

# Traumatic Brain Injury Rehabilitation in New Zealand: Current Practice Review

A Report for NZGG and the Accident Compensation Corporation



November 2004

## Executive Summary

- A Current Practice Review (CPR) of traumatic brain injury (TBI) rehabilitation services in New Zealand was undertaken as part of a larger project to produce evidence based guidelines for the management of TBI in New Zealand
- The review comprised a postal survey of TBI rehabilitation providers along with a postal survey of TBI consumers in New Zealand
- There were 49 respondents from providers who met the criteria of managing at least 3 people with TBI in the last year or 10 in the last 5 years.
- 36 of the responses were from providers of non-residential rehabilitation services (managing a total of 4668 clients in the previous 12 months) and 13 were from providers of residential rehabilitation services (managing 452 clients in the previous 12 months)
- There were 420 responses from consumers
- Responses from providers and consumers were provided from all regions of New Zealand
- Results showed considerable variety in the extent, structure and practice of TBI rehabilitation services in New Zealand including little or no consistency in the use of standardised assessment and outcome measurement, use of protocols, audit or other quality improvement measures
- There has been a shift away from DHB-provided services with only 42% of residential clients and 9% of non-residential clients being managed by DHB providers.
- Residential TBI rehabilitation services tend to be low-volume (mean around 16 clients per year when responses from providers managing across multiple sites are considered) and not specialised in TBI rehabilitation
- There was considerable support from consumers (76%) and non-residential providers (63%) for 1 or 2 specialist TBI rehabilitation centres in New Zealand but residential providers (38%) did not support this idea
- About half the consumers that answered the question felt that people with TBI got a good deal from TBI rehabilitation services and around 60% felt that TBI rehabilitation services focussed on goals that were important for them
- Consumers were, in general, happy with ACC services although a substantial minority (around 40%) were unhappy with these services. Much of this discontent seemed to involve training and turnover of case managers
- Open ended responses from providers about effective interventions, barriers to effectiveness, gaps in services and ideas for better services provided a lot of information, presented as verbatim responses in this report
- The Short Form 12 (SF12) instrument which was used as part of the consumer survey was sensitive to reductions in health status among people with TBI and is quick and simple to use

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## Introduction

In 2003, the Accident Compensation Corporation of New Zealand (ACC) commissioned a guideline for the assessment and management of traumatic brain injury (TBI) rehabilitation in New Zealand. The overall contract for that work is held by the New Zealand Guidelines Group in conjunction with the Medical Research Institute of New Zealand, the University of Otago, and Massey University. As part of the overall contract for the guideline, ACC requested a review of current practice in TBI rehabilitation in New Zealand. This report describes that review and includes a survey of TBI rehabilitation providers and a survey of TBI consumer opinion related to TBI rehabilitation practice in New Zealand.

The current practice review (CPR) allows a ‘snapshot’ of TBI rehabilitation provision in New Zealand in 2004. The intention was to provide a combination of reasonable breadth (i.e. as many providers from all over the country as possible) as well as sufficient depth (i.e. detail of individual services) to allow some comparison of ‘international best practice’ as described in the TBI guideline with what actually happens in New Zealand now. In this way, gaps in services nationally, or in specific regions of the country, could be identified and steps taken to improve service provision. There was no intention to undertake an audit of TBI rehabilitation services against a standard. Such a standard does not currently exist, although this may happen as part of the guideline process. Therefore, this CPR is based on self reports from individual services. In an effort to provide a counterpoint to these responses, we undertook a survey of consumer opinion about the provision of TBI rehabilitation services in New Zealand. We hypothesised that consumers would have a rather different view of what TBI rehabilitation providers did than the providers themselves. The consumer survey was undertaken using a database of consumers from consumer support organisations. Inevitably the responses of consumers who are members of, or associated with, consumer support organisations are not necessarily representative of all people who have had a TBI in New Zealand. Furthermore, many of these people may have had their experience of TBI services many years before, so that comments may reflect a situation that no longer pertains. Nevertheless, we feel that the comments of a sufficiently large group of TBI consumers are valuable in that they highlight particular issues of concern to them and may provide a dose of ‘reality’ to TBI providers and funders of those services.

This report describes the aims of the review, the method used in obtaining the survey results, describes the main results from the surveys and discusses the main findings. Included as appendices are the survey instruments and Ethics Committee approval for the consumer survey.

### *Aim*

The Current Practice Review (CPR) was conducted in the context of the development of evidence based guidelines for the management of TBI in New Zealand. At the time that the review was conducted, the guideline development was restricted to TBI rehabilitation and therefore the focus of the survey was TBI rehabilitation providers. The review was undertaken to meet the following objectives:

1. Describe features of the **structure** of TBI rehabilitation services in New Zealand in 2004 (type of service, where provided, where referrals come from, staffing, education)
2. Describe the **extent** of TBI rehabilitation services in New Zealand in 2004 (geographical coverage, size, volumes, coverage of important sub-populations by ethnicity, age, diagnosis)

3. Describe the degree of **specialisation** of TBI services using this as a potential proxy for rehabilitation service ‘quality’ (by extrapolation from stroke rehabilitation research)
4. Describe TBI rehabilitation **practice** including use of evidence based guidelines, quality control tools, validated assessment and outcome measures
5. Identify **barriers** to ‘ideal’ service delivery, **interventions** that providers feel make a difference and document ideas of TBI providers about ways to **improve** service delivery
6. Describe the **views of consumers** of TBI services on those services, including their experience of ACC case management

**Method**

This was a postal survey of TBI rehabilitation providers and a separate survey of consumers of TBI services.

***TBI Rehabilitation providers survey***

This was actually 2 separate questionnaires: one for providers of predominantly **residential** rehabilitation services for people with TBI and one for providers of predominantly **non-residential** rehabilitation services for people with TBI.

Residential providers of rehabilitation services are those where the client stays overnight, often for extended periods. Non-residential providers in contrast provide rehabilitation services for people who live separately from the provider, usually in their own homes. Some providers operate in both situations (e.g. a DHB might provide inpatient rehabilitation for TBI clients as well as an outpatient ‘Concussion Clinic’ service). Providers were asked to complete both questionnaires if they provided residential AND non-residential TBI rehabilitation services.

The survey instrument was 12 pages long and included a question on the first page aimed at identifying only providers who managed at least a minimum of TBI clients:

If your service HAS NOT managed at least three people in the last year or ten people in the last five years with TBI, please just tick the box and return the questionnaire in the envelope provided

.....O

Thus, providers with very occasional contact with TBI clients (<2 per year) were specifically excluded from this survey.

The survey instrument was reviewed by, and ‘signed off’ by the New Zealand TBI Guideline Development team. The survey was conducted by the Medical Research Institute of New Zealand.

*Identifying TBI rehabilitation providers*

The survey was sent to all providers of TBI services identified by ACC or by consumer organisations (Brain Injury Association of New Zealand [BIANZ] and Head Injury Association of New Zealand [HIS]) or known to exist by the research team. There was considerable overlap in these sources. There were a large number of providers in the ACC list that provided home support services for a range of clients, few, if any, of whom had TBI.

Providers of both residential and non-residential TBI rehabilitation services were asked to complete both questionnaires. Providers operating at multiple sites, but providing the same sort of service at those sites, generally completed one survey only and it was difficult to be sure how some of the answers to questions might relate to individual sites.

The survey was specifically targeted at providers of rehabilitation services for people with TBI. We made no attempt to survey other types of TBI providers e.g. accident and emergency services.

We made the following commitment to providers:

*Provider names will not be identified in any material produced from this review and ACC will have no access to provider-specific information. Responses will be grouped to avoid identification of providers.*

This has affected our ability to present some of the material collected in the survey as some information (particularly numbers treated and number of separate provider sites) will effectively identify certain providers.

#### *Response rate*

One hundred and twenty questionnaires were sent out and 88 received back or follow-up phone call revealed that the provider did not meet the criteria for inclusion in the survey i.e. crude response rate of 73%. Reviewing the list of non-responders, the majority were providers of home support rather than clearly rehabilitation providers and we suspect that many of these would not have met the criteria for inclusion in the survey.

Of the 88 responses received, 49 met the criteria for sufficient numbers of people with TBI to be included in the analysis. These comprised 36 non-residential providers and 13 residential providers. One of the residential providers has 12 separate sites and another residential provider operates on 2 sites. Thus these data cover 25 separate residential sites.

### **Consumers survey**

This was an 11 page instrument, mailed out to possible consumers of TBI services with a stamped, addressed envelope provided for responses. Approval was given by the Wellington Ethics Committee.

#### *Identifying consumers*

Consumers were identified through the membership of the Brain Injury Association of New Zealand and the Head Injury Society of New Zealand. They were asked to distribute the survey instrument through their branch network. All responses were anonymous and there was no option for reminder letters as the research team had no way of knowing who had not responded to the original letter.

#### *Response rate*

Approximately 2000 questionnaires were distributed to the consumer support organisations. 420 people responded (crude response rate of 21%). Of the 420 respondents, 323 people (77%) indicated that they had completed the questionnaire themselves with or without some

assistance. 89 people (21%) indicated they were carers completing the survey on behalf of someone with a TBI and the remaining 9 respondents (2%) did not answer the question.

*Measuring health status: TBI rehabilitation consumer survey*

One section of the consumer questionnaire consisted of an internationally validated, generic (general) health status measure, known as the Short Form 12 (SF 12). The SF 12 was designed to measure general health and quality of life concepts relevant across different age and health population groups, and was also specifically designed for self-administration. It covers general physical functioning through to social functioning and mental health, the results being expressed by two 'summary' scores: the Physical Component Summary (PCS) and the Mental Component Summary (MCS). The PCS and MCS have a range of 0 – 100 (higher scores refer to better health) and are calculated by using a relatively complex algorithm on individual test scores. The algorithm was designed so that in a representative sample of the general population the mean score would be 50, and the standard deviation 10.

## Results: TBI providers

Results are provided here largely as tables, unaccompanied by much in the way of comment. A summary of the key results appears in the 'Discussion' section. Readers are invited to check responses against the questions actually asked in the relevant surveys (see Appendix A)

### 1. Structure of services

#### 1.1 Service type

Respondents were asked to self-describe the type of service they provide under the following headings:

Service type	No. of responses
Active residential rehab	10
Residential rehab support	2 (although one of these clearly provides 'active residential rehab')
Residential other	1 (Early intervention and education in a hospital setting)
<b>All residential</b>	<b>13</b>
Non residential assessment and treatment	21
Non residential assessment only	7
Non residential vocational rehab	2
Non residential other	6 (Field officer support in community; Home based rehabilitation; Home based rehab/living skills coaching; Homecare provider to ACC, DHBs and private clients; Community care once transferred, not initial rehab; Predominantly treatment, small amount assessing)
<b>All non-residential</b>	<b>36</b>
<b>Combined total</b>	<b>49</b>

#### 1.2 DHB vs not

Practice patterns for TBI rehabilitation have changed substantially in the last 10 years. Previously, hospital-based providers were the main (often only) provider in many regions. Many DHBs have chosen to 'exit' provision of TBI assessment and rehabilitation services and this gap has been filled by private providers. The following table collates numbers of clients treated rather than numbers of providers.

Provider type	DHB provider	No of clients treated (% of total)
Residential	No	264 (58%)
	Yes	188 (42%)
<b>Total residential</b>		<b>452 (100%)</b>
Non-residential	No	4230 (91%)
	Yes	438 (9%)
<b>Total non-residential</b>		<b>4668 (100%)</b>

### 1.3 Where managed

Providers were asked where the clients were generally managed.

Service location	Clients, N (% of total)
<b>Non residential</b>	
Client home or workplace	2350 (51)
Hospital Outpatient Dept	353 (8)
Private Community Facility	1947 (42)
<b>Residential</b>	
Community facility	17 (4)
Dedicated TBI unit	86 (20)
Designated TBI within AT R R	31 (7)
General AT & R Unit	133 (31)
Houses in community	161 (38)

### 1.4 Source of referrals

Approximately 65% of referrals to the non-residential rehabilitation services surveyed were from ACC case managers, with a further 20% received from hospital inpatient services and GPs. Very few referrals were received from other rehabilitation services. Other sources of referral cited by non-residential rehab services include: Self referrals by clients or their families, private companies or insurance companies, other health professionals e.g. social workers, occupational therapists, and Maori services.

Approximately 65% of referrals to the residential rehabilitation services surveyed were from hospital inpatient services, however approximately 20% were also received from ACC case managers. Very few referrals were received from other rehabilitation services or GPs. Other sources of referral cited by residential rehab services include: Outside agencies, other hospitals, and NASC agencies.

### 1.5 Criteria for acceptance of referrals to service

Type of service	Criteria mentioned
Residential	'ACC criteria' 23% Most of the rest 'needs inpatient rehabilitation'. If age limits, generally 16-65 years, one service lower limit 14 years.
Non-residential	Varied, many mention ACC contracts. Some very open: 'Request for assessment or rehab' or 'any brain injury'. 2 services mentioned safety of workers as part of acceptance criteria

Accept referrals in following situations:	Residential providers	Non-residential providers
	%	
History of alcohol abuse	77	78
History of drug dependence	77	78
History of mental health disorder	85	95

## 1.6 Staff available and core team

Providers were asked which staff were employed by their service and then which staff formed a 'core team' which saw all patients.

For residential providers, in answer to the question: "Thinking of the staff makeup within your TBI Rehabilitation Service, what is their professional expertise? (*tick as many as apply*)" all services included nursing, OT and physio expertise, most included speech language therapy. Two thirds had a psychologist and 50% had a rehabilitation physician on staff. A further 17% had a neurologist on staff and 8% had 'another medical practitioner' leaving 25% who didn't tick any of the available medical staff boxes. These services said that they had access to medical health practitioners either 'always' or 'usually'. When asked about a 'core team' that saw all patients, the use of medical staff was more limited.

### Residential

Members of core team for most clients	% (cumulative %)
Minimum Med specialist, nurse, OT, PT	42% (42)
Minimum non-specialist medical, nurse, OT, PT	17% (59)
Minimum nurse, OT, PT	17% (76)
Other (OT/nurse, OT alone, PT/OT)	25% (100)

For residential providers, there was a large variability in staffing. Most commonly there were combinations of nursing, OT, PT and psychology expertise. Around 50% of services had medical staff as part of the service. Most services claimed access to necessary discipline expertise 'usually', 'often' or 'always' even when these were not part of the staff of the service. The 'core team' that saw most clients tended to be more limited in extent as shown in the table.

### Non-residential

Members of core team for most clients	% (cumulative %)
Minimum medical, OT, psychologist	17% (17)
Minimum medical/psychologist	10% (27)
OT and at least one other discipline, non medical	27% (54)
Psychologist only	33% (87)
Other (OT alone, health assistants alone, 1 team without OT, 1 team without psychologist)	13% (100)

## 1.7 Staff competencies and education

Staff and training	Residential providers	Non-residential providers
		%
Staff with Maori/Pacific background	69	41
Staff with cultural training	62	81
Regular training for patients/families	62	47
Regular training for staff	90	69

### **1.8 Information for families and carers**

	Residential providers	Non-residential providers
	%	
Written information for patients/families	100	94
Information and education developed by	In house, 2 services with 'service educator'	In house (90%), others a mixture of sources
Information from consumer support groups	77	69
Information specifically for Maori or Pacific people	31 (appears largely generic?)	19 (produced from within service)

### **1.9 Use of support agencies for people with TBI**

	Residential providers	Non-residential providers
	%	
Access to 'field officers' from support agencies for people with TBI	100	81
Routine involvement of 'field officers' during residential rehabilitation	23	Not applicable
Routine involvement of field officers after discharge	47	Not applicable

## 2. Extent of services

### 2.1 Location of services

We attempted to identify geographical gaps in services.

Non residential

<b>City or region</b>	<b>No. of services</b>
Auckland	13
North of Auckland	4
Hamilton	1
Tauranga	1
Whakatane	1
Gisborne	3
Turangi	1
Napier/Hastings	5
Hawkes Bay, not Napier/Hastings	1
New Plymouth	3
Palmerston North	1
Wanganui	1
Masterton	2
Wellington	4
Nelson	2
Christchurch	5
Canterbury, not Christchurch	3
Greymouth	1
Dunedin	3
Central Otago	1
Invercargill	1

Residential

<b>City or region</b>	<b>No. of services</b>
Whangarei	1
Auckland	5
Hamilton	1
Gisborne	1
Rotorua	1
Taupo	1
Napier	1
Palmerston North	2
Masterton	2
Lower Hutt	1
Wellington	1
Nelson	1
Blenheim	1
Christchurch	1
Greymouth	1
Timaru	2
Dunedin	1

At face value, there is a reasonable geographical spread of both non-residential and residential service providers. There are some odd clusters of providers (e.g. 9 separate non-residential providers in Gisborne and Hawkes Bay) but without linking this information to numbers of people treated, it is hard to make any comments about possible over or under servicing on a population basis. As some providers were unable to provide a breakdown of numbers at multiple sites it is impossible to provide accurate data about numbers treated in specific areas.

