



Traumatic Brain Injury in Adults

Stakeholder Findings Report

A report on the experiences and knowledge of stakeholders across the continuum of care

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Your time, experiences and knowledge is much appreciated and has ensured depth to this findings report, which in turn will inform the development of an ACC National Strategy for people with a Traumatic Brain Injury (TBI).

Executive summary

Objectives

The objective was to explore with stakeholders, across the continuum of care for Traumatic Brain Injury (TBI), their knowledge and experiences of TBI services in terms of what is working well, what is not working so well and how things could be improved for the future.

The goal is to improve outcomes for people with TBI and their families / whanau, by improving access to high quality appropriate services.

The findings will inform a national evidence based strategy on TBI services for adults. This findings report is not the view of ACC, rather it is a summary of stakeholder themes.

Stakeholders

Stakeholders valued the opportunity to have their views heard and that there would be a second chance for input before a strategy was confirmed by ACC.

Stakeholders included family / whanau of people with TBI, service providers, health and rehabilitation professionals, researchers, recognised experts in the field, advocacy and support agencies and ACC staff. In total 164 stakeholders had input, with 57 of those responding on behalf of a group or organisation, so reflected wider input. Client research was undertaken by another organisation. Their report along with seven ACC led research reports, are all available on ACC's website www.acc.co.nz/for-providers/clinical-best-practice. Results from this research are referred to throughout this document where common themes/feedback has been identified.

Findings

Similar themes between stakeholders

Overwhelmingly the themes were the same from all groups of stakeholders (and in turn these were supported by the evidence reports and the client interview report).

There is no one example of where the entire system works well or

- No experience where the whole system works well
- Acute phase working best

Key Themes when things are working well

- Timeliness
- Knowledge of TBI
- Involvement of family
- Meaningful activities
- Communication
- Coordination

consistently. Stakeholders could recount episodes when parts of the system had worked well, but equally they were countered by examples of when it had not. This was more so for the post acute phase of rehabilitation and community integration than the acute phase which overall, although had room for improvement, stakeholders reported works reasonably well.

Timeliness

- Fast response in acute and early multi disciplinary rehabilitation, with rehabilitation starting in the acute phase
- Early start of (rehabilitation) supports at every phase and no delays at transition points

Knowledge of TBI

- Skilled experienced staff and teams in TBI, both within ACC and with providers
- People who listened and respected the person or their family/whānau opinion

Involvement of family/whānau

- Clear communication and early information to clients and family/whānau
- Family/whānau being involved and supported in their own right

Meaningful rehabilitation / activities

- Reduce or prevent social isolation issues in the community by providing day programmes and support options, therefore reducing the incidence of depression and increasing rehabilitation outcomes
- Flexible and innovative supports
- Meaningful (to the person) rehabilitation goals and day time activities; being active
- Structured routine
- Understanding of the impacts of fatigue and loss of executive function

What doesn't work so well

- Poor knowledge of TBI and implications
- ACC focus on the the short term clients not in NSIS
- Information and support – both for the person and their family

Communication and coordination

- Clear transparent communication
- Coordination / liaison person between all parties, who are skilled in TBI

Poor knowledge of TBI

- Generally a lack of awareness and knowledge of TBI e.g. in a range of providers, in some parts of ACC and in the community. Some reported that at times TBI is being missed for diagnosis, due to this or a focus on the injury that can be “seen”
- Providers may be generic, working with people with a range of injuries and / or illnesses, and don't always have TBI specific information or expertise

ACC focus and systems

- Naturally ACC's overall focus is on the short term nature of the majority of their clients. However at times this is an issue for those with longer term needs if they aren't registered on the national serious injury case load (NSIS)
- Key performance indicators for staff can constrain staff when working with clients who may have medium to longer term needs
- Clients and families not feeling listened to therefore rehabilitation goals or processes don't meet their needs
- Lack of flexibility or innovation in some instances
- Perception that at times ACC withdraws supports and compensation, based on set timeframes, not outcomes or rehabilitation progress
- Service contracts not being flexible enough to meet the needs of this group; limited time frames and type of services
- High number of changes of case managers (both from internal movement and turnover)

Information and support

- Lack of support and information for clients and family/whānau, at the right time and in an accessible language
- Lack of support for family/whānau in their own right
- Difficult transition points and delays (can be months) with rehabilitation services being put in place in the community, compromising outcomes
- Conflicting messages for clients and families
- Lack of coordination between services and multiple assessments being required
- Data gaps impacting on ability to benchmark and measure outcomes

