitative nature (such as the FIM or CIQ) in this study would have reduced our subject pool considerably, and may have prohibited retrospective analysis.

Results of our analyses revealed functional ability at discharge from primary rehabilitation (DRSatDC) to be a significant predictor of functional independence as measured by FIL. As the length of time between discharge (DRSatDC) and outcome (FIL) ratings increased, the predictive value of these DRSatDC ratings

remained stable; for individuals more than 7 years after injury, DRSatDC predicted more than half (55%) of the variance in FIL ratings. FIL ratings differed significantly as a function of living disposition. Individuals residing with their family after injury were found to have significantly lower FIL ratings than those living independently, supporting the notion that families may provide long-term supervisory services.<sup>43</sup>

In this study, injury severity variables previously identified as predictive of outcome, such as GCS and duration of loss of consciousness,<sup>44</sup> did not lend to the prediction of rehabilitation outcome, as measured by FIL. This may be explained, in part, by the relatively high injury severity of individuals in such a state program. Initial GCS scores of 8 or below have been associated with poor outcome,<sup>45</sup> and the mean GCS for this sample was 5.4, with 75% of participants at GCS 8 or below. Individuals with such severe injuries may never achieve a full range of functional outcomes, and this may explain why functional status at discharge from rehabilitation emerged as such a stable and significant long-term predictor of functional rehabilitation outcome.<sup>46</sup> Had our sample been more broadly distributed across the injury severity continuum, initial severity variables may have contributed as better predictors.

The literature remains equivocal regarding the relationship between injury severity and outcome at 1 year after injury,<sup>23,47,48</sup> at 5 years postrehabilitation,<sup>49</sup> and 10 years after injury.<sup>39</sup> As well, hallmark studies establishing a link between injury severity and outcome<sup>46,50</sup> are from a different time and health care delivery system, from which "outcome" may represent a different process than modern-day "rehabilitation outcome." It is unclear whether the documented relationship between measures of severity and outcome in these studies reflect differences in

rehabilitation programs, outcome categories, or less severely skewed samples.

Rehabilitation therapists routinely provide qualitative summaries of patients' functional abilities in discipline-specific discharge reports, yet none of the rehabilitation discharge summary reports we reviewed provided DRS scores or an equivalent functional measure. Considering the strong association between functional measures at discharge from rehabilitation and long-term outcome measures, as well as the stability of such long-term outcome measures,<sup>51</sup> our results suggest that such documentation should be standard practice.

Large-sample, statewide databases, integrating participant data from multiple rehabilitation hospitals, are not standard in TBI research. The development of the FIL was initially driven by the clinical demands of neuropsychological consultation for the PHIP. A scale had to be sufficiently robust to accommodate the variability in patient records, focus on functional independence (the program goal), and have adequate reliability and validity to assist the consultation process. By having an easily scored outcome measure, we addressed the absence of a universally documented outcome measure in the PHIP charts and have been able to help guide case management for the State Head Injury Program. Our database integrates patient information from a variety of sources and serves as a tool for developing sample-based data, which has allowed us to generate and test useful hypotheses,<sup>52</sup> address quality assurance,<sup>53,54</sup> help guide rehabilitation planning,<sup>55</sup> and inform decisions regarding potential to benefit from services.

For prospective assessments conducted by PHIP case managers, we established an assessment protocol, which included key injury and demographic data, the DRS, and the FIL. This protocol allowed clinical judgments to be made with a level of empirical support

while we were validating the FIL as described in this article. Several states and provinces have programs similar to that of Pennsylvania and may benefit from our experience where the FIL has been used as a guide for neuropsychological consultation in four primary ways.

1. Case managers provide FIL and DRS ratings to allow for objective monitoring of quality assurance and effectiveness of treatment. These biannual ratings are compared with baseline assessments for ongoing monitoring of rehabilitation progress.
2. In cases in which PHIP providers were thought to be ineffective, the FIL data, concurrent with other clinical and programmatic evaluations, were used in decisions to transition clients to more successful treatment programs and even terminate provider contracts.
3. The database has been used to track FIL ratings over time. Where FIL ratings were found to be stable over multiple years, suggesting that the "likelihood to continue to benefit from active rehabilitation" had diminished, many such individuals were moved to more maintenance-based services.
4. A number of long-term care patients were shown by successive FIL scores to have reached asymptotic recovery. These data were used to direct policy decisions for the development of a new Medicaid waiver/Community Care program in another government department designed to serve such individuals.

Consequently, the Department of Health and the Department of Public Welfare of the Commonwealth of Pennsylvania and the Board of Brain Injury Services of Simcoe County Ontario, which provide rehabilitative services for individuals after TBI, have since adopted the FIL as part of the standard intake assessment.

A number of limitations merit consideration. Although relationships may be observed between variables, the archival nature of the research precludes cause-and-effect statements. However, the use of regression analysis and the measurement of the temporal relationship between predictor and outcome variables in this study do lend to observational statements. The dependent measure used, the FIL, is ordinal. Although the literature is replete with studies that treat ordinal data as interval,<sup>5,56,57</sup> this remains a violation of the assumptions of multiple regression analysis. In addition, the multiple regression analyses conducted in this study, specifically stepwise analysis, have the potential to capitalize on the relationships between predictor variables, and thus produce spurious results. However, multiple regression is the best analysis technique for these data and no other statistical method would have been appropriate. To be sure, we carefully controlled for multicollinearity among predictor variables, findings were nearly identical during split-half reliability checks and variables remained highly predictive even when considering the impact of time after injury. A final, and important, shortcoming to this study is that these data may be most generalizable to severe brain injury. However, many state programs, Medicaid waiver programs, and other "funders of last resort" share similar demographic patterns, and thus may benefit from our experience with the Pennsylvania programs.

Future research may address a number of remaining questions. These findings need to be cross-validated with other severe TBI samples, especially to replicate the absence of injury severity variables in prediction of rehabilitation outcome. Similarly, although individuals with more mild-to-moderate brain injuries may experience a similar range of functional needs described by the FIL, its utility within these populations is, as yet, unclear. The FIL would benefit from further psychometric analysis, for both retrospective and prospective assessments, as well as within other neurologically impaired populations (e.g., stroke, multiple sclerosis.)

In conclusion, we present a measure of functional outcome, the FIL, which allows for reliable and valid retrospective extraction of qualitative data from long-term postrehabilitation reports, as well as current and ongoing assessments. We identified the DRS, measured at discharge from primary rehabilitation, as a significant predictor of long-term TBI outcome, as measured by the FIL. This predictive ability remains stable as the number of years between DRS and FIL ratings increases up to 7 to 14 years after injury. Ratings of functional ability at discharge from primary rehabilitation, long-term FIL, and living disposition help guide postacute rehabilitation planning within state or regional head injury programs. The FIL has been a useful tool for both retrospective and prospective assessments of TBI outcome in Pennsylvania for the last 6 years.

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