## **2.2 Numbers treated in last 12 months**

There was considerable variation in the numbers of clients treated by different providers. The table shows that there are providers who assess or manage very few clients in a 12 month period and others that are responsible for a large proportion of the total national workload. There are some clear discrepancies in these data, with very low numbers of people apparently managed by ‘vocational rehabilitation’ services for example. Most likely, providers of ‘assessment and treatment’ services are also providers of ‘vocational rehabilitation’ services, or we have failed to identify significant providers of vocational rehabilitation services. It is clear that for most providers of residential rehabilitation services, this is a low volume business with a median of only 18 clients per provider receiving active residential rehabilitation i.e. less than 2 per month. This figure may deceive however. Two of the larger providers operate across multiple sites. Inclusion of individual site data would dramatically lower the average for active residential rehab (to 16 per year), most likely with a median figure between 10-16.

<b>Service type (n)</b>	<b>Clients managed in last 12 months</b>			
	<b>Sum</b>	<b>Average</b>	<b>Min</b>	<b>Max</b>
<b>Non-residential</b>				
Vocational rehab (2)	13	7	3	10
Other (6)	50	13 (median 4)	3	30
Assessment and treatment (22)	1727	128 (median 43)	8	700
Assessment only (7)	2190	365 (median 50)	40	1564
<b>Residential</b>				
Rehabilitation support (2)	31	16	7	24
Other (1)	29	29	29	29
Active residential rehab (10)	392	39 (median 18)	5	161

## **2.3 Numbers of Mild, Moderate, Severe TBI by service type**

We would expect that most people with TBI managed in a residential setting would be in the severe TBI category. In general this was the case (66% severe) although there were substantial numbers of ‘moderate TBI’ (27%) and around 8% were categorised as ‘mild TBI’. To some extent this may reflect confusion about the definitions of TBI severity (based on Glasgow Coma Score at first presentation).

For non residential providers, the expectation was that most clients would be in the ‘mild TBI’ category. This was not borne out by the data however. For ‘assessment and treatment’ services there were roughly equal numbers of mild (45%) and moderate (40%) with a substantial number of severe TBI clients (14%). For ‘assessment only’ services, there were more moderate TBI (56%) than mild TBI (26%) and again, a significant number of people with severe TBI (18%).

## 2.4 Ethnicity and age extremes by service type

We tried to ascertain whether important subpopulations had adequate access to TBI rehabilitation services. From the responses this seems to be the case. There was one specialist children's TBI service. For other services, <18years should be interpreted as meaning 15-18 years as no other service catered for children aged <15 years.

These are presented as actual numbers and percentages but they are derived from provider's estimates of percentages in each category and a wide margin of error should be allowed.

### Non Residential

Service type	N	<18yr	>65yr	Maori	Pacific	Asian
		N (% of total)				
Assessment and treatment	2437	353 (14)	139 (6)	421 (17)	249 (10)	107 (4)
Assessment only	2190	323 (15)	214 (10)	401 (18)	345 (16)	180 (8)

### Residential

Service type	N	<18yr	>65yr	Maori	Pacific	Asian
		N (% of total)				
All	452	24 (5)	5 (1)	96 (21)	49 (11)	15 (3)

## 2.5 Specialist services provided for important sub-populations

Providers were asked if they provided specialist services for particular sub-populations as listed

Group	Non residential	Residential
	% of respondents answering 'yes'	
<18 years	24	50
>65 years	70	42
Maori	82	73
Pacific	73	40
Other ethnicities	50	40
Coexisting Mental Health disease	79	75
Drug and alcohol	73	75
Comments	Alcohol/drug dependency is significant! Use interpreter service where applicable Do have access to Pacific Island consultant advisory services.	Theoretically for mental health and drug/alcohol the service is available though it is skeletal Services exist for mental health and substance dependence but cooperation is difficult Have a good working liaison with mental health and A&D services.

### 3. Specialisation

#### 3.1 Case mix

One consideration for ‘quality’ of TBI rehabilitation providers is whether TBI rehabilitation is their ‘core business’ or not. We might expect that providers of rehabilitation services with a small proportion of TBI clients would have more difficulty maintaining specialist skills/staff in this area.

For non-residential providers the percentage of TBI clients managed ranged from 1% to 100%. For 56% of the non residential providers surveyed, individuals with TBI were the majority of their total clients. In terms of numbers of clients assessed or treated, 87% of ‘assessment and treatment’ clients were managed by services where 50% or more of their workload was TBI and 96% of ‘assessment only’ clients were assessed by a service where 50% or more of their workload was TBI. All the non-residential ‘other’ and ‘vocational rehab’ services reported that TBI was not a majority of their workload.

For residential providers, the situation is more complex. 241/392 (61%) of patients undergoing ‘active residential rehabilitation’ were managed in services where 50% or more of their workload was TBI rehabilitation. Neither of the ‘residential rehabilitation support’ or residential ‘other’ providers were TBI specialised (<50% of workload TBI). Most providers had at least 20% (up to 75%) stroke patients managed in the services providing TBI rehabilitation

### 4. Practice

#### 4.1 Waiting times

Waiting times	Non-residential providers	Residential providers
	%	
No waiting time	21	17
2 to 7 days	21	50
1 to 3 weeks	45	33
> 3 weeks	12	0

The main reasons for waiting are:

Reason for wait	Non-residential providers	Residential providers
	%	
The time indicated is a target response time	21	17
There is a waiting list	29	25
Waiting to receive approval from ACC	18	42

Low priority referral	0	0
Shortage of appropriately trained staff	29	0
Other reason	4	17

For non-residential rehabilitation services the most commonly cited reason for clients having to wait for rehabilitation services was that there is a shortage of appropriately trained staff. This reason was mentioned by the majority of providers as either the main or a secondary reason for waiting.

For residential rehabilitation services the main reason for waiting was that the provider was waiting to receive approval from ACC. 9 out of the 13 residential providers cited this as either the main or a secondary reason for waiting.

Other reasons for waiting included:

- limited neurologist time
- limited neuropsychologist time
- Client delays - often there is a delay due to the client, family/whanau not being available to visit the provider.

#### **4.2 Review and Follow-up Services**

- Only 6% of the non-residential providers surveyed provide a routine review for all patients post discharge
- Only 15% of the residential providers surveyed provide a routine review for all patients post discharge

The frequency and type of routine review for non-residential services was very variable and ranged from 6 monthly review, review on ACC request, a concussion clinic phone review at 6-8 weeks post discharge, a back-up coaching service and referral to a BIA liaison officer.

The frequency and type of routine review for residential services was more consistent, including medical appointments 6 to 8 weeks post discharge followed by further appointments as determined by the doctor, psychology review when appropriate, phone review at 1 and 3 months post discharge, review for concussion and or mild TBI; 2 weeks then 4 weeks post discharge. Post discharge review appears to be heavily dependent on ACC. Provision of more routine review was cited as something that providers would like to provide.

- 40% of the non-residential providers surveyed provide other follow-up services post discharge.
- 62% of the residential providers surveyed provide other follow-up services post discharge.

For non-residential providers these other follow-up services included occasional informal advice, non routine medical and psychological review and support, non routine telephone follow-up, referral to BIANZ. Again follow-up services were dependent on ACC with many providers stating that follow up services were only available if requested by ACC. Some providers stated that they would like the provision of follow up services to be more formalised.

Residential providers offered follow-up services including, rehab in the community, respite care, assessments in the community, Training for Independence programmes, social rehabilitation assessment services, paediatric consultant reviews, GYM membership, and vocational rehab programmes.

GPs were able to request a review in 72% of the non-residential services and in 91% of the residential services. Families and patients were also able to request a review in 68% of the non-residential services and in 66% of the residential services.

A large number of the non-residential and residential services that were surveyed only provide review if the patient is self-funded or if they have ACC approval.

**4.3 Collection of routine data**

Providers were asked a series of questions about collection of routine data, measurement of outcomes, use of protocols and audit.

	<b>Residential</b>	<b>Non-residential</b>
	%	
Discharge destination	69	
Length of stay	92	
Discharge ADL	62	25
Vocational status		42
Residential status		33
Standardised measures	69 (mostly FIM, FIM+FAM or Barthel)	33 (none specified)

**4.4 Satisfaction and audit of residential rehabilitation services**

85% of residential providers surveyed routinely measure consumer satisfaction. It was common for the providers surveyed to give out a satisfaction survey at discharge and many providers also conducted satisfaction surveys during a patients stay. For some providers these included asking the views of both residents and their families. Some providers also published the results of the surveys. The ‘quality circle’ approach and resident meetings were also used by providers to gain the views of consumers.

54% of the residential providers routinely asked funders about their satisfaction with the services provided the most commonly cited method for this was through ACC audits and surveys to funders. The responses suggest that there may be a need for more clearly defined relationships and accountability structures between providers and funders and that both parties could benefit from constructive feedback.

9 of the 13 residential providers surveyed conduct audits at the ‘patient level’. The audit tools used was very varied between providers and they were often focused more at a ‘service level’ than the ‘patient level’. It was most common for providers to use audit tools developed in-house, other tools mentioned include, HAPNZ review/accreditation and ISO certification.

10 of the 13 residential providers surveyed conduct audits at the 'service level'. Audit tools used included, Clinical indicators from Australasian Faculty of Rehab Med, the ISO system, Health and disability sector standards, reviews involving service users, HAPNZ.

#### 4.5 Use of 'Routine protocols' for assessment and service coordination

Residential providers

Assessment of:	% Yes
Physical function	92
Cognitive function	92
Goal setting	100
Discharge planning	100
Common problems after TBI	77
Service coordination	
Integrated clinical pathway	50

Origin of protocols for assessment ( <i>verbatim responses</i> )	Physio usually Berg balance, OT usually BRISC.
	Developed within service as per best practice guidelines
	Locally developed
	Some standardised tools, other developed within the service.
	Physical / Cog / Emotional generic tools. Goal setting/DC planning self generated.
	Formal standardised tests for physical function and cog/emotional function; developed within service for goal setting and D/C planning.
	Either in-house protocols or derived from contract requirements.
	Developed within our service. Based on the ICF endorsed by WHO.
	ACC - TBI guidelines 1998. Stand therapy assessments e.g. PEDI, 9MFM-66 etc. Goal setting/Discharge planning - service developed. Ylisaker et al 2001. Educating students with TBI themes and recommendations. Ylisaker and Theaney 1998. Collaborative brain injury interventions. Positive everyday routines. Also WHO 2002 (ICIDH 2 and ICF)
	Developed within own services - also use external assessments e.g. berg balance, AMPS, Rivermead behaviour, COTNAB, LOTCA.
	International protocols and tools and our own in house standards e.g. COTNAB; TREIVETTI balance scale, FIM etc.
	Developed within service
	Stroke guidelines – standardised assessment tools are used as required.
Origin of protocols for management of common problems following TBI	Use hospital procedures based on best practice. Modified on case by case basis. PTA management; Restraint; Behavioural management. For behavioural – Specialising policy; Spasticity/seizures - accepted practice. 1. Risk assessment (general)2. Challenging behaviour. 3. Budget management A & D. All developed in house. Developed within our service - core team meetings. [DHB] guidelines; service specific protocols e.g. Paediatric and orthopaedic consultants review - botox, medications, splinting, etc for

	<p>spasticity; behavioural disturbances - team approach with clinical neuropsychologist formulating a collaborative individual programme. Most developed within unit but assessment tools and 'treatments' utilise well documented 'tools' from NZ and worldwide. Developed within service - CPI/Restraint</p>
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## 4.6 Assessment tools

### Non-residential

Routinely assess:	% Yes	Main tools mentioned
Premorbid function	92	Interview, WAIS III, NART, academic records if available
Current function	96	'Neuropsych assessment', interview
Severity TBI	96	GCS, PTA, LOC, 'reports'
Prior TBI	96	History
Mental health disorder	96	Interview, BDI, HAD
Drug use	96	Interview
Family situation	96	Interview, 'reports'

### Residential

Routinely assess:	% Yes	Main tools mentioned
Premorbid function	100	Interview, Minimental, PEDI
Current function	92	FIM, Berg, COGNISTAT, Westmead PTA scale, AMPS, Barthel, neuropsych assess, therapy assessments
Severity TBI	92	GCS, PTA, LOC, WHIM, LOTCA
Prior TBI	100	History, medical notes
Mental health disorder	100	Interview, BDI, 'liaison with mental health services'
Drug use	100	Interview, liaison with A&D services
Family situation	100	Interview, 'standardised social work questionnaire'

## 4.7 Discharge planning from residential rehab services

Forty two percent of services used formal discharge criteria. When asked for a description of these discharge criteria the responses varied from 'FIM' to 'Set for patient case by case. Functional gains with consideration for supports/discharge location/degree of recovery' with most suggesting some sort of functional level needed to be achieved prior to discharge. Two services mentioned 'ACC timeframes' playing a role in discharge. All but one service (92%) routinely used multidisciplinary discharge summaries.

## 4.8 Making decisions

Providers could choose multiple options.

Of residential providers, 54% reported making decisions on client care based on evidence based guidelines or international expert opinion although no service identified specific guidelines. All services indicated that decisions were made on the basis of consensus among the MDT members.

For non-residential providers, 53% reported making decisions based on evidence based guidelines or international expert opinion, 57% according to contract requirements, and 87% by consensus with service and ACC

## 5. Interventions - barriers - improvements

Providers were asked to identify the interventions that they felt made the most difference to clients, barriers to achieving best results and any suggestions for improvements in services.

### 5.1 Interventions that make the most difference

These are presented as verbatim responses with minor editing to limit duplication.

Non residential providers

- Client focus/client driven and personalised care – increasing acceptability of and compliance to rehabilitation plans. Including:
  - Holistic and individualised needs assessments and goal setting and the creation of appropriate rehabilitation plans. Reflecting client strengths, interests, etc in rehabilitation plans
  - Involvement and working together with clients, their family/whanau and ACC case managers
  - Selecting the most appropriate members of staff to care for patients (depending on the personality, nature, or interests of staff)
- Good neuropsychological assessments - to inform the rehab plans for OT's, Physiotherapists and Clinical Psychologists
- Good neuropsychological review for evaluation of rehab progress and adjustment of rehab plans
- The early diagnosis and treatment of TBI
- Treating headache, sleep disturbance, depression and dizziness
- Effective pain management
- Inclusion of educational goals for clients
- Provision of either psychotherapy or behaviourally based therapy addressing those issues which interfere with rehabilitation. E.g. grief, acceptance, family issues, and re-inventing a positive sense of personal identity.
- Living skills coaching
- Modelling of appropriate behaviour.
- Intensive rehabilitation followed by monitoring and involvement by family
- Motivational input
- Providing holistic support, understanding, acceptance and education
- Social context of facility - constant positive feedback, building of self-esteem,
- structure of rehab pathway
- Ability to link to day programs when appropriate
- Good relationships between staff, ACC case managers, clients and their families
- Multidisciplinary integrated team with a wide range of available rehabilitation skills and expertise in TBI rehabilitation

Residential providers

Rehabilitation Environment:

- All services provided on one site
- Supportive, safe and encouraging environment

- Individual self contained units which give opportunities for privacy and personal space
- Provision of accommodation for family members
- Customised residential rehabilitation, as similar to home environment as possible

The approach:

- Specific goal orientated programmes, with cognitive rehabilitation and an emphasis on integration back into the community.
- Integrated goal setting rehabilitation plans
- Inter Disciplinary Teams with excellent communication skills
- Removing any psycho active medications
- Managing behavioural disturbances during recovery
- Effective management of discharge into the community
- A family model of rehabilitation, with participation of family/whanau
- Support of knowledgeable staff, especially medicine and psychology
- A multidisciplinary permanently employed team
- A focus on self-adjustment issues post injury
- Functional mobility training and an emphasis on skills specific to the home and school environments
- Intensive individual rehabilitation programmes
- Links with community groups
- Access to ongoing slow stream rehab under supervision of qualified staff
- Immediate support and information/education for patient and family

## 5.2 ACC

Level of support from ACC for care plans from providers:

	<b>Non-residential services</b>	<b>Residential services</b>
Very helpful	25%	7%
Helpful	61%	23%
Unhelpful	9%	53%
Very unhelpful	3%	15%

The perceived helpfulness of ACC in supporting TBI rehabilitation services to construct and implement care plans differed between non-residential and residential services, with non-residential services being more satisfied with the level of support that ACC provides to them. 68% of the residential providers surveyed stated that ACC's support was unhelpful or very unhelpful compared to 86% of non-residential providers who described ACC support as helpful or very helpful.