Themes for the Future

Overall it was believed that if the issues in what doesn't work well can be addressed, then that is what is needed for the future. In summary this is:

- TBI training
- Change some of the ACC focus to concentrate on longer term clients not in NSIS
- Increase service quality
- Improve transitions
- Build relationships
- Timely information
- Support family / whānau
- Raise awareness of TBI
- Improve data
- Foster research
- Use technology

- Train ACC staff who work with people with TBI, in TBI
- ACC to recognise the medium to long term nature of recovery from TBI including acknowledging and supporting slower return to work processes
- Higher quality and TBI expert services
- Planned and effective service transitions, preferably with a coordination / mentor / broker person to assist through transitions and difficult patches
- Positive and supportive relationships, building trust between parties
- Better and timely information provided to the client and their family / whānau
- Have meaningful (to the person with TBI) rehabilitation goals and activities
- Recognise and support the needs of the family/whānau
- Raise awareness in general of TBI
- Improve data and foster applied research
- Use technology more widely and innovatively e.g. tele-rehabilitation

1 Background and Objectives

1.1 Objectives of a strategy

- Improve outcomes
- Gather inputs
- Wide range of stakeholders
- What should the future look like

The objective was to explore with stakeholders, across the continuum of care for Traumatic Brain Injury (TBI), their knowledge and experiences of TBI services in terms of what is working well, what is not working so well and how things could be improved for the future.

The goal is to improve outcomes for people with TBI and their families / whanau, by improving access to high quality appropriate services.

In 2011 ACC commissioned a project to start to develop a national strategy for adults with a TBI¹.

This report is a findings report that will input to the strategy development. The phase of information gathering for this findings report ran from June 2011 to March 2012.

The purpose for the project was to look at the continuum of services and supports for TBI in New Zealand and to assist with developing the first strategy to guide and inform future ACC service design, procurement, service development and measurement of moderate to severe TBI services and outcomes. The strategy will be evidence based.

1.2 NZ Guideline

There is a 2006 New Zealand evidence-based best practice guideline² for acute management, diagnosis, and rehabilitation of TBI. The guideline identified gaps in knowledge of the incidence of TBI in New Zealand; gaps between what services currently provide and the complex needs of TBI clients (treatment of alcohol and drug, mental health issues; cultural needs); and the lack of a uniform approach to standardised assessment and outcome measures. The guideline also noted the lack of specialisation of TBI services in New Zealand, and proposed that (while noting the lack of strong evidence for this proposal) creation of one or more TBI centres for acute care and early rehabilitation could improve outcomes.

¹ Age 16 years and over. Children were excluded due to different pathways and workforces.

² Evidence-based Best Practice Guideline (2006). Traumatic Brain Injury: Diagnosis, Acute Management, and Rehabilitation. New Zealand Guidelines Group, Wellington.

ACC is committed to taking a system wide approach to developing a national strategy for TBI to address some of the guideline’s points with the express desire to inform service design and how it purchases services.

2 Methodology

2.1 Stakeholders

- 8 groups of stakeholders
- 164 people had input

The following stakeholder groups were identified to participate in the interviews :

1. Family/whānau³ of people with a TBI
2. Service providers, across the continuum (i.e. from retrieval and acute through to long term rehabilitation and social supports)
3. Academic researchers in the field of TBI
4. Representative bodies (such as nursing, general practice, allied health - including social work)
5. ACC staff (including branch, the return to independence service, the national serious injury service and corporate based staff)
6. TBI advocacy and support groups (such as the Brain Injury Association and the Head Injury Society)
7. NGOs (e.g. representing people who are deaf or have optical needs, due to a TBI)
8. Government agencies (the Ministry of Social Development and the Ministry of Health as funders of services for people with TBI or their family/whānau).

In total 164 stakeholders had input. Table 1 shows an overall summary by stakeholder group.

Table 1 Stakeholder Interviews Numbers

	Number	%
Family Interviews	33	21%
ACC Staff	50	31%
Health Professionals / Orgs	57	35%

Researchers	3	2%
Maori Specific	3	2%
Email responses	14	9%
Totals	164	100%

57 of those responded on behalf of a group or organisation, so reflected wider input.

Of the email responses two were family/whānau and the rest health / rehabilitation professionals or organisations.

2.2 Stakeholder Selection

Family/Whānau of people with a TBI

- Agencies assisted with family / whānau selection
- ACC staff at branch and national levels
- Provider stakeholders across the continuum
- Focus groups and in depth interviews

The Brain Injury Association (BIA) or the Head Injury Society (HIS) were approached in the geographic regions chosen for the study, to seek their assistance for recruiting family/whānau. They willingly assisted and also acted as a host agency for the meetings (venue, tea and coffee, and introductions).