### 5.3 Problems, barriers, solutions from provider perspective

Providers were asked a series of questions to explore this area.

*Within the limits of resources available do you think people in your region get a good deal from TBI rehabilitation services?*

Provider type	% Yes	Comments with 'Yes'	Comments with 'No'
Residential	73	Yes they do but I feel this applies only to those who can ACCESS services. We have a number of community teams but lack residential services we are the only ones in [large south island region]. Dependent on CM referral. Team developed for public health system therefore all disciplines available. Employees well educated and access to updated info always available.	Limited neuropsychology within hospital, Limited Psych support.
		In the greater Auckland region there are 40 residential beds; Community rehab service to see clients at home; interdisciplinary team available for phone consultation; Team of life skill coaches working in the community; Family/whanau education.	For severe TBI services too fragmented in a small country therefore no concentration of expertise in one or two places. No specialist TBI services available. Inadequate follow-up of people who spend a few days in hospital and don't access rehab services.
		Clients who come to us come to a purpose built rehab centre. We have an interdisciplinary team set up TOTALLY client focused with a rehab model built around the client. The smallest detail is IAX in this unit. The standard of care and motivation of the team in regards rehab is outstanding. Come visit us.	Have noticed a national trend coinciding new AR and RS contracts for shorter stays and reduced service levels. Also use of RS to provide rehabilitation.
		There are definitely not enough resources, providers or funding for the non-acute phases of rehabilitation.	Some clients discharged from hospital to home should not have occurred i.e. they should have been linked into a rehab facility either as an inpatient or on TI. Difficulties can also arise with families struggling with the grief etc and the difficulties in assisting clients to have rehab in their own homes.
		ACC appears to pick a service to be "flavour of the month" and refers everyone whether an appropriate service or not. We can make recommendations to case managers but as we have no contract they can choose to ignore us (and often do).	
Non-residential	61	Mostly yes. Important that ACC case managers are upskilled in TBI - as this helps a huge amount in the quality of care that their clients receive. Work preparation programmes designed specifically for people with TBI a big gap - they are included in standard work prep programmes but there are not ideal for people with TBI.	Its OK and certainly has improved in the last 3 yrs. Now have residential, day programmes, conc clinic, and indiv program in community - still need a 'drop-in' facility; still need much more support for dual diagnosis esp mental health + TBI; still need (Govt) Health support for BIA liaison worker and crisis management team for TBI

		Those referred yes, but believe that the knowledge re specific and immediate intervention re mild TBI is not generally understood within health providers in community. Concern re lack of access for [rural region] clients due to limited resources for our services.	TBI continue to fall between cracks - Hospitals are poor at referring to concussion clinics as are GPs. These front -line services are the ones who determine level of service and unless GPs are better educated with TBI and Hospital services (and GPs) begin to use concussion clinics then people like us get referrals too far down the track.
		Actually mostly - there are a lot of resources however [region] has a vast rural areas and this does effect the availability of resources to our clients. A lot of clients don't know what they are entitled to! Often resources are available but the client may be particularly difficult to manage. There is a shortage of skilled caregivers and often the amount payable to my employees is minimal due to ACC contract rates. TIL programmes provide more financial gain. From an employers point of view it is often difficult to get vocational support in industry.	For mild to moderate TBI the TBI is not always identified. Rehab needs are not always identified. HOWEVER, good for severe TBI.
		People with mild traumatic brain injury and post concussion syndrome get properly assessed and treated. This is believed to hasten recovery.	Services are variable, and still a number of gaps in what is offered and when.
		In larger regions/cities there is a good base of assessment providers, with an experienced team of clinicians.	Generally poor point of contact assessment and treatment services (GP A+D clinics) and very small proportion of TBI populations screened by our service.
		Some people receive excellent input and funding. Recruitment is an issue for positions and hours of work. Some individuals have much better funding when they hold their own care package compared to contracted providers.	Referral is frequently late - negative expectation and actual functional failures are frequently already present.
		They receive a comprehensive range of services as long as the recommendations are put into place. There are a wide range of assessment and therapeutic services available which are of high quality.	No rehabilitation available for children as an inpatient
		From what I gather, talking to colleagues around the country, Auckland is probably the best served region. Availability of specialised providers elsewhere is limited it seems.	Not sufficient resources to manage referrals; Not sufficient contract dollars to employ the qualified staff required.
		It appears people in Auckland region get a better deal than those outside the region (greater options). However still a number for who the options don't fit well.	
		Good range available from acute hosp care where staff have good knowledge. Good private practitioners working in [region] with experience in BI Rehab. Have worked very hard to develop strong working links with other services e.g. Vocational placement and they are usually open to the support we provide with and for the clients.	

## 5.4 Gaps

### Residential providers

There is no age-appropriate rehab setting for younger persons. There is inadequate age appropriate longer term residential support.
Home support. Residential therapy intensive programs able to cope with the difficult patients that may have a history of social inappropriate behaviour, alcohol or drug abuse. Difficulty providing TIL coaches.
For severe TBI services too fragmented in a small country therefore no concentration of expertise in one or two places. No specialist TBI services available. Inadequate follow-up of people who spend a few days in hospital and don't access rehab services.
Problems with post-discharge rehab provision in rural areas in [large area in South Island]. NB also there is no BIA or HI society in [city] so no field officer support available in Dunedin.
A RESIDENTIAL service in South Auckland would mean less travel to visit family members who are residents.
Gaps vary across the country. General impression is that there are greater service delivery opportunities for clients than the funders are able or willing to fund.
The clients tend not to stay with us long - the evenings after therapy gone home is boring making clients want to leave.
Funding for equipment to access the curriculum for children in schools. Services for children with moderate TBI and repeated mild TBIs.
We cover a huge area [in North Island] and there can be difficulties if someone wishes to have rehab in their own homes. It is OK if they live in [city] but can be a struggle if they live in the country. Some concern over the experience of OTs, Physios etc providing brain injury rehab in smaller areas.
1. Transport; 2. Limited no. of ACC approved facilities; 3. Under resourced and overworked case managers; 4. Lack of clinical knowledge case managers; 5. Funding restrictions; 6. Sometimes unrealistic time frames in which to achieve the objectives; 7. Inconsistent application interpretation of contract specs.
No day care facilities; no transport; DHB only seem to deal with acute services - nothing long term.
Large geographic rural area. All services have problems with recruitment and retention of qualified staff. One huge gap is lack of trained carers and no-one accepting responsibility to provide training for carers.

## Non-residential providers

Shortage of skilled caregivers, poor rates due to ACC contract terms, vocational support, psychological support often delayed and they are too busy too. Travel to and from appts, rehab etc. Client compliance issues, ignorance of specified provider to recognise the issues/need vs support offered or available.
Activities they can lock into to suit their particular disability.
There is only one clinical psychologist in [South Island region]. People living in [region] have to travel a long way for assessment. Treatment providers only visit weekly.
Training for support staff.
Supported return to work, access to psych support, family therapy are all available.
Not enough hours allowed for the client to meet their needs holistically
Non-acc clients don't get the same service/rehab opportunities as ACC clients. Remote locations are hard to service.
No specific head injury outpatient rehabilitation services.
Facility to provide group work within ACC contracts (Psychological Services) for people with TBI. E.g. Self-awareness group - would like to run one but no contract to do this currently.
Vocational support back to work lacks, as does family therapy, discussion with other "peers" or "expert teams".
Services are generally available but those who might benefit from them are not always referred.
More resources to lead to better detection rates - rehab is a need - we tend to assess but we could greatly benefit from resources to rehab people following TBI. We need for trained clinical staff.
It appears paediatric services appear to lack a cohesive IDT for assessment and treatment. Public knowledge re concussion and possible consequences.
1. Good point of contact services; 2. Interventional (rather than assessment) psychology; 3. Service co-operation (particularly A + D, Mental Health).
lack of providers in [South Island region]. ALSO NB that there is no HI society in [city] so no access to support gps.
Family therapy/counselling
1. Decreasing number of Clinical Psychologists with good rehab expertise; 2. Decreased experienced service providers in the Voc rehab area leading to inconsistent services and outcomes and client dissatisfaction; 3. Social and family support (e.g. BIA very limited).
Return to work, life skills for more disabled, support for families.

Lack of involvement on part of ACC of range of providers
It would be good if Vocational contracts were adjusted to respond more appropriately to the needs of TBI claimants. Non ACC clients are poorly supported in all areas.
Very strongly return to work issues need to be addressed. Often work placement agencies are not knowledgeable about TBI and use pre-morbid qualification in determining competency. The clients are often unable to cope in the placement; stress builds up and they lose the job. This impacts on self esteem etc.
A big gap for provision of support for families. Options for return to work seem to be highly dependent on individual skill and knowledge of those in vocational rehab area. There are only TWO Brain Injury Liaison officers for whole of Auckland region. They do a great job but there should be more.
Lack of services for ongoing rehab treatment and support in rural areas. Late referral for rehab E.G. "concussion" treated cursorily at time of accident by GP, Emergency services etc and patient later (months or more) is referred with major difficulties as a consequence of little /no rehab/information/ guidance immediately after injury.
Access to Psych support and social work support; Acc does not always see the need for this; If identified does not always agree to fund it.
still need a 'drop-in' facility; still need much more support for dual diagnosis esp mental health + TBI; still need (Govt) Health support for BIA liaison worker and crisis management team for TBI - ESPECIALLY crisis intervention, psychological support for families/carers and RTW - SLOWER continuum for TBI.
1. Funding restraints mean cant have people who are still in hosp attending meaning often referrals come to us after discharge from hospital; 2. Vocational rehab providers don't have a good knowledge of TBI but we are able to support clients through the process.

## 5.5 Specialist TBI units

Providers were asked to comment on the following statement:

*“It would be in the best interests of people with severe TBI to have one or two specialist facilities for managing severe TBI in New Zealand, similar to that which exists for spinal cord injury”.*

Provider type	% Agree	Comments
Non-residential	63	
	Agree	More integrated care with multidisciplinary approach, to prevent fragmentation currently present.
		Assures equality of care and makes it more likely that high quality of care is given to all.
		To ensure that the TBI persons have the best possible treatment, care and follow-up that spinal injury clients receive to ensure that the best possible outcomes for these clients is available.
		NZ has a small population. It is best to have 1 good specialist facilities than a number of small ones. Less cost to the tax payer.
		I agree especially for those patients from peripheral centres who do not always receive comprehensive rehabilitation services on discharge from acute care.
		A return to some form of meaningful activity is a fundamental requirement in my view (that activity may or may not be formal, paid employment). For many with moderate/severe TBI, that requirement is never attained. Specialist facilities could include what were once called "sheltered workshops".
		Agree for severe TBI. I think this is done reasonably well. My concern is the poor or neglected services for mild to moderate TBI.
		Totally agree. AT present many people have TBI and are discharged without proper follow up. There are cities in NZ who have little or no rehab available. It should be compulsory for Medical to refer after ANY trauma or concussion then the difficulties experienced later would be much lessened.
		BUT NOT to be on site of a hospital. SOCIAL MODEL not medical model. Based on Howard Jackson's TRU model, Liverpool or ANAGRAM, Canada. Get people into daily routines, including doing work/tasks ASAP in a "work" environment, so need different contexts on site, on a small farm. (ref Tim Wallace - impt of returning to office even 10 min a day - relating to people other than med profs. Re-establishing routines ASAP. Positive to have a centre of excellence for TBI but NOT an institution.
		Specialist service required. Population base (and client volumes) small - centralise expertise if possible.
		The area of expertise is very specialised.
		The majority of my clients are SCI - the benefits of specialist facilities are enormous. This is not only for the clients but their families, caregivers and care teams. Provides better education for all through a collective of specialist then operate fro one area BUT outreach would be required to ensure that those needing care/assistance/review were able to access it. (i.e. we use Burwood very often).
		It is a specialised field; hard to manage in a home setting; relatives of clients need to go somewhere for support; would be a one stop shop of specialists.
	Disagree	
		Assessment services should be based in clients own home and community where family can be involved in each stage.

		I consider it important that people are supported in the community as much as possible. Particularly the communities they wish to remain in.
		Lack of family in area and support facilities as described in other questionnaire filled out by this service (no. 102)
		Not for MTBI as remained in community and often have jobs to continue with.
		1. So imp't for rehab to be about using re/learning skills in normal, usually environment e.g. community facilities and community gps rather than always being with people who are brain injured; 2. Very vital that clients lives are able to continue as normally as possible during rehab – not being away for long periods of time. BI rehab can go on for years. The best place is by someone's lives continuing but getting assistance from a specialist service as required. It is so imp't the people learn to see the brain injury as part of their life - not who they are.
		TBI rehab needs input from family, friends, workplaces etc and for this reason should occur within the patients' context as much as possible.
		Disagree strongly. If community reintegration is the primary goal to be achieved for people with TBI, rehab is best provided in their own communities and will involve family and significant others.
		Need good centers - several - close to home. Not useful to have clients attending away from home.
		From a community providers point of view - a specialist unit would not facilitate rehabilitation in rural NZ, family involvement and generally would not serve the vast majority of TBI survivors who are mild - moderate. May also over medicalise rehabilitation.
		Needs to be community based, individualised and offered by multiple providers with different profiles. Assessment and rehabilitation need to be ongoing and closely followed through – personal independence, vocational rehab, psychological adjustment etc.
		This could potentially remove people from existing support structures which are critical to rehab. Better if such specialist services can be provided regionally so they are accessible for the person's family/support system. Aids integration of service delivery.
		Prefer to have patients treated as close to family and own community as possible.
		TBI occurs too often to rely on the availability of resources at a national centre. Also - there are numerous logistical problems with sending people away for treatment when we really need to assess their capacity to function in their home environments - better family support if services provided locally.
Residential	38% agree	
	Agree	For severe TBI this is crucial. Too few severe TBI patients annually are looked after/managed by too many services around NZ.
		Specialised knowledge required as per SCI. Especially around the challenges of behaviours, lack of insight and memory issues that can arise. Education and support to families/significant others would then be appropriate to their need rather than 'lip service' or incorrect information that can be given.
		Rehabilitation of children with TBI is a specialist area and should be based on clinical pathways and evidence based practice developed by clinicians with skills and experience developed in collaboration with families.
		Although head injuries are on the decline. These clients have unique complex issues that need to be assessed and treated in specialised rehab setting.
		In principle a good idea BUT family/whanau play a big role in rehabilitation - their absence may affect rehab/recovery rate. Having expertise all on one site is a huge advantage.

	Disagree	People with severe TBI lose friends and support quick enough. They need to be managed locally as their support network can be maintained and educated along with the patient. Any patients from the North who go to Auckland do not receive a better service they just become isolated.
		1. What happens to family relationships in the meantime; 2. Smaller facilities - in local areas; 3. Support is easier to access.
		Need to be much more integrated in community. Family and friends are huge part of recovery and this is imperative - cannot be achieved when dictated by location. Providers should be more encouraged and supported to provide some of these beds at each facility.
		Focus would only be on severe or severe to mod plus I am not convinced it would make a significant impact on outcome versus \$\$\$ soaked up. A specialist unit is a fraction of a second compared to the long term community needs of people with TBI. Once the acute phase is over a lot of focus needs to go into building life time supports and adjusting to injury consequences. Mild and mod injuries need attention too.
		Interventions are mainly cognitive/behavioural and not dependent on high level technology as in spinal cord injury. Acute phase of TBI Rehab should be provided in all major (base) hospitals although specialist facilities are useful for slow stream rehab for patients with severe TBI
		Rehab requires input from family, work, friends etc. Having patients too far away from home creates enormous additional burden and disruption to families.
		TBI rehab needs specialist facilities BUT the rehab is better provided close to the individuals home and community - to utilise the supports, facilitate home-based therapy, promote generalisation skills learnt. Family participation crucial and maintaining social contact also essential to prevent isolation later on. + and - for both. Agree – keeps expertise level of staff to a maximum but less chance to share information or see different styles working. Disagree means long separations or difficult situations for families.
		Family support/ability to try functioning in usually environment is very important and not possible to same extent at site distant from home.

## Results: Consumers

Results from the consumer survey are largely descriptive and/or qualitative. Verbatim comments are written *in italics* and indented.

### 6. Injury classification and demographic details, including work status

#### 6.1 Injury classification: Traumatic brain injury; acquired brain injury; chemically induced brain injury.

While most respondents (90%) would be classified as having had a TBI, a small number appeared to have damage due to chemical exposure (abbreviated here as CBI), or other types of acquired brain injury (ABI) including various types of stroke, epilepsy and tumours. Some of these people were accessing ACC funded services and their data is included in some parts of the analysis.

##### Injury type

	Number of respondents	% of total sample
TBI	379	90.20%
ABI	34	8.10%
CBI	7	1.70%

#### 6.2 Severity of initial injury

Severity of injury was classified broadly into two categories according to whether respondents had lost consciousness for less than 12 hours (mild/moderate TBI) or more than 12 hours at the time of initial injury (severe TBI). More respondents reported having had a severe TBI (55%) than a mild or moderate TBI (39%).

##### Severity of injury

	Mild/Moderate (% of total sample)	Severe injury (% of total sample)	Severity of injury unknown (% of total sample)
Total Sample (n = 420)	171 (40%)	217 (52%)	32 (8%)
TBI respondents only (n = 379)	148 (39%)	208 (55%)	23 (6%)

#### 6.3 Average age and time since injury

The average time since injury (SD) for respondents with TBI was 12 (10.5) years, similar to the average for the whole sample at 12.4 (11.5) years. In terms of age, the average for TBI respondents was 45.2 years (SD = 13.3), while that for the whole sample was again very similar at 45.6 years (SD = 14.1).

##### Average age / time since injury

	Mean (TBI only)	SD	Median	Range
Time since injury (years)	12.4 (12)	11.5 (10.5)	8.5 (8.5)	0.25 – 69
Age of respondents (years)	45.6 (45.2)	14.1(13.3)	46 (46)	4 - 90

## 6.4 Gender

As expected with TBI higher numbers of respondents were male, the TBI sample being 67% male and 33% female. The figures were still very similar with the acquired brain injuries added in, at 66% male and 34% female.

Gender

	Male (TBI only)	Female (TBI Only)	Unknown
Number of participants	275 (254)	144 (124)	1
Percentage of total sample	66% (67%)	34% (33%)	0.24%

## 6.5 Regional representation: Locality and rural versus urban respondents

All questionnaires were distributed by local BIANZ and HIS branches to preserve the anonymity of respondents, so it is not known how many questionnaires were sent out in each region. Clearly some regions are not really represented in this survey, in particular Canterbury and Gisborne, while others are represented very well for their population in particular Northland and Hawkes Bay.

Participant responses by region

Region	Number of respondents (TBI respondents only)	Percentage of total sample (TBI respondents only)
Auckland	86 (78)	20.4% (20.6%)
Northland	50 (46)	11.9% (12.1%)
Waikato	32 (32)	7.6% (8.4%)
Bay of Plenty	46 (41)	10.9% (10.8%)
Gisborne	1 (0)	0.2%
Hawkes Bay	62 (50)	14.7% (13.2%)
Taranaki/Manawatu-Wanganui	22 (22)	5.2% (5.8%)
Wellington	61 (55)	14.5% (14.5%)
Marlborough	8 (8)	1.9% (2.1%)
Tasman	1 (1)	0.2% (0.3%)
Nelson	14 (13)	3.3% (3.7%)
Westland	14 (12)	3.3% (3.2%)
Canterbury	1 (0)	0.2%
Otago	8 (7)	1.9% (1.8%)
Southland	13 (12)	3% (3.2%)
Unknown	1 (1)	0.2% (0.3%)

Respondents were categorised as rural or urban (table 6) according to whether they lived within 20 km of a city with a population of more than 50 000 people. According to this classification just over 65% of the respondents with TBI were urban, while almost 35% would be classified as rural.

### Rural vs urban respondents

	Number of respondents (TBI respondents only)	% of total sample (TBI respondents only)
Urban	278 (248)	66% (65.4%)
Rural	142 (131)	34% (34.6%)

### 6.6 Ethnicity

As is usual with ethnicity, respondents were asked to ‘tick as many boxes as applied’ to describe the ethnic group they belonged to. All except one respondent ticked at least one box to describe their ethnicity, most being either NZ European (87%) or Maori (11%). A small number (19 people) identified with more than one ethnic group.

#### Ethnicity

	Number of respondents (TBI only)	% of total sample (% of TBI respondents)
NZ European	367 (331)	87.2% (87.3%)
NZ Maori	44 (40)	10.5% (10.6%)
Cook Island	1 (1)	0.25%
Samoan	1 (1)	0.25%
Chinese	2 (2)	0.5%
Indian	5 (5)	1%
Other	18 (16)	4.3%

### 6.7 Current work status

Almost half (46%) of those with TBI were on ACC earnings related compensation, with many concurrently undergoing work trials, working part-time or doing voluntary work. A further 20% of TBI respondents indicated that they were in paid work, either full or part-time. Nearly 14 % of TBI respondents were on a sickness or invalid benefit, often indicating that they had been exited from the ACC scheme, or did not qualify for ACC for such reasons as living overseas at the time of their accident.

#### Work Status

	Number of respondents (TBI respondents only)	% of total sample (TBI only)
Paid work more than 30 hrs a week	33 (29)	7.8% (7.7%)
Paid work less than 30 hrs a week	52 (49)	12.4% (12.9%)
ACC	179 (175)	42.5% (46.2%)
Sickness/invalid benefit	62 (52)	14.7% (13.7%)
Working in the home	18 (16)	4.3% (4.2%)
Student	15 (13)	3.6% (3.4%)
Retired	25 (15)	5.9% (4%)
Seeking work	14 (13)	3.3% (3.4%)
Other	15 (15)	3.6% (4%)

## 7. Experience of Rehabilitation

In this section of the questionnaire respondents were asked a series of brief open and closed questions. Most questions related to their own experience of rehabilitation but some centred on TBI rehabilitation in general.

### 7.1 Type of rehabilitation service

Almost 12% of respondents with TBI indicated that they had not attended a rehabilitation service of any kind. In terms of the types of rehabilitation services respondents had attended, active residential rehabilitation; vocational rehabilitation; and services aimed at promoting independent living; were each attended by around 25% of respondents. Almost 13 % of respondents had attended a concussion clinic at some stage, while close to 25% of respondents indicated that they had attended “other” types of rehab services. These ‘other’ services were most often psychology or neuropsychology services; outpatient services at a local hospital (usually OT, sometimes physio or SLT also); private OT; physical fitness orientated such as gym; home support; or support group centres such as Stewart Centres.

Type of rehabilitation service attended

	Number of respondents (TBI respondents only)	% of total sample (TBI only)
No Rehab service attended	51 (44)	12.10% (11.6%)
Residential active rehab	95 (86)	22.60% (22.7%)
Residential support service	46 (41)	11% (10.8%)
Service aimed at promoting independent living	110 (103)	26.10% (27.2%)
Day activity centre	82 (73)	19.50% (19.3%)
Concussion clinic	49 (49)	11.60% (12.9%)
Vocational rehab service	90 (82)	21.40% (21.6%)
"Other" rehab service	94 (89)	22.30% (23.5%)

### 7.2 Ability of rehabilitation service to focus on goals that were important to respondents

59% of respondents with TBI felt that the rehabilitation services had focused on goals that were important to them (table 10), while 24% felt that the service had not done this. Many who felt that the service had not focused on important goals felt that the goals had been unrealistic and that there was a lack of real TBI expertise from the service providers. Many also mentioned that the goals appeared to be ‘ACC driven’ rather than individualised.

*Seemed more related to keeping ACC happy, with monitoring work hours.  
Everyone says they are independent but at the end of the day all answer to ACC and try to achieve ACC's aims*

*Focused on what they were instructed/contracted to do. But with head injury there is nothing visible, nothing broken to see. “So try harder”, “I know exactly how you feel” comments. If you look normal you are OK.*

Did the rehabilitation service focus on goals that were important?

	Number of respondents (TBI only)	% of total sample (TBI only)
Yes	245 (222)	58.20% (58.6%)
No	99 (90)	23.50% (23.7%)
Partly	6 (5)	1.40%
Don't know	10 (9)	2.40%
Not applicable	36 (32)	8.60% (8.4%)
Question not answered	24 (21)	5.70% (5.5%)

When it came to helping achieve the goals that were important (Table 11) 60% of respondents felt that the service had been ‘very successful’, ‘successful’ or ‘satisfactory’. In terms of the reasons given for this, it was most often attributed to either the quality of the staff (in particular constructive advice and support), or to respondents’ own self-motivation and commitment. Respondents who indicated ‘satisfactory’ often appeared to be attributing any failure to achieve goals to a ‘lack of potential’ (for example due to the severity of their injury) rather than to a ‘failure’ on the part of the rehabilitation service itself.

### **7.3 Good advice and good follow up.**

*Consistent staff, one-on-one help from OT well informed about brain injury. Formed good relationship with trust, warmth and respect both ways. Also good Neuropsych to inform me.*

*Allowing me to take one step at a time and mastering it before moving on to the next stage*

*Self-commitment, and encouragement from life skills tutor and OT.*

*Too early i.e. OT very soon after injury and my goals were in hindsight unrealistic. I didn't understand at that stage what the effects of my injury were*

Success of rehabilitation service in helping achieve results that were important

	Number of respondents (TBI only)	% of total sample (TBI only)
Very successful	52 (49)	12.40% (12.9%)
Successful	76 (71)	18.10% (18.7%)
Satisfactory	124 (110)	29.50% (29%)
Unsuccessful	60 (56)	14.30% (14.8)
Very unsuccessful	34 (31)	8.10% (8.2%)
Don't know	4	1%
Not applicable	35	8.30%
Question not answered	35	8.30%

At the other end of the scale 23% of respondents felt that the service had been ‘unsuccessful’ or ‘very unsuccessful’ in helping them to achieve goals that were important to them. Most respondents in these groups cited reasons related to lack of understanding, expertise or interest in TBI from rehabilitation staff; unrealistic goals; and undue pressure from ACC case managers. Many of them expressed frustration that they just weren’t listened to, but many also acknowledged that the severity of their injury had an effect on the ultimate results of their rehabilitation.

*Not understanding head injury, not listening to clients, not following guidelines for TBI.*

*Not being listened to.*

*I present well so misunderstood how disabled I actually was. Culture of bullying at provider and not treated well by many staff members as a complete person, I felt so intimidated I pushed to be discharged , when really I needed further care.*

*No commitment or ‘buy in’ by the ACC syncophants, who are only interested in pushing you out rather than treating you*

#### **7.4 Satisfaction with rehabilitation service: Regional description.**

The ability of the rehabilitation services to deal with issues important to TBI consumers can also be described on a regional basis. The tables below show basic satisfaction with rehabilitation services in different regions, in terms of goals focused on and goals achieved. Later in this report respondents’ satisfaction with ‘TBI rehabilitation in general’ is also presented (both overall and regional results).

Did the rehabilitation service focus on goals that were important: Regional presentation

Region(n = number of respondents from that region)	% of respondents who did not receive rehabilitation	% of respondents from the region who indicated ‘Yes’	% of respondents from the region who indicated ‘No’
Auckland (n = 78)	6%	73%	15%
Bay of Plenty (n = 41)	7%	41%	37%
Canterbury (n = 1)			100%
Hawkes Bay (n = 50)	14%	60%	26%
Marlborough (n = 8)	25%	37.5%	37.5%
Nelson (n = 13)	15%	54%	15%
Northland (n = 46)	11%	70%	15%
Otago (n = 7)	14%	57%	29%
Southland (n = 12)	33%	42%	25%
Taranaki/Manawatu-Wanganui (n = 22)	14%	55%	25%
Tasman (n = 1)	100%		
Waikato (n = 32)	13%	66%	16%
Wellington (n = 55)	7%	56%	29%
Westland (n = 12)	25%	25%	33%

The results presented are descriptive (presented as percentages of regional totals only) and it should be noted that consumer response from some regions was quite small. However it appears that on a regional basis, services in Northland, Auckland and to a lesser extent Waikato did better than average when it came to focusing on important rehabilitation issues. It was the same trend when it came to achieving the goals that were important (table below).

**Success of rehabilitation services in helping achieve results that were important to consumers**

Region (n = number of respondents from that region)	% of respondents who did not receive rehabilitation	% of respondents who indicated services were 'very successful', 'successful' or 'satisfactory'	% of respondents who indicated services were 'unsuccessful' or 'very unsuccessful'
Auckland (n = 78)	6%	73%	18%
Bay of Plenty (n = 41)	7%	61%	27%
Canterbury (n = 1)			100%
Hawkes Bay (n = 50)	14%	60%	24%
Marlborough (n = 8)	25%	50%	25%
Nelson (n = 13)	15%	54%	31%
Northland (n = 46)	11%	70%	13%
Otago (n = 7)	14%	57%	14%
Southland (n = 12)	33%	33%	33%
Taranaki/Manawatu-Wanganui (n = 22)	14%	50%	32%
Tasman (n = 1)	100%		
Waikato (n = 32)	13%	69%	16%
Wellington (n = 55)	7%	53%	29%
Westland (n = 12)	25%	42%	17%

Areas where consumers were less happy with service providers in terms of goal focus and achievement tended to be the regions with both low response numbers and with low population densities (or more 'rural' regions). Southland, Westland and Marlborough also had higher percentages of respondents who had not received any rehabilitation at all. However two regions which do not fit such a profile are Bay of Plenty and Wellington. In these regions 37% and 29% of respondents (respectively) felt that rehabilitation services had not focused on important goals, while 27% and 29% respectively felt that the service had been 'unsuccessful' or 'very unsuccessful' in helping them achieve important goals.

**7.5 Therapy most useful during rehabilitation**

Respondents were asked what type of treatment or therapy they found most useful in terms of rehabilitation, and while answers were understandably variable there were common themes that emerged. Many people mentioned both occupational therapy and psychological/counselling services as being very constructive. Speech language therapy and fatigue/stress management were also often specifically mentioned. A large number of respondents mentioned either physiotherapy, or fitness based activities such as gyms, swimming, or hydrotherapy programmes. Comments suggested that some of these respondents had physical injuries which responded well to this type of therapy, but also that the empathy/attitude of such staff or just the positive nature of exercise based activities were

an important factor in the rehabilitation process. A prominent theme to emerge from the responses was the value of peer group support and being able to meet/discuss issues with other people who have TBI.

*Support/interaction from people with similar problems or those who had dealt with or understand TBI. Stewart Centre and men's group were excellent.*

*Sharing ideas, problems and coping strategies*

*Going to BIA meetings*

### **7.6 Opportunities for review after discharge from rehabilitation service**

Of the respondents with TBI, 37 or 9.8% indicated that they were still using some form of service at the time of the survey and were not able to comment about opportunities for review post discharge. The other group who were not able to comment were the 44 (11.6%) who had previously indicated that they did not attend any form of rehabilitation service. This left 298 people with TBI possibly able to comment in some way about opportunities for review post discharge, and of these 138 or 46% had opportunity for review either at their own request, at their GP's request or at a set time in the future. 124 or 42% indicated that they did not know what their opportunities for review were. 27 or 9% of respondents felt that there was no opportunity for review.

*No-one suggested this*

*No, but my file was left open*

*ACC just ended the contracts and when I felt I needed help was told that everyone had day to day or life problems and just to get on with life*

#### **Opportunities for review after discharge**

	Number of respondents (TBI only)	% of respondents able to comment on discharge review, n = 329 (TBI only, n = 298)
Still attending treatment	40 (37)	
No opportunity for review	33 (27)	10% (9%)
Review after D/C at own request	67 (57)	20.4 (19.1%)
Review after D/C at my GP's request	42 (39)	12.8% (13.1%)
Review after D/C at a set time in the future (e.g. 3 months)	47 (42)	14.3% (14.1%)
Don't know about review opportunities	130 (125)	39.5% (41.9%)

### **7.7 Information (written or verbal) provided by the service**

Around 60% of respondents found the written or verbal information provided by rehabilitation services helpful, very helpful or satisfactory. 20% indicated that it was not helpful, while 16% indicated either that no information was provided or that the question was

‘not applicable’. Respondents were less inclined to make additional comments, but from those that did it was clear that many find the information provided by groups such as BIA NZ and HIS very useful.

#### Information provided by the service

	Number of respondents (TBI only)	% of total sample (TBI only)
Very helpful	80 (72)	19% (19%)
Helpful	98 (91)	23.30% (24%)
Satisfactory	70 (66)	16.60% (17.4%)
Not helpful	42 (35)	10% (9.2%)
No information provided	44 (40)	10.50% (10.6%)
Not applicable	23 (19)	5.40% (5%)
Question not answered	62 (55)	14.70% (14.5%)

## 8. Effectiveness of TBI rehabilitation services

### **8.1 Within the limits of available resources do people with TBI get a good deal with respect to rehabilitation?**

38% of people with TBI thought that they had a reasonably good deal with respect to their rehabilitation, 42% thought that they didn't, and 7% indicated that they felt it was variable. 5.3% indicated that they were unsure (didn't know) while 9% of respondents did not answer the question.