The agencies were given a list of criteria of the potential mix of family/whānau being sought. This included age, ethnicity, length of time from injury, rural and urban and varying family/whānau relationships to the person with the TBI (e.g. spouse, parent, sibling etc).

With this approach there could have been a perception of selection bias. However, families interviewed had a range of experiences similar to each other, and this was believed to minimize any selection bias.

In addition a few family names were identified via the client focus group letters that ACC sent out. These names were passed on to the interviewer.

Originally a focus group approach was chosen for the interviews, however due to a limited availability of people several one to one in-depth interviews (face to face or telephone) were also conducted. Focus groups were held mainly in the premises of the associations for the purpose of having a neutral (non ACC)

location. For others, a venue agreeable to them was chosen (e.g. a local café).

Family/whānau were offered a choice of a \$30 grocery or petrol voucher to thank them for their time and input.

ACC staff

Interviews were held with ACC National Serious Injury Service staff, Return to Independence Service staff and Branch staff, the majority of them being in focus groups. There was one group teleconference and one individual interview.

Branch meetings incorporated a mix of branch staff, return to independence service and serious injury staff. There was a mix of case managers, service coordinators, team leaders, branch advisors and national managers. One focus group included the branch manager.

The locations were:

Southland Otago Canterbury Wellington Waikato Auckland, and
Northland

Other stakeholders

To identify who within the stakeholder groups should be approached, initially individual names or specific organisations were canvassed via key personnel within ACC. As the project progressed additional names were identified via the interviews themselves. Consideration was also given to geographic locations to focus on rural and urban mix, south and north islands and the location of key acute and residential rehabilitation providers. The locations were the same as for the ACC staff interviews.

The majority of these stakeholders were interviewed in face to face meetings. Where this was not possible, telephone or one to one in-depth interviews occurred.

The representative bodies approached canvassed their members themselves, and provided feedback mainly via email and telephone interviews.

2.3 Analysis and report writing

In every interview the interviewer took notes. Analysis involved summarising the inputs and distilling them into themes.

This report is a record of that analysis.

A selection of interviewee quotes have been included to illustrate the common themes that were expressed.

2.4 Disclaimer

This findings report is a summary of what the interviewees reported. There has been no additional testing to ensure accuracy levels. However there were many common themes and a lot of congruence in what was reported, so it could be concluded that this report summarises the situation well for people with TBI and TBI services in New Zealand.

Where stakeholder statements or themes are supported by evidence, this is noted.

This review was at a strategic level for the express purpose of developing a Strategy for TBI services in New Zealand. It was not a clinical audit; therefore no formal evaluation of the quality of clinical practice has been made.

3 Findings from stakeholder interviews

3.1 Introduction

There was an overwhelming consensus of themes for both what is working well, not so well and what might be a priority for future change or development.

The findings are presented in three parts:

1. Overview
2. Specific parts of the continuum
3. Common themes

The findings reported in Part One: Overview are representative of all stakeholder groups. Part Two shows where separate stakeholder groups have reflected any differences. Part Three is additional overarching themes, or topics, that emerged across the whole system or several parts of the system.

Part One: Overview

- Variety of experiences
- Variety of reasons why experiences are different
- Delays at transition an issue
- Being “cut off” from ACC an issue
- Lack of TBI knowledge meant lack of understanding

It wasn't till the wheels were falling off that I went to the doctor and eventually they diagnosed that I had a brain injury from ages ago

This section provides a brief synopsis of what was reported to be working well, or not, and why. Further sections go in to more detail about each of these points.

There were widely varying reports of what aspects of the overall continuum, or system, worked well or not. It was evident that stakeholder perceptions were influenced by a variety of individual factors, ranging from:

- client and family/whānau own mental/coping state at the time
- how much people felt they were listened to
- the quality, type and timeliness of information
- the extent of TBI specific knowledge both within ACC and in providers
- whether the TBI was diagnosed early or at a later stage, e.g. months or years later when things were going awry
- the amount and timeliness of support and / or counselling for family/whānau members
- perceived gaps, or not, in services, especially related to services once the client was back in the community
- perceived delays in community supports being set up post transition from inpatient residential rehabilitation
- whether people with a TBI, or their family/whānau, felt they had been “cut off” from services or ACC without the ability to return if things in their lives changed
- the way ACC worked (systems, processes, information, compensation)
- variation in ACC case manager skill and the perceived lack in their specific TBI expertise; the manner in which they worked such as attitude towards the client and their family/whānau and ability to be flexible and innovative with supports and solutions
- the high turnover or changes in case managers

3.2 Factors that make it work well

- TBI knowledge and expertise
- People being listened to
- People being seen in their own context
- Early intervention
- Family/whānau involvement
- Accessible information
- Planned transitions
- Coordination

They opened their ears and listened to us as a whanau

Overall there was high consensus of when things do work well and why that is.