*Some people are real good and others lose their cool. You have to have a good understanding of head injury. Could be a bit more respect you still have feelings even if your brain is mush.*

#### Good deal for people with TBI with regard to rehabilitation?

	Number of respondents (TBI only)	% of total sample(% of TBI respondents only)
Yes	150 (142)	35.60% (37.5%)
No	178 (158)	42.30% (41.7%)
Variable	27 (25)	6.40% (6.6%)
Don't know	23 (20)	5.50% (5.3%)
Question not answered	42 (34)	10.00% (8.9%)

Again, many people who answered ‘yes’ supplied ‘qualifying’ comments which tended to be of a similar nature. For example that for them it had been good but they knew of others who had not been as lucky; that it depended where you lived; that they felt it was better now than in the past; that it was good as long as they had someone to ‘advocate’ for them or as long as they knew what to ask for;

*I did but not so sure about others.*

*Years ago no, but at the present point, YES.*

*As long as you have a caregiver to hassle for help or you may slip between the cracks.*

*I believe services are generally there and available, HOWEVER more focus needs to be on the TBI victim as a person who has 24 hours a day to cope with, not 8 hours of work, which most rehab is focussed on getting you ready for. Keeping a seminormal family life together with a TBI is hard enough without having the constant pressure/stress of being an ACC statistic in so far as dollars spent/hours working!*

Many of those who answered 'no' to this question commented that TBI is poorly understood by ACC; the general public (for example in their workplaces); and most health professionals including GPs and those who work in acute medical facilities. Respondents frequently made reference to poor initial diagnosis and management of TBI, as well as long term management and rehabilitation. Again people felt it depended where you lived or who the service provider was. Many commented on the fact that people with TBI are often not good at presenting their own needs or advocating for themselves – that their 'cognitive' needs and the ongoing nature of their problems do not fit well into the ACC system of 'rehabilitation' and management.

*Not enough skilled/educated experts with knowledge of limiting effects of brain injury, especially in ACC. Lack of allowance in legislation for the special requirements of TBI.*

*While hospitalised for nearly two months, the issue of TBI was never raised – the emphasis was entirely on my physical recovery*

*I found it hard to get help as I didn't know how to get it*

*TBI need strong motivated carer or family to fight for them. Unless TBI is 'brain dead' he battles for everything i.e. continuing physio, financial help etc*

*Nature of TBI means we lack insight and can't always communicate our needs properly. However ACC are slow in helping or offering any help. In fact WINZ have been helpful in getting me where I am today, not ACC!*

*People do not understand as you look 'normal'. But ACC have been good so far, I just worry about my future*

These results can again be explored for regional differences, and the table below presents the results for general satisfaction with the deal for TBI rehabilitation on a regional basis. The results were very similar to those presented earlier, when the questions were more specifically about the performance of rehabilitation service providers. That is, respondents from rural or less populated regions and respondents from Wellington and Bay of Plenty, seem more likely to indicate that the deal for TBI rehabilitation in general was not good. Out of 39 respondents from Marlborough, Southland, Otago and Westland only four people in total thought TBI rehabilitation got a good deal and three of these people were from Westland.

Good deal for people with TBI with regard to rehabilitation?

Region(n = number of respondents from that region)	% of respondents who did not receive rehabilitation	% who indicated 'yes'	% who indicated 'no'	% who indicated that it is 'variable'
Auckland (n = 78)	6%	47%	31%	5%
Bay of Plenty (n = 41)	7%	37%	49%	5%
Canterbury (n = 1)			100%	
Hawkes Bay (n = 50)	14%	40%	36%	12%
Marlborough (n = 8)	25%	0%	88%	
Nelson (n = 13)	15%	54%	38%	
Northland (n = 46)	11%	43%	46%	4%
Otago (n = 7)	14%	0%	57%	
Southland (n = 12)	33%	8%	75%	
Taranaki/Manawatu-Wanganui (n = 22)	14%	50%	45%	5%
Tasman (n = 1)	100%			
Waikato (n = 32)	13%	38%	25%	3%
Wellington (n = 55)	7%	29%	42%	15%
Westland (n = 12)	25%	25%	50%	8%

## 8.2 Main gaps that exist for people with TBI in terms of services

There were varied comments concerning the gaps that exist for people with TBI in terms of services, but again common themes did emerge. Commonly expressed again was the perception that treatment providers, ACC case managers and the public in general lack knowledge or awareness of TBI, which in turns affects the way people with TBI are 'treated', or prevents early consideration/diagnosis when the TBI is mild or moderate. Many people commented that it can be very hard to find out what services might actually be available. Also that in many cases they had to 'chase help' rather than have help offered or suggested - for example when they left an acute care facility such as a hospital or emergency department.

The word 'unseen' came up frequently throughout the entire survey, the inference being that there is not a lot of awareness in the general community about TBI, compounded by the fact that the signs aren't obvious (compared to if someone was in a wheelchair).

*In our case were discharged from hospital – 24 hour supervision required and no help offered at all. Had to chase services ourselves from ACC.*

*Budget support, life type support. With TBI is not a visible injury it is quite difficult for people to understand. Gap in support for 'mild' TBI – not recognised enough and effects can be so great*

*TBI people look alright but are not. If in wheelchair we'd be OK. Banks and others should have services for TBI clients (i.e. who make mistakes due to memory loss etc – e.g. have on file that have head injury so if forget to transfer money or forget appointment, don't charge you for it anyway.*

More specific gaps included fragmented or poorly co-ordinated services, and poor access to services especially for those who live rurally. For example many respondents referred to seemingly repetitive assessments; constant waiting between 'recommendations' and 'approval' for services; and providing the 'same old' information to new case managers and new providers; and so on. For those living more rurally even if they can come to the city for rehabilitation services there are often problems with transport, accommodation, somewhere to rest for what is probably an exhausting day of appointments. But this sort of 'auxiliary' help or support, or the more 'social' needs of rehabilitation are not provided for within the ACC system or legislation. Quite a few respondents also referred to the lack of ongoing support; supported workplaces; and the failure to support carers. Finally there was frequent specific mention of ACC and either a constant fight to keep services, or constant worry that services will be stopped.

*Coordination, between ACC top brass with the lesser employees who deal with the person with TBI. Also the lack of support to carers for TBI affected subjects.*

*Where to find support and advocacy. Didn't find it easy at all, assessor was arrogant and abusive, would have liked support then.*

*Awareness of TBI within general public. Lack of suitably funded day programmes, constructive ones. Employment lack of support for employers to employ brain injured clients in part-time work.*

*Reviews and assessments are needed that are patient focussed rather than meeting requirements of ACC who have a financial interest in 'outcomes'.*

*ACC spends vast amount of money reviewing your case. When you ask for support for retraining etc they are slow to respond.*

*TBI do not know what they need. Few GPs know. Specialists rarely recommend anything they can't provide as no-one seems to 'work together'. Cannot get case managers to return calls or other correspondence and delays in getting approval to appropriate rehab takes months and years. Focus on getting back into work without retraining and doing 35 hours so claimants can come off ACC books. Access poor – I had to leave Tauranga to get treatment and Auckland's busy environment is not conducive to a TBI so I can't get good work here.*

### **8.3 Specialist centres for managing TBI in New Zealand**

76% of respondents with TBI favoured having one or two specialist centres for treating severe TBI similar to that which currently exists in New Zealand for managing spinal cord injury. 10% did not favour this suggestion while 15% either didn't know or did not answer the question.

### Agree with having specialist centres for TBI

	Number of respondents (TBI only)	% of overall sample (TBI only)
Yes	315 (286)	74.80% (75.5%)
No	41 (38)	9.70% (10%)
Unsure/don't know	26 (20)	6.20% (5.3%)
Question not answered	38 (35)	9% (9.2%)

There appeared to be a variety of reasons for why people were supportive of this idea. Some people had attended specialist-type centres previously and had found them useful.

*I have a spinal injury and found that it was my 3 months in Burwood SIU that gave me back a measure of control and confidence in my life. An equivalent brain injury rehabilitation service would have been equally rewarding. Burwood taught me how to handle life in a wheelchair. For my head injury all I got was lots of sessions with speech therapists (and endless IQ tests).*

*I found the ISIS center in Dunedin provided what was needed at different stages. When I returned home ACC provided and continue to provide good support services.*

Certainly many people felt it was more likely that they would receive expert care, less fragmentation and would 'know' where to go for further help. Some felt that for the first time it would allow TBI rehabilitation to be 'specialised' rather than just 'slotted in' amongst the general workload of facilities and treatment providers.

*The people doing the job would be better informed and trained. Repeat questioning over and over could be eliminated with all information at hand allowing professionals to follow up their next step well informed.*

*General medical community don't seem to understand TBI*

*Especially for severe TBI – a one stop shop so to speak where information, assistance, knowledge and understanding are to the fore with rehabilitation as well.*

*Without specialist facilities the people involved with rehab have too broad a spectrum of ideas. Specialist facilities would be based on TBI only.*

*Then TBI person would be dealing with dedicated person who understands TBI – helpful as they would understand and levied in one. They would know if you are telling the truth and to be believed is to be half way there.*

Many respondents had 'qualifying' points to add to their answer and a large number noted that their support was conditional on access to family/friends - that their support, along with familiar surroundings was of key importance. Also frequently noted was the need for back up to be available once discharged from such a facility, and that the focus should be on eventual community re-integration. Some respondents felt specialist centres would also be beneficial to people with less severe injury.

*But it wouldn't work too well if it was far away. You need your family/friends around to help and encourage you.*

*But only if really WELL trained staff and clear pathway for LONG term rehab plan i.e. graduated plan over years if necessary.*

*Can't believe there isn't something like this. Also for less severe it would be good to be able to access suitable specialized services early on and as simply as possible.*

*Depending on how is set up and who is providing facilities.*

*"Not if takes money away from community funding e.g. Day centres."*

More than half of those who did not support specialist centres gave the likely distance from family support as the main reason. Others felt that treatment should be available 'wherever' you live and that even more people would 'miss out' if specialist centers were around.

*Family is who goes the long haul after an accident like this. To be without them during all this would have taken away ALL my hope. I would not have wanted to live or even try to live without them!*

*Because it is important for people with TBI need family and friends support. Specialist facilities are absolutely essential however.*

*Too many people miss out now as it is let alone this way.*

## **9. ACC case management**

### **9.1 Helpfulness of case manager**

Respondents were asked to rate how helpful they had found their ACC case manager in the overall planning and management of the rehabilitation process following their TBI. They were also specifically asked to comment on the rating they had given.

45% of respondents indicated that their case manager had been helpful or very helpful, but many of these also supplied a 'rider' in the comments section. The common theme emerging from such qualifying comments were that the standard was variable and that the turnover of their case managers was very high.

*Finally got a competent case manager after YEARS who could see that I wanted to get back into the workforce*

*Initially the planning and management was excellent. More recently the constant changing of case managers has meant that I have felt let down*

*To start with case manager was brilliant but as time moves on and ACC restructures could have 2 or 3 in a year - gets confusing!*

### Helpfulness of ACC case management in overall rehabilitation process

	Number of respondents (total with TBI = 379)	% of respondents with TBI
Very helpful	82	22%
Helpful	88	23%
Variable	27	7%
Unhelpful	59	16%
Very unhelpful	56	15%
Don't know/question not Answered/not applicable	67	18%

38% of respondents with TBI indicated that they found the ACC case management to be variable, unhelpful, or very unhelpful; while 18% either 'didn't know', didn't answer the question at all, or felt that it was 'not applicable' to them. The most common reasons for indicating 'not applicable' appeared to be either having the original accident while living overseas (therefore not eligible for ACC funding) or having been exited from the scheme some time previously. Common themes centred again on the variability and high turnover of case managers and the perception that most case managers lack basic knowledge about the condition of TBI.

*Case managers very overloaded; did not turn up to appointments; did not provide ongoing rehab assistance; hard to get hold of; changed frequently; no understanding of TBI; ACC change structure regularly*

*Little or no understanding of TBI, emphasis strong on return to work no matter what, not listening to how I was feeling - appeared to have her own agenda. Finally requested a change of case manager*

*Seems hard work getting her to implement any sort of program. Very hard to find out what services are available to you. Seems her mission is to get you off ACC without providing real rehabilitation or training. Generally, ACC and dealing with ACC is hard work and stressful.*

*Improved over years to be very helpful but initially very impractical (egg wanted him to bus to physio though he couldn't walk to bus stop!). Always seemed cross until he returned to full time work.*

*Does not understand TBI and effects. She is bully, righteous and all wants it to "exit" for her KPI's. ACC left me by myself for almost 2 years - I will never forgive them for this.*

## 9.2 Regional differences of case management 'helpfulness'

It is possible to look more closely at some of the descriptive data by breaking the demographic information into groups such as region, age, time since injury and work status. Table 2 describes the case management according to region.

Case management by region (% of all respondents in that region)

	Very helpful/helpful	Variable	Unhelpful/very unhelpful	Don't know/not answered/n/a	Total
Auckland	35 (45%)	6 (7%)	23 (29%)	14 (18%)	78
Bay of Plenty	21 (51%)	2 (5%)	11 (27%)	8 (20%)	41
Hawkes Bay	21 (42%)	6 (12%)	10 (20%)	13 (26%)	50
Marlborough	1 (13%)	1 (13%)	4 (50%)	2 (25%)	8
Nelson	8 (62%)	0	4 (31%)	1 (8%)	13
Northland	25 (54%)	0	14 (30%)	7 (15%)	46
Otago	3 (43%)	0	2 (29%)	2 (29%)	7
Southland	6 (50%)	0	3 (25%)	3 (25%)	12
Taranaki/Manawatu-Wanganui	7 (32%)	0	14 (64%)	1 (5%)	22
Tasman			1 (100%)		1
Waikato	18 (56%)	2 (6%)	4 (13%)	8 (25%)	32
Wellington	21 (38%)	9 (16%)	17 (31%)	8 (15%)	55
Westland	2 (17%)	0	7 (58%)	3 (25%)	12

In some regions the numbers are quite small and the results should be interpreted with caution. For example despite apparent poor results in regions like Westland and Taranaki/Manawatu-Wanganui, some particularly positive comments were attributed to case managers in these regions.

*The ACC would help with any needs, they still help now. My case manager is brilliant.* (Westland)

*Absolutely wonderful – total understanding. I looked so well but inside was turmoil. She knew!* (Taranaki/Manawatu-Wanganui)

## 9.3 Case management results by age and time since injury

The following table looks at case management results in terms of age, and time since injury. There may be a slight trend towards increasing time since injury for those who considered their case managers to be 'unhelpful' or 'very unhelpful'.

Case management by age and time since injury, severity of injury.

	Very helpful	Helpful	Variable	Unhelpful	Very unhelpful
Average age (no. of respondents)	45 years (n = 82)	44 years (n = 88)	43 years (n = 27)	49 years (n = 59)	42 years (n = 56)
Average time since injury	9.4 years	9.9 years	8.7 years	11.6 years	11.7 years

### 9.4 Case management by severity of injury and rural/urban location

The next table presents case management results according to severity of injury, and rural versus urban dwellers. Respondents with severe injury head injury seemed slightly happier with their case management than those with more moderate injury, and those in urban areas tended to be more satisfied than those in rural areas.

Case management by severity of injury and rural versus urban respondents (% of total group)

	Very helpful	Helpful	Variable	Unhelpful	Very unhelpful	Total number of respondents
Mild/moderate	23 (16%)	34 (23%)	12 (8%)	28 (19%)	30 (20%)	148
Severe	56 (27%)	48 (23%)	12 (6%)	28 (13%)	24 (12%)	208
Urban	57 (23%)	56 (23%)	24 (10%)	36 (15%)	30 (12%)	248
Rural	25 (19%)	32 (24%)	3 (2%)	23 (18%)	26 (20%)	131

(“Total number of respondents’ column includes respondents who did not answer the question about case management, or responded “don’t know” or “not applicable”).

### 9.5 Case management by work status

When looking at the results in terms of current work status the numbers are again quite small so it is difficult to draw firm conclusions. Those respondents working full time were most likely to indicate satisfaction with their case management in terms of both their rating and the comments they made.

Case management results in terms of current work status (% of total respondent group)

	Very helpful/Helpful	Variable	Unhelpful/very unhelpful	Total no. of respondents in the group
Paid work at least 30 hrs a week	19 (66%)	1 (3%)	5 (17%)	29
Paid work less than 30 hrs a week	24 (49%)	5 (10%)	13 (27%)	49
ACC	88 (50%)	15 (9%)	52 (30%)	175
Sickness/invalid benefit	15 (29%)	0	18 (35%)	52
Retired	4 (27%)	2 (13%)	5 (33%)	15
Working in the home	7 (44%)	1 (6%)	8 (50%)	16
Seeking work	7 (54%)	0	5 (38%)	13
Student	3 (23%)	3 (23%)	4 (31%)	13
Other	2 (13%)	0	5 (33%)	15

Fulltime worker

*Did have many changes but all very helpful*

Those working part time and on ACC were slightly more likely to indicate satisfaction than dissatisfaction with their case management, often making comments to 'qualify' their rating.

*Helpful as long as someone in my circumstance has a caregiver to push them for assistance*

Most of the respondents who indicated a 'variable' standard of case management made comments to support their rating. For example,

*Countless case managers. With each one have to "sell" my status. Some are very good, others ineffective. May be overloaded. All very stressful and exhausting. Trying to be independent but no continuity across the whole period of injury, between having work and then collapse.*

*Varied with each one. Had many, 2 very helpful the rest unhelpful.*

## **9.6 Respondents with chemically induced brain injury (CBI)**

There was a small group of respondents (four male, three female) who indicated their brain injury was the result of ongoing exposure to chemicals or solvents. The average age of this group was 56 years old, and the regions they came from were Northland (2), Auckland (1), Nelson (1), Westland (1), Bay of Plenty (1), and Wellington (1). Five of the seven had claims accepted by ACC, two describing their case manager as 'helpful', the other three indicating their case managers as either unhelpful or very unhelpful. Only one of these respondents had not had some sort of rehabilitation provided. Comments made by this group of respondents were all of a similar nature. That is, that the perceived focus from ACC was on assessment and perhaps on removal from the scheme rather than on rehabilitation.

*ACC spend a lot of time and money on obtaining specialist advice from treatment providers with regard to rehab plans and then it seems to totally disregard this advice and do as it pleases. (rated case manager as 'helpful')*

*Over the years put through medical assessment and a plan is made and generally its not implemented e.g. working with physio, contracting prospective employment. They don't seem to understand what brain injury problems are. (rated case manager as 'unhelpful')*

One 'CBI' claimant expressed a view that was commonly expressed by those with TBI, that the symptoms of brain injury tend to be cognitive, emotional and ongoing where the ACC system itself is geared more towards physical injury and recovery.

*My brain injury is solvents from workplace so no sudden TBI more gradual deterioration. ACC do best within boundaries that govern them, never going to 'return to normality' so the constant badgering from ACC ends up being more destructive than the injury itself. What is rehab, what is normality, what is a stable and productive life??? The legislation has no idea!*

## 9.7 Extra comments

Respondents were invited at the end of the questionnaire to make any extra comments if there was anything else they wanted to say that had not previously been covered in the survey. Some commented on the limitations of the questionnaire itself (too long, some of the questions too hard to understand) and there were a variety of other issues raised. Many respondents took the opportunity to discuss ACC again and raise issues related to the management of TBI rehabilitation by ACC.

*Should be a section within ACC purely designated to TBI so those you deal with actually understand it properly (e.g. they use terms like “take him out of his comfort zone” – but for someone with a head injury that means exhaustion and then compounded by being pushed again while in that state). Not treated with understanding just trying to get off books. Ends up making me even more anxious and stressed and becomes vicious circle.*

*1. ACC should not be involved in funding TBI rehab as it is so long term and doesn't fit with their brief 2. Support for family members (especially care givers and children of those with TBI) should be available. 3. Basic lack of understanding of TBI by not just public but so called professionals (i.e. can look good physically but hidden side effects). 4. Public and professions “devaluing” ability and extent of problems. 5. TBI is not a “one size fits all” situation.*

*ACC too hard pushing clients off books which end up adding to people's problems. People considered numbers only – i.e. business model only. Some ACC case managers should not be working with people as their personality is so poor/not suited.*

*ACC doesn't seem to recognize the family i.e. major bread winner unable to work needs support at home by wife. ACC and WINZ expect wife to work but I am unable to look after young children without support – too much stress on family, marriage and all may fail.*

*ACC can be very unprofessional and unhelpful e.g. Told to “be a big boy and manage my fatigue. Everyone gets tired”. Won't help at all*

Many respondents and family members described how their lives had been ‘turned upside down’, highlighting some of the specific struggles they have had either in the past or ongoing. The importance of family support came up frequently; issues around support or recognition for carers; and worry for the future. One respondent in particular who was an experienced health professional with a background in rehabilitation re-iterated the importance of having consumer input in to the development of the new TBI guidelines. She offered to contribute herself, either to facilitate or be part of any such consumer input if required.

Throughout the survey there were factors which were consistently raised by respondents with respect to both their experience of rehabilitation after TBI and their perception of ACC. When it came to case management, high turnover of case managers and their perceived lack of training (that is, understanding of the basic symptoms associated with TBI) were consistently highlighted as being barriers in the rehabilitation process. Lack of knowledge of TBI was also

attributed to providers of rehabilitation and medical practitioners. Many respondents pointed out that people with TBI frequently lack overt physical symptoms, and that the cognitive effects of TBI are often poorly understood.

*Poor knowledge of ACC, GP and most people. They don't really know how to explain your symptoms so they make it up. They insist that if you have the right attitude you can be cured*

*Seems that it is a hidden disability – cause you look normal you are OK. Many people don't understand a brain injury and because it affects people in different ways they cannot put you into a category. As a consequence they don't know what to do with you or what your needs are.*

Another factor frequently raised was the high variability in standard of case managers, and the apparent 'adversarial approach' of some. Many respondents also commented that they felt the legislation under which ACC operates was limiting, in that it doesn't have scope for ongoing support or the social needs which become paramount.

*[ACC case manager] very helpful but the whole system is structured around saving money ahead of really offering a format that encourages employers to bother employing people like me*

*Believe services are generally there and available, however TBI victim has 24 hours a day to cope with, not just 8 hours of work, which most rehab is focused on getting you ready for. Keeping a semi-normal family life together with a TBI is hard enough without having the constant pressure/stress of being an ACC statistic in so far as dollars spent/hours working!*

## **10. Health Status of TBI consumer respondents**

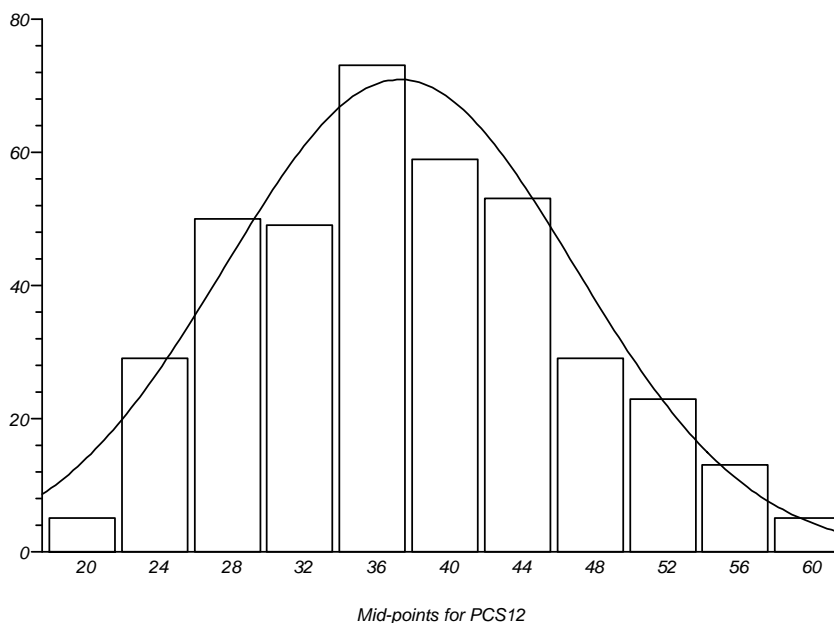
### **10.1 Reported health and well-being of survey respondents: SF 12 summary scores**

The table below shows average physical component summary and mental component summary scores for the SF-12 (PCS 12 and MCS 12). For the physical health components (PCS 12) the average was consistent at 38 for the overall sample and within the subgroups of traumatic, chemically induced and acquired brain injury. The expected average score in a general population would be 50 with a standard deviation of 10, so the physical functioning in this brain injured population was well below average. This is probably not unexpected, however people with chronic disability often actually rate their health and well-being more highly than expected. When it comes to mental component summary scores (MCS 12) there was more variation but the average reported health and well-being was still very much worse than that expected for the general population (50). The average MCS 12 for the TBI group was 40 and that for the ABI group was 42. For the small group of respondents with chemically induced brain injury they reported very poor mental health scores at an average of only 34. The graphs show that the results are not particularly skewed (i.e. a small number of very low results bringing down the mean) but that the whole graph is shifted to the left.

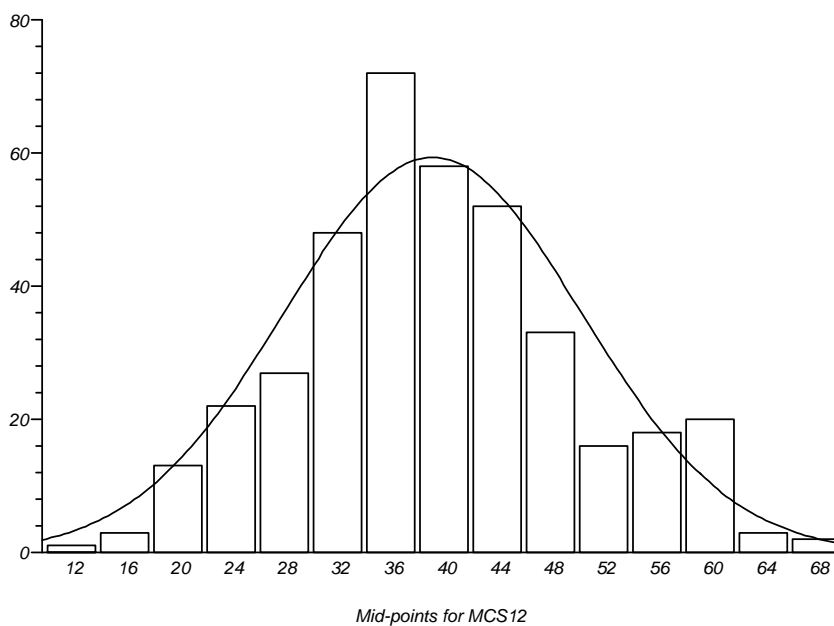
PCS 12 and MCS 12 scores: Respondents to the TBI rehabilitation survey

	Average PCS 12 (SD)	Average MCS 12 (SD)
Overall survey sample	38 (9)	40 (11)
TBI only	38 (9)	40 (11)
CBI only	38 (8)	34 (9)
ABI only	38 (10)	42 (11)

Histogram for PCS12



Histogram for MCS12



### **10.2 Reported health status and well-being according to injury severity**

Table 2 shows physical and mental health scale summaries according to whether TBI respondents had experienced a milder or more severe TBI. Of interest is the fact that those with severe head injuries actually reported slightly better general health and well-being (higher average summary scores) than those with mild to moderate injury.

Table 2. PCS 12 and MCS 12 for mild/moderate and severe TBI

	Average PCS 12 (SD)	Average MCS 12 (SD)
Mild/Moderate TBI	37 (8)	38 (9)
Severe TBI	39 (9)	41 (12)

### **10.3 Reported health and well-being according to work status**

When reported health status of respondents is explored in terms of work status the results (Table 3) appear reasonably consistent. Those respondents in full time work reported higher average health and well-being than those in part-time work. Respondents on ACC, a sickness benefit or those who were retired reported very similar (lower) levels of health and well-being (in particular physical health) which would appear to fit logically with their work status.

Table 3 PCS 12 and MCS 12 according to work status

	Average PCS 12 (SD)	Average MCS 12 (SD)
Full time work (Paid)	46 (9)	44 (12)
Part time work (Paid)	40 (8)	41 (9)
ACC	36 (8)	39 (11)
Sickness benefit	36 (8)	40 (11)
Retired	36 (10)	41 (10)

### **10.3 Health and well-being of respondents who received rehabilitation versus those that did not**

While the majority of respondents with TBI received some form of rehabilitation, 44 respondents reported that they did not receive any rehabilitation at all. The group who received rehabilitation of some sort reported an average PCS 12 of 38, and an average MCS 12 of 40. This was slightly higher than the average for the group who did not receive rehabilitation, with the PCS 12 at 36 and the average MCS 12 at 38.

## Discussion

### *Main points*

This Current Practice Review is unique in describing, at a national level, the extent, structure and practice of TBI rehabilitation services in New Zealand. The findings complement a previous survey of rehabilitation providers conducted in Auckland by the Disability Resource Centre which didn't focus solely on TBI. The current review is also unusual in that it provides comments from over 400 consumers of TBI services on the extent, practice and perceived quality of those services.

There are large amounts of data presented in this report and some care needs to be taken with the interpretation of that information (see 'cautions' below). Nevertheless, some broad conclusions can be drawn.

Firstly, there is considerable variety in extent, structure and practice of TBI rehabilitation services in New Zealand. Different providers, apparently providing the same service under the same contract, appear to have different mixes of staff, different approaches to referrals, different degrees of specialisation in TBI, and different approaches to assessment of quality and quality improvement. This presumably reflects an absence of any consensus about what constitutes 'best practice' in TBI rehabilitation but may also be influenced by contract arrangements, particularly price. One hopes that the New Zealand TBI Guideline will provide more direction about 'best practice'. However, services will only be able to deliver on these directions if contracts are aligned with them.

Secondly, there has been a combination of a shift away from DHB-provided services and an aggregation of privately provided services by a small number of large private providers, both in residential and non-residential TBI rehabilitation. This CPR can not draw any conclusions about whether these trends are 'good' or not, simply that they have occurred. Without some formal audit of services (preferably both of process and outcome), no conclusions can be drawn about service quality. With the shift away from DHB-provided services, there appears to be a trend towards less use of medical staff as 'core team' members, particularly medical specialists. This mirrors what has happened in the UK although would be unusual in North American and continental European TBI rehabilitation services, particularly residential services.

Thirdly, residential TBI rehabilitation services tend to be low-volume (for TBI clients) and not specialised in TBI rehabilitation, a combination that would suggest that most people with (severe) TBI are being managed in environments that might not be ideal for TBI clients and by staff who don't see TBI clients as their 'main business' and/or for whom they have special training. International evidence supports the idea that best results for TBI rehabilitation come from dedicated TBI rehabilitation teams in a TBI-friendly environment. On this subject, most rehabilitation providers disagree with the idea of having one or 2 TBI specialist centres in New Zealand (similar to the 2 spinal cord injury units) but a clear majority of consumers agree. The usual argument against such specialist centres (too hard for the family, travel etc) don't seem to outweigh the perceived advantages of better quality care in the eyes of consumers who have experienced current TBI care in New Zealand.

Fourthly, consumers, in general, are not in agreement with the statement that 'people with TBI get a good deal from TBI rehabilitation services in New Zealand' and there is a

substantial (around 40%) proportion of consumers that are unhappy with ACC services (primarily case management) for people with TBI. Illustrative verbatim responses are included in this report and a full copy of all verbatim responses involving ACC has already been forwarded to ACC.

Providers gave a large variety of responses to questions about perceived barriers and gaps in TBI rehabilitation in New Zealand and these are reproduced in full in the report so that the reader can make up his/her own mind about this information. This also obtains for information from providers about what they see as the key interventions for people with TBI.

Data about health status in the consumer survey are based around the SF12, a 12 question, internationally validated tool that gives a reasonable picture of a person with a health problem. For studying groups of people with TBI, this measure has much to commend it (simple, quick, able to be completed by phone or on paper, able to be completed by proxy, excellent statistical properties). The main burden on health status revealed in this survey is on aspects of both physical and mental functioning with substantially lowered mean values compared to population norms.

### ***Cautions***

In surveys of this type, one must always be careful in drawing too much out of what is simply descriptive data. The survey instruments are provided so that readers can check responses against the questions that prompted them. Specific cautions include:

1. The survey was generally completed by one person from a service – this may have been a clinician or manager who may have had different perspectives in particular areas.
2. For some services operating at multiple sites, a single questionnaire was completed implying consistency of operation across sites which may not necessarily be the case.
3. Some services providing ‘active residential rehabilitation’ for some clients may also provide ‘residential support’ for others and this might have affected some of the responses e.g. staffing levels and expertise
4. The response rate for the provider survey, although high by usual standards of postal surveys, was still not complete. Total numbers were relatively small and it is possible that services that didn’t respond could be systematically different from those that did, introducing bias into the results as presented here.
5. The consumers that responded to the questionnaire all belonged to, or were associated with, one of two consumer support organisations for people with TBI in New Zealand. The responses of this group could differ significantly from those of all people with TBI. Furthermore, a subset of this group responded and may have been more likely to hold, for example, negative views of service provision and ACC.
6. As mentioned previously, the mean time from injury of consumers that responded was around 12 years, so that views on service provision may include services that no longer exist or have improved substantially since then.