These findings are consistent with the international literature about what is required to achieve good outcomes for people with TBI.

The most reported categories were (in no particular order as they are all important):

- early identification, assessment, treatment and rehabilitation
- TBI specific expertise in the right place (for both ACC and providers)
- individual ACC case managers having the TBI knowledge and experience (e.g. “life experience”, being a parent themselves, ability to ask difficult questions)
- being listened to and being able to talk about the issues with someone who understands
- motivation and support to structure the day for the client
- fatigue management strategies
- understanding of the impact of fatigue
- support to find and remain in work
- effective rehabilitation that is based on activities that matter to the person and their family/whānau including meaningful day activities and reduction or prevention of social isolation
- family/whānau involvement from the start
- accessible information early and ongoing, for the person and their significant others (e.g. family/whānau, friends, employers)
- a non linear approach where people or their family/whānau can seek further rehabilitation or assessment input later; and / or a defined period for “recall” is set so gains can be monitored and maintained
- an experienced person to help coordinate across services and supports and that has the ability to “make things happen”
- planned for and smooth transitions, including a multi discipline approach

When asked what were the top distinguishing features of a good or effective

service the common denominator was that the person and their family/whānau were listened to, their own context was considered and they were all part of the planning and rehabilitation.

Outcome measurements for people with TBI linked to services and perceptions of what worked well or not, are not currently undertaken. Therefore there was no ability to consider the factors reported to make things work well, and their impact on actual outcomes.

3.3 Not working so well

❖ Summary

- ➔ Directly converse of working well factors
- ➔ Information gaps for GPs, intensive care and orthopaedic staff
- ➔ Missed diagnosis

Where stakeholders reported things were not working so well, the examples and reasons were mostly the direct converse of the reported factors that do make it work well.

In terms of early detection and TBI information, the other specific gaps repeatedly mentioned were information and support for general practitioners (GPs) and for intensive care and orthopaedic staff.

GPs often see people who may have not been diagnosed with a brain injury, or who have been discharged, but then later things go wrong. Fatigue may still be an issue for people and they don't know why.

The broken bone is fixed but no one thinks to look at other potential issues from a major trauma event. Compulsory screening for TBI post a significant or major trauma event should be in place

3.4 ACC specific issues

❖ Lack of TBI knowledge or expertise especially in the branches

- ➔ Level of TBI knowledge
- ➔ Knowledge gaps impact on decisions and services
- ➔ Organisational systems could be better to support staff in TBI
- ➔ Quality and type of services available
- ➔ Perceived profiling delays

Although there were some exceptions, concerns were expressed about some ACC internal systems, processes and levels of individual expertise around TBI.

Examples where improvements could be made included:

- understanding the difference between TBI and a head injury
- increased TBI knowledge in turn improving staff confidence and outcomes in working with people with TBI, and their family/whānau
- knowing how to recognise a good neuropsychological report and how to interpret and use these and other forms of assessment reports, leading to fewer requests for repeated reports
- understanding the impact and nature of TBI fatigue and loss of executive function, and how long this can be an issue
- understanding the importance of planned and often slow return to work, or other activity
- allocating case managers in region so communication can be in person where that is the most appropriate option for the person with TBI

We are measured on getting people off the books

Back to work for more than 30 hours or more a week is what we are measured on

They (that is, ACC) just want to get us off their books

Why do providers who only know about mental health or intellectual disability (supported living) get contracts to work with people with TBI? They know

❖ Internal Incentives

It was commonly perceived by all groups of stakeholders that a barrier to good practice and outcomes for people with TBI was the internal incentives and key performance indicators for ACC front line staff.

For example people reported being measured for getting “people off the books”.

❖ NSIS Profiling and Contact Centre Delays

Concerns were expressed with the ACC NSIS profiling process and criteria, however once these were tested the delays were not as great as perceived.

E.g. the actual average profiling timeframe was 48 calendar days (6.8 weeks) for severe TBI and 43 calendar days (6.1 weeks) for moderate TBI. The range was 22 days (2 weeks) to 63 days (9 weeks).

The fact that ACC uses different moderate and severe TBI criteria than the

nothing about TBI and no one monitors this or measures them on the quality of their work. We don't refer to them unless we have no other option

We have many OTs who we refer to who have no expertise in TBI. We need fewer but specialist staff to get good outcomes for clients and us

World Health Organisation was a concern for some, as they felt some people who should be profiled into the NSIS are not and therefore cannot get access to the services that would support them the best⁴.

❖ Quality of Services

Stakeholders queried the level of TBI expertise in some providers and what service specifications they might be working to. Internal ACC staff also noted that procurement services do not treat them like internal customers and that they should ask them what services they want and who are good providers.

Many staff reported not referring to providers who they don't believe provide a good service, as evidenced by previous client outcomes and feedback.

➔ Conclusion

All stakeholders agreed that the presence and combination of any one or more of the above issues led to poorer outcomes for the person and often their family/whānau also. This in turn may impact on outcomes and liability from ACC's perspective.

Many stakeholders agree with the proposition that taken together these issues represent an organisational and cultural challenge for ACC. This is particularly so for the longer term claims who are not profiled as NSIS but who will potentially not meet the recovery target that apply to the majority of non TBI clients.

There may be better ways to manage meaningful engagement and outcomes for these clients.

3.5 Support agencies

❖ The Brain Injury Association (BIA), the Head Injury Association (HIA), Stewart Centre, Challenge Trust and Dunedin Training Centre

Clients and family/whānau praised the work, information and services the support agencies provided. Many reported these agencies provide help with meaningful day activities and support groups to prevent isolation along with assistance to help them find other supports and receive valuable information and advice. The evidence shows a reduction in social isolation leads to better outcomes and less risk of depression and suicide.

- ➔ Clients and families strong on the value of support agencies
- ➔ Variable other

stakeholder views on value of support agencies

- Research strong on importance of support groups reducing isolation

Some ACC staff in the NSIS found the BIA and HIS a very useful resource for their clients.

The only social functions I go to now are with the HIS, as people understand me. I don't have to worry about blurting out something odd

3.6 Family / whānau feedback

- Variation in what works well
- What works well is dependent on the ACC case manager – case managers are key
- Listen to us!
- Understanding TBI behaviours important
- Support and information for the family
- More TBI knowledge needed - everywhere
- Reduce social isolation
- Plan for the future

❖ Summary

Family members who participated included spouses, parents, siblings, one friend and one grandparent. They reported being willing to participate as they wanted to tell their story and hoped it would help make the system better for others in the future.

The majority of families interviewed reported that at different times, different parts of the system had worked well. Only one family reported that nothing had ever gone well from the time of the injury, including the need to have multiple assessments on an ongoing basis.

Many felt whether things worked well, or not, was completely dependent on the ACC case manager they had at the time. Also when people understood TBI related behaviours that helped a lot. Knowing where to refer to and offering support to the family/whānau is also very important.

One family reported that the residential rehabilitation provider was very good at giving them information and knowing where they were up to as a family/whānau.

❖ Support and information for clients and family/whānau themselves

Very few family/whānau had been offered support themselves (e.g. two family/whānau had been offered counselling), even though the majority

ACC has funded a person to work with him, just for a few hours a week but it has made all the difference. For the first time in 10 years we are happy with how things are

ACC spent a lot of energy supporting the employer. Now he is back at work full time

They (the rehabilitation provider) pushed us so we could learn too and know what to expect. It was so necessary. They knew more than us of course about what we could expect when we all went home

We would have liked information on TBI, what to expect, entitlements, support groups and how to deal with our son with TBI

That OT, she just created dependency because she didn't understand (TBI). We had to fight to

thought it would have been very useful either for them and / or others in the family/whānau e.g. the children.

They all believed they didn't get enough of the right information early enough.

A few ACC staff said they refer couples who may be having difficulties to the national relationship counselling service, i.e. Relationships Aotearoa.

❖ **Services for the person with TBI**

There was a mixture of feedback on whether the services and supports, were sufficient or not, and not one person reported that all supports and services were good.

Examples of what was working well or not reinforced there is a lack of TBI expertise and knowledge across the sector.

❖ **Social isolation**

Social isolation and the level of vulnerability with others taking advantage of them, was a significant issue for a lot of the family/whānau. One type of support that had worked well for some was when a support person could assist with planning, routines and accessing community based social activities.

Where social supports to prevent or reduce isolation were included all reported increased satisfaction for the person and the family/whānau member.

As already noted, reducing social isolation is reported by the evidence as improving long term outcomes.

❖ **Planning for the future with the family/whānau**

Family/whānau