### ***Further work***

The information in this review can be used as a benchmark for future reviews of TBI rehabilitation services in New Zealand. The provision of the survey instruments in this report allows for accurate repeat surveys in the future. The main point of this CPR was to allow a description of the current state of NZ TBI rehabilitation services against which ‘international best practice’, as described in the NZ TBI guideline, can be compared. It may be useful to explore some services more fully as part of systematic audit of services against standards set in that guideline. Generally that type of audit reflects structure and process issues.

Ultimately, what ACC needs to know is whether services deliver better outcomes for people with TBI. Formal research projects are generally required to answer that sort of question. Where the intervention is multifaceted (e.g. environment, staff, techniques, intensity) and case mix is very variable, study design can be problematic. However, appropriate designs do exist to test such interventions. In particular, Clinical Practice Improvement methodology would be very useful in this situation.

Based on this work with consumers, and our previous work in a prospective TBI cohort study, we believe that the SF12 (or SF36) represent excellent tools for simple outcome measurement in TBI populations and should be trialled as routine measurement tools.

## **Appendix A: Survey instruments**

NB: some of the formatting of the original surveys has been scrambled by the insertion of the survey files in this larger document.

## ***TBI Rehabilitation – Consumer Survey***

The New Zealand Guidelines Group is currently developing guidelines for management of Traumatic Brain Injury (TBI). Part of that process requires feedback from people with direct personal experience of TBI rehabilitation services in New Zealand. If you have had a traumatic brain injury (TBI) or if you care for someone who has had a TBI please complete the following questionnaire and return it in the stamped self-addressed envelope provided. By doing so you will be contributing significant information to the guideline development process. You will notice that we use the term traumatic brain injury shortened to 'TBI' throughout the questionnaire rather than 'head injury' as that is the term which will be used in the guidelines when they are published.

**PLEASE NOTE** that this questionnaire does not ask for information which could identify you. In addition any material from this survey will be presented in such a way that it will not be possible to identify individual people who respond. We aim to publish the results of the survey in the Brain Injury Association newsletter as well as present the results in the TBI guideline. The results should be available by early 2005.

Please confirm your participation by ticking the appropriate boxes below (*please tick as many as apply*):

- |  |                       |
|--|-----------------------|
| • I have had a traumatic brain injury (TBI)  | <input type="radio"/> |
| • I am a carer of someone who has had a TBI  | <input type="radio"/> |
| • I understand that information from this questionnaire is anonymous                                 | <input type="radio"/> |
| • I understand that information from this survey will contribute to the TBI guideline review process | <input type="radio"/> |

Firstly here are some general background questions

1. Have you had a traumatic brain injury (TBI)?

Yes

No

If "yes", how long ago did it happen? \_\_\_\_\_

If “yes”, did you lose consciousness for (*please tick one box below*)

- Less than 12 hours
  - More than 12 hours
- 

2. Do you care for someone who has had a TBI?

Yes  No

If “Yes”, how long ago did it happen? \_\_\_\_\_

If “Yes”, did they lose consciousness for (*please tick one box below*)

- Less than 12 hours
  - More than 12 hours
- 

3. Are you being assisted to fill out this questionnaire?

Yes  No

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4. What sex are you?

Male  Female

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5. What age are you now? \_\_\_\_\_

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6. What **region** of New Zealand do you live in? (e.g. Hawkes Bay, Southland, Auckland) \_\_\_\_\_

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7. Do you live within 20 km of a city with a population of **more than 50,000** people?

Yes

No

8. Which ethnic group do you belong to (*mark the box or boxes which apply to you*)

**NZ European**

**Tongan**

**NZ Maori**

**Niuean**

**Cook Island Maori**

**Chinese**

Samoan

Indian

Other (such as Dutch, Japanese, Tokelauan). *Please state* .....

9. Are you working? (*Mark the box which best applies to you*)

**Paid work at least 30 hours per week**

Paid work less than 30 hours per week

Working in the home

Currently seeking work

Sickness benefit

ACC

Retired

Student

Other (e.g. Voluntary work) \_\_\_\_\_

**The next set of questions are commonly used for health surveys of the general population. They ask for your views about your health and how well you are able to do your usual activities. If you are unsure about how to answer a question, please give the best answer you can.**

10. In general would you say your health is: *(please tick the box that best describes your answer)*

- Excellent
- Very Good
- Good
- Fair
- Poor

11. The following questions are about activities you might do during a typical day. Does **your health now limit you** in these activities? If so, how much?

- **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf? *(tick one box only)*

- Yes, limited a lot*
- Yes, limited a little*
- No, not limited at all*

- Climbing **several** flights of stairs *(tick one box only)*

- Yes, limited a lot*
- Yes, limited a little*
- No, not limited at all*

12. During the **past 4 weeks**, how much of the time have you had any of the following problems with your work or other regular daily activities **as a result of your physical health?** *(tick one box only)*

- **Accomplished less** than you would like

All of the time

Most of the time

Some of the time

A little of the time

None of the time

- Were limited in the **kind** of work or other activities (*tick one box only*)

**All of the time**

Most of the time

Some of the time

A little of the time

None of the time

13. During the **past 4 weeks**, how much of the time have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)?

- **Accomplished less** than you would like (*tick one box only*)

All of the time

Most of the time

Some of the time

A little of the time

None of the time

- Didn't do work or activities as **carefully** as usual (*tick one box only*)

All of the time

Most of the time

Some of the time

A little of the time

None of the time

14. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)?

- Not at all
- A little bit
- Moderately
- Quite a bit
- Extremely

15. These questions are about how you feel and how things have been with you **during the past 4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the **past 4 weeks**...

- Have you felt calm and peaceful?

- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time

- Did you have a lot of energy?

- All of the time
- Most of the time
- Some of the time
- A little of the time

None of the time

- Have you felt downhearted and depressed?

All of the time

Most of the time

Some of the time

A little of the time

None of the time

16. During the **past 4 weeks**, how much of the time has your **physical health or emotional problems** interfered with your social activities (like visiting friends, relatives, etc)?

All of the time

Most of the time

Some of the time

A little of the time

None of the time

*Now here are some questions about your rehabilitation following the TBI*

17. What type of TBI rehabilitation service did you (or the person you care for) attend?

**A residential rehabilitation service (providing active rehabilitation)**

A residential support service

A service aimed at promoting independent living in the community

A concussion clinic

A vocational rehabilitation service

Other (*please describe*) \_\_\_\_\_

Did the TBI rehabilitation service focus on achieving goals that were important to you?

Yes  No

*Comments*

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18. How successful was the rehabilitation service in helping to **achieve** the results or goals that were important to you?

Very successful

Successful

Satisfactory

Unsuccessful

Very unsuccessful

*What do you think the main reason for this was?*

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19. What intervention or particular therapy did you find the most useful or helpful?

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20. After discharge from the rehabilitation service was there an opportunity to return for a review of progress or needs?

At your request

At your GP's request

At a set time in the future (e.g. 3 months after discharge)

Don't know

*Comments* \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

21. Did you find the information (either written or verbal) provided by this service

Very helpful

Helpful

Satisfactory

Not helpful

No information provided by the service

*Comments -*  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

22. How helpful did you find the ACC case manager in the overall planning and management of the rehabilitation?

Very helpful                      ρ

Helpful                              ρ

Unhelpful                         ρ

Very unhelpful                 ρ

*(It would be useful if you are able to expand in more detail on the answer provided above)*

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23. Within the limits of resources available do you think people with TBI get a good deal with respect to their rehabilitation?      **Yes / No**

*Please comment*

*further*

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24. In your experience what are the main gaps that exist for people with TBI in terms of services etc. (For example accessing particular types of therapy or care; poor access to review when required; poor access to particular service types etc)



**Thank you very much for taking part in this survey. If there is any other information you could contribute that has not been covered by this questionnaire please feel free to do so below**

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**Survey of TBI Rehabilitation Service Providers in New Zealand (residential services version)**

The New Zealand Guidelines Group is currently developing guidelines for management of Traumatic Brain Injury (TBI). Part of that process is a review of current practice by providers of TBI services throughout New Zealand. We would like you to complete the following questionnaire and return it in the stamped self-addressed envelope provided. By doing so your TBI rehabilitation service will be contributing significant information to the guideline development process. Provider names will not be identified in any material produced from this review and ACC will have no access to provider-specific information. Responses will be grouped to avoid identification of providers. We will provide a summary of the responses from all providers to all services that respond.

If you wish to contribute to the consultation process for the TBI guideline, with or without completing this questionnaire, please tick the appropriate box at the bottom of this page.

Please note that this questionnaire is aimed predominantly at providers of **residential TBI services**. We are also sending a slightly different questionnaire to providers of **non-residential TBI services**. If you have specific questions regarding completion of this survey please contact Julie Myers on ...

**Contact details:**

Name of the Rehabilitation service:.....

Person completing this questionnaire:.....

Job title of the person completing this questionnaire:.....

Address:.....

.....

Telephone:.....

Email:.....

**Please indicate by ticking the box if you would like to be involved in the consultation process for the new TBI guidelines .....0**

**If your service HAS NOT managed at least three people in the last year or ten people in the last five years with TBI, please just tick the box and return the questionnaire in the envelope provided .....0**

## Traumatic Brain Injury (TBI) Rehabilitation Services Provider Survey

1. What type of TBI Rehabilitation Services do you provide? (*tick as many as apply*)

Active residential Rehabilitation	<input type="checkbox"/>
Rehabilitation Support	<input type="checkbox"/>
Transition to Independent living	<input type="checkbox"/>
Other ( <i>Please describe</i> )_____	<input type="checkbox"/>

2. How many people with TBI were seen by your service over the **last 12 months** ? \_\_\_\_\_

3. And of these people with TBI seen by your service over the last 12 months please estimate the percentage who had originally sustained a:

- Mild TBI (defined here as Glasgow Coma score 13-15 at initial assessment) .....%
- Moderate TBI (defined here as GCS 9-12 at initial assessment) .....%
- Severe TBI (defined here as GCS <9 at initial assessment) .....%

And what proportion were:

- Less than 18 years of age .....%
- More than 65 years of age .....%
- Maori .....%
- Pacific people .....%
- Asian .....%

4. Where is your TBI rehabilitation service usually provided?

General AT & R or rehabilitation unit (not TBI specific)	<input type="checkbox"/>
Designated area for TBI patients within an AT & R unit	<input type="checkbox"/>
Dedicated TBI Rehabilitation Unit	<input type="checkbox"/>
General Medical ward	<input type="checkbox"/>
Outpatient Department	<input type="checkbox"/>
Community facility	<input type="checkbox"/>
Other ( <i>Please describe</i> )_____	<input type="checkbox"/>

5. Does your TBI rehabilitation service provide or have access to specialist services for the following groups:

- |  |            |           |
|--|------------|-----------|
| • People who are less than 18 years of age         | <b>Yes</b> | <b>No</b> |
| • People who are over 65 years of age              | <b>Yes</b> | <b>No</b> |
| • People who are Maori                             | <b>Yes</b> | <b>No</b> |
| • Pacific peoples                                  | <b>Yes</b> | <b>No</b> |
| • Other specific ethnic groups                     | <b>Yes</b> | <b>No</b> |
| • People with co-existing mental health conditions | <b>Yes</b> | <b>No</b> |
| • People with drug or alcohol dependency           | <b>Yes</b> | <b>No</b> |

*Comments*

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6. What are the main criteria your TBI rehabilitation service has for accepting referrals?

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7. Does your service accept referrals for people with TBI who also have:

- Alcohol dependency **Yes** **No**
- Drug dependency **Yes** **No**
- A mental health condition **Yes** **No**

8. Referring to the overall **rehabilitation** case-mix for your service, please indicate the proportions for each condition:

- TBI rehabilitation .....%
- Stroke rehabilitation .....%
- Geriatric rehabilitation .....%
- Other rehabilitation .....%

9. IN GENERAL, what is the time from receiving a referral to when you are able to provide rehabilitation services or support for your clients

- No waiting time ρ
- Between two and seven days ρ
- Between one and three weeks ρ
- More than three weeks ρ

10. If you are not able to see clients as soon as the referral is received what are the reasons for this  
(Tick as many as apply)

	<b>Main reason</b>	<b>Other reasons</b>
The time indicated above is our target response time	ρ	ρ
There is a waiting list	ρ	ρ
Waiting to receive approval from ACC	ρ	ρ
Low priority referral	ρ	ρ

Shortage of appropriately trained staff

ρ

ρ

Other (*please give details*)

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11. What percentage of your referrals come from:

- Acute hospital inpatient services .....%
  - Other TBI rehabilitation services .....%
  - Other general rehabilitation services .....%
  - General practitioners .....%
  - ACC case managers .....%
  - Other (*Please provide a brief description*)
- 
- 

12. Does your service have or routinely use protocols or guidelines for:

- |  |            |           |
|--|------------|-----------|
| • Assessment of physical function                | <b>Yes</b> | <b>No</b> |
| • Assessment of cognitive and emotional function | <b>Yes</b> | <b>No</b> |
| • Goal setting                                   | <b>Yes</b> | <b>No</b> |
| • Discharge planning                             | <b>Yes</b> | <b>No</b> |

If “yes” please note the origin of the particular guidelines or protocols? For example were they developed within your service or perhaps sourced from outside (if so where from?)

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13. Does your service have or routinely use a standardised approach to care, i.e. an integrated clinical pathway?                      **Yes**                      **No**

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14. Does your service have or routinely use protocols for the management of common specific problems post TBI (for example spasticity, seizures, behavioural disturbances)?

Yes No

- If “yes”, please list them below and note their origin. For example were they developed within the service, or perhaps sourced from outside (if so, where from)?

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15. In terms of assessing prognosis and/or developing care plans, what **information** does your TBI rehabilitation service collect on a **routine basis** (*please tick all which apply*). NB: Please also note **how** this information is collected (for example by the taking of patient history, using GCS or PTA, using the FIM or BDI etc)

Pre-morbid functional status      ρ  
(method or measure used) \_\_\_\_\_

Current functional status      ρ  
(method or measure used) \_\_\_\_\_

Severity of TBI      ρ  
(method or measure used) \_\_\_\_\_

Prior TBI      ρ  
(method or measure used) \_\_\_\_\_

Mental health condition ρ  
(method or measure used) \_\_\_\_\_

Prior drug use      ρ  
(method or measure used) \_\_\_\_\_

Family situation and supports      ρ

(method or measure used) \_\_\_\_\_

16. Within your TBI rehabilitation service who is responsible for implementation of the rehabilitation care plan?

Primarily a designated key worker  $\rho$

Primarily an entire multidisciplinary team (MDT)  $\rho$

Other \_\_\_\_\_  $\rho$

17. Does your service have or routinely use any **formal** discharge criteria?

**Yes**                      **No**

(If "yes" what are they, for example are they time limited, function limited, other limitations?)

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18. Does your service routinely have or use multidisciplinary discharge summaries? **Yes**  
**No**

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19. How are appropriate services for individual clients decided upon by your TBI rehabilitation services?

Evidence-based guidelines  $\rho$  (please specify) \_\_\_\_\_ International

expert opinion  $\rho$  (please specify) \_\_\_\_\_

Consensus among MDT  $\rho$

Other  $\rho$

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20. Thinking of the staff makeup within your TBI Rehabilitation Service, what is their professional expertise? (tick as many as apply)

Nursing  $\rho$

Occupational Therapy  $\rho$

Physiotherapy	ρ
Speech-language therapy	ρ
Clinical Psychology	ρ
Social work	ρ
Family therapy	ρ
Rehabilitation Physician	ρ
Neurologist	ρ
Other medical practitioner	ρ
Other ( <i>please describe</i> )	

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21. Is your service able to provide (or does it have access to) services from **health professionals** to meet the current needs of your clients? (*circle the most appropriate answer for each profession*)

<b>Medical:</b>	<i>Never</i>	<i>Hardly Ever</i>	<i>Often</i>	<i>Usually</i>	<i>Always</i>	<i>N/A</i>
<b>Neurology:</b>	<i>Never</i>	<i>Hardly Ever</i>	<i>Often</i>	<i>Usually</i>	<i>Always</i>	<i>N/A</i>
<b>Nursing:</b>	<i>Never</i>	<i>Hardly Ever</i>	<i>Often</i>	<i>Usually</i>	<i>Always</i>	<i>N/A</i>
<b>Physiotherapy:</b>	<i>Never</i>	<i>Hardly Ever</i>	<i>Often</i>	<i>Usually</i>	<i>Always</i>	<i>N/A</i>
<b>Occupational Therapy:</b>	<i>Never</i>	<i>Hardly Ever</i>	<i>Often</i>	<i>Usually</i>	<i>Always</i>	<i>N/A</i>
<b>Speech-language Therapy:</b>	<i>Never</i>	<i>Hardly Ever</i>	<i>Often</i>	<i>Usually</i>	<i>Always</i>	<i>N/A</i>
<b>Psychology:</b>	<i>Never</i>	<i>Hardly Ever</i>	<i>Often</i>	<i>Usually</i>	<i>Always</i>	<i>N/A</i>
<b>Social work:</b>	<i>Never</i>	<i>Hardly Ever</i>	<i>Often</i>	<i>Usually</i>	<i>Always</i>	<i>N/A</i>
<b>Other:</b> ( <i>specify</i> ) _____	<i>Never</i>	<i>Hardly Ever</i>	<i>Often</i>	<i>Usually</i>	<i>Always</i>	<i>N/A</i>

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22. In your TBI rehabilitation service are there health professionals with whom most clients work?

**Yes    No**

If “yes” which health professionals are in this core team?

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23. Does your service have access to specialist clinical advice and specialist support for staff when required? **Yes No Sometimes**

- *Who is the specialist clinical advice or support commonly provided by?*

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- *How long does it usually take before the support or advice can be provided?*

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24. Thinking about Maori and Pacific clients, does your service have:

- Staff with an appropriate ethnic background **Yes No**
- Staff with special training (cultural) **Yes No**
- Access to appropriate outside staff (for example from Maori or Pacific health units)

**Yes No**

25. Does your TBI rehabilitation service routinely have:

- Regular education sessions for patients and families **Yes No**
- Written information for patients and families **Yes No**
- Regular education sessions for staff **Yes No**
- Opportunities for collaboration with other service providers **Yes No**

If “yes” who develops the information or education? For example is it developed within the service or perhaps sourced outside (if so, where from)?

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26. Overall, what intervention does your service provide that you think makes the most difference to outcome?

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27. After discharge from your TBI rehabilitation service:

- Does your service routinely review all patients? **Yes** **No**

If “yes”, when does this generally occur? (and how often?) \_\_\_\_\_

- Does your service provide any other follow-up services? **Yes** **No**

If “yes”, what are these services? \_\_\_\_\_

- Can GP’s request review? **Yes** **No**

- Are patients or their families able to self-refer for review? **Yes** **No**

If you answered “no” to all three ‘review’ questions (i.e. reviews not provided routinely, at GP request or at family/self request), in what circumstances might patients be reviewed by your service?

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28. Please describe the level of support your TBI rehabilitation service receives from ACC in constructing and implementing care plans

Very helpful  $\rho$

Helpful  $\rho$

Unhelpful  $\rho$

Very unhelpful  $\rho$

*(It would be useful if you are able to expand in more detail on the answer provided above)*

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29. Does your service routinely collect **information** on patients treated and/or their outcomes. For example

Discharge destination  $\rho$

Discharge ADL  $\rho$

Standardised measures  $\rho$  (*specify*) \_\_\_\_\_

Length of stay  $\rho$

Other

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30. Does your service routinely measure consumer satisfaction? **Yes** **No**

(*If so please specify how this is done*)

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31. Does your service routinely measure funder satisfaction? **Yes** **No**

(*If so please describe briefly how this is done*)

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32. Does anyone in your service routinely audit the rehabilitation service provided

• At patient level **Yes** **No**

If yes, what audit tool is used?

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• At Service level **Yes** **No**

If yes, what audit tool is used?

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33. Does your service use patient information provided by patient support groups such as The Brain Injury Association of New Zealand Incorporated, the Head Injury Society of New Zealand, or overseas organisations? **Yes** **No**

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If “yes” who has provided this material?

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34. Does your service provide any material or patient information specifically aimed at Maori or Pacific people? **Yes** **No**

If “yes” what was the origin of the material (for example was it developed within the service or perhaps sourced from outside; if so where from)?

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35. Does your service have access to Brain Injury Association liaison officers or Head Injury Society field workers? **Yes** **No**

36. Does your service routinely involve Brain Injury Association liaison officers or Head Injury Society field workers?

- while TBI rehabilitation services are being provided **Yes** **No**
- at or after discharge from your service **Yes** **No**

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37. Within the limits of resources available do you think people in your region get a good deal from rehabilitation services? **Yes** **No**

*(Please expand on your answer)*

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38. What gaps exist for people with TBI in your region? (for example accessing care or services due to transport difficulties; no facilities for minimum dependency residential care; poor access to particular service types etc)

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39. While a providing a perfect TBI rehabilitation service may not always be possible, we are very interested to hear any particular barriers to care your service has identified. Suggestions for overcoming the barriers would also be extremely useful.

Barrier to care	Suggestion for improvement

If there are barriers to care which **previously** existed but which your service successfully **overcame** this information would also be valuable:

Previous barrier to care	Solution Applied

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40. Please comment on the following statement:

“It would be in the best interests of people with severe TBI to have one or two specialist facilities for managing TBI in New Zealand, similar to that which exists for spinal cord injury clients”.

**Agree / Disagree**

*(Please give reasons)*

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**Thank you very much for taking part in this survey. If there is any other information you could contribute that has not been covered by this questionnaire please feel free to do so.**

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**Survey of TBI Rehabilitation Service Providers in New Zealand (non-residential services version)**

The New Zealand Guidelines Group is currently developing guidelines for management of Traumatic Brain Injury (TBI). Part of that process is a review of current practice by providers of TBI services throughout New Zealand. Please complete the following questionnaire and return it in the stamped self-addressed envelope provided. By doing so your TBI rehabilitation service will be contributing significant information to the guideline development process. Provider names will not be identified in any material produced from this review and ACC will have no access to provider-specific information. Responses will be grouped to avoid identification of providers.

If you wish to contribute to the consultation process for the TBI guideline, with or without completing this questionnaire, please tick the appropriate box at the bottom of this page.

Please note that this particular questionnaire is aimed at **non-residential service providers** whose clients have returned to (or never left) the community following a mild, moderate or severe TBI. We have sent a slightly different questionnaire to providers of **residential TBI services**. If you have specific questions regarding completion of this survey please contact Julie Myers on ...

**Contact details:**

Name of the Rehabilitation service:.....

Name of the person completing this questionnaire:.....

Job title of the person completing this questionnaire:.....

Address:.....

Telephone:.....

Email:.....

**Please indicate by ticking the box if you would like to be involved in the consultation process for the new TBI guidelines .....O**

**If your service HAS NOT managed at least three people in the last year or ten people in the last five years with TBI, please just tick the box and return the questionnaire in the envelope provided .....O**

# Traumatic Brain Injury (TBI) Rehabilitation Services

## Provider Survey

1. Is your TBI rehabilitation service predominantly:

- |                                     |   |
|-------------------------------------|---|
| An assessment service only          | ρ |
| An assessment and treatment service | ρ |
| A vocational rehabilitation service | ρ |
| Other ( <i>please describe</i> )    |   |
- 
- 

2. Thinking back over the **last 12 months** how many people with TBI were seen by your service? \_\_\_\_\_

And of these people with TBI seen by your service over the last 12 months please estimate the percentage who had originally sustained a:

- Mild TBI (defined here as Glasgow Coma score 13-15 at initial assessment) .....%
- Moderate TBI (defined here as GCS 9-12 at initial assessment) .....%
- Severe TBI (defined here as GCS <9 at initial assessment) .....%

And what proportion were:

- Less than 18 years of age .....%
- More than 65 years of age .....%
- Maori .....%
- Pacific people .....%
- Asian .....%

3. Where is your TBI rehabilitation service usually provided?

Hospital outpatient department	ρ
Private facility based in the community	ρ
Client workplace	ρ
Client home or place of residence	ρ
Other ( <i>please describe</i> )	

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4. Does your TBI rehabilitation service provide or have access to specialist services for the following groups

- |  |            |           |
|--|------------|-----------|
| • People who are less than 18 years of age         | <b>Yes</b> | <b>No</b> |
| • People who are over 65 years of age              | <b>Yes</b> | <b>No</b> |
| • People who are Maori                             | <b>Yes</b> | <b>No</b> |
| • Pacific peoples                                  | <b>Yes</b> | <b>No</b> |
| • Other specific ethnic groups                     | <b>Yes</b> | <b>No</b> |
| • People with co-existing mental health conditions | <b>Yes</b> | <b>No</b> |
| • People with drug or alcohol dependency           | <b>Yes</b> | <b>No</b> |

(*Any comments*)

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5. What are the main criteria your TBI rehabilitation service has for accepting referrals?

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6. Does your service accept referrals from people with TBI who also have

- |                      |            |           |
|----------------------|------------|-----------|
| • Alcohol dependency | <b>Yes</b> | <b>No</b> |
| • Drug dependency    | <b>Yes</b> | <b>No</b> |

- Mental health conditions **Yes** **No**

7. Referring to the overall **rehabilitation** case-mix for your service, please indicate the proportions for each condition

- TBI rehabilitation .....%
- Non-TBI rehabilitation .....%

8. IN GENERAL, what is the time from receiving a referral to when you are able to provide rehabilitation services or support for your clients

- No waiting time ρ
- Between two and seven days ρ
- Between one and three weeks ρ
- More than three weeks ρ

9. If you are not able to see clients as soon as the referral is received what are the reasons for this? (*Tick as many as apply*)

	<b>Main reason</b>	<b>Other reasons</b>
The time indicated above is our target response time	ρ	ρ
There is a waiting list	ρ	ρ
Waiting to receive approval from ACC	ρ	ρ
Low priority referral	ρ	ρ
Shortage of appropriately trained staff	ρ	ρ
Other ( <i>please give details</i> )		

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10. What percentage of your referrals come from:

- Acute hospital inpatient services .....%

- Other TBI rehabilitation services .....%
- Other general rehabilitation services .....%
- General practitioners .....%
- ACC case managers .....%
- Other (*Please provide a brief description*) \_\_\_\_\_  
\_\_\_\_\_

11. In terms of assessing prognosis and/or developing care plans, what **information** does your TBI rehabilitation service collect on a **routine basis** (*please tick all which apply*). NB: Please also note **how** this information is collected (for example by the taking of patient history, using GCS or PTA, using the FIM or BDI etc)

Pre-morbid functional status  $\rho$   
(method or measure used) \_\_\_\_\_

Current functional status  $\rho$   
(method or measure used) \_\_\_\_\_

Severity of TBI  $\rho$   
(method or measure used) \_\_\_\_\_

Prior TBI  $\rho$   
(method or measure used) \_\_\_\_\_

Mental health condition  $\rho$   
(method or measure used) \_\_\_\_\_

Prior drug use  $\rho$   
(method or measure used) \_\_\_\_\_

Family situation and supports  $\rho$



14. Is your service able to provide (or does it have access to) adequate services from health professionals to meet the current needs of your clients? *(Please circle one answer for each profession)*

<b>Medical</b>	<i>Never</i>	<i>Hardly Ever</i>	<i>Often</i>	<i>Usually</i>	<i>Always</i>	<i>N/A</i>
<b>Neurology</b>	<i>Never</i>	<i>Hardly Ever</i>	<i>Often</i>	<i>Usually</i>	<i>Always</i>	<i>N/A</i>
<b>Nursing</b>	<i>Never</i>	<i>Hardly Ever</i>	<i>Often</i>	<i>Usually</i>	<i>Always</i>	<i>N/A</i>
<b>Physiotherapy</b>	<i>Never</i>	<i>Hardly Ever</i>	<i>Often</i>	<i>Usually</i>	<i>Always</i>	<i>N/A</i>
<b>Occupational therapy</b>	<i>Never</i>	<i>Hardly Ever</i>	<i>Often</i>	<i>Usually</i>	<i>Always</i>	<i>N/A</i>
<b>Speech-language therapy</b>	<i>Never</i>	<i>Hardly Ever</i>	<i>Often</i>	<i>Usually</i>	<i>Always</i>	<i>N/A</i>
<b>Psychology</b>	<i>Never</i>	<i>Hardly Ever</i>	<i>Often</i>	<i>Usually</i>	<i>Always</i>	<i>N/A</i>
<b>Social work</b>	<i>Never</i>	<i>Hardly Ever</i>	<i>Often</i>	<i>Usually</i>	<i>Always</i>	<i>N/A</i>
<b>Other</b> <i>(specify)</i> _____	<i>Never</i>	<i>Hardly Ever</i>	<i>Often</i>	<i>Usually</i>	<i>Always</i>	<i>N/A</i>

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14. In your TBI rehabilitation service are there health professionals with whom most clients work? **Yes No**

If “yes” which health professionals are in this core team?

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15. Thinking about Maori and Pacific clients, does your service have:

- Staff with an appropriate ethnic background **Yes No**
- Staff with special training (cultural) **Yes No**
- Access to appropriate outside staff (for example from Maori or Pacific health units) **Yes No**

16. What intervention does your service provide that you think makes the most difference to outcome?

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17. Does your TBI rehabilitation service routinely have:

- |  |            |           |
|--|------------|-----------|
| • Regular education sessions for patients and families         | <b>Yes</b> | <b>No</b> |
| • Written information for patients and families                | <b>Yes</b> | <b>No</b> |
| • Regular education sessions for staff                         | <b>Yes</b> | <b>No</b> |
| • Opportunities for collaboration with other service providers | <b>Yes</b> | <b>No</b> |

If “yes” who develops the information or education? For example is it developed within the service, or perhaps sourced from outside (if so where from)?

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18. Does your service have or routinely use any **formal** discharge criteria?

**Yes**                      **No**

(If “yes” what are they, for example are they time limited, function limited, other limitations?)

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19. After discharge from your TBI rehabilitation service:

- |  |            |           |
|--|------------|-----------|
| • Does your service routinely review all patients? | <b>Yes</b> | <b>No</b> |
|--|------------|-----------|

If “yes”, when does this generally occur? (and how often?) \_\_\_\_\_

- Does your service provide any other follow-up services? **Yes** **No**

If “yes”, what are these services? \_\_\_\_\_

- Can GP’s request review? **Yes** **No**
- Are patients or their families able to self-refer for review? **Yes** **No**

If you answered “no” to all three ‘review’ questions (i.e. reviews not provided routinely, at GP request or at family/self request), in what circumstances might patients be reviewed by your service?

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20. Please describe the level of support your TBI rehabilitation service receives from ACC in constructing and implementing care plans

- Very helpful  $\rho$
- Helpful  $\rho$
- Unhelpful  $\rho$
- Very unhelpful  $\rho$

*(It would be useful if you are able to expand in more detail on the answer provided above)* \_\_\_\_\_

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21. Does your service routinely collect information on patients treated and/or their outcomes?

For example

- Discharge ADL **Yes** **No**
- Vocational status **Yes** **No**
- Residential status **Yes** **No**
- Standardised measures (*please specify*) **Yes** **No**

- 
- Other (*please describe*)
- 
- 

22. Does your service use patient information provided by patient support groups such as the Brain Injury Association of New Zealand Incorporated, the Head Injury Society of New Zealand, or overseas organisations? **Yes** **No**

23. Does your service provide any material or patient information specifically aimed at Maori or Pacific Peoples? **Yes** **No**

If “yes” what was the origin of the material (for example was it developed within the service or perhaps sourced from outside; if so where from?)

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24. Does your service have access to Brain Injury Association liaison officers or Head Injury Society field workers? **Yes** **No**

25. Within the limits of resources available do you think people in your region get a good deal from rehabilitation services? **Yes** **No**

(*Please expand on your answer*)

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26. What gaps exist for people with TBI in your region? (For example lack of supported return to work, access to psychological support, family therapy or other particular services, etc)

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27. While providing a perfect TBI rehabilitation service may not always be possible, we are very interested to hear any particular barriers to care your service has identified. Suggestions for overcoming the barriers would also be extremely useful.

Barrier to care	Suggestion for improvement

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If there are barriers to care which **previously** existed but which your service successfully **overcame** this information would also be valuable:

Previous barrier to care	Solution Applied

28. Finally, please comment on the following statement:

“It would be in the best interests of people with severe TBI to have one or two specialist facilities for managing severe TBI in New Zealand, similar to that which exists for spinal cord injury”.

**Agree / Disagree** (*please give reasons*)

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**Thank you very much for taking part in this survey. If there is any other information you could contribute that has not been covered by this questionnaire please feel free to do so.**

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**Appendix B: Ethics committee approval for consumer survey**

Provided as hard copy only for ACC and New Zealand Guideline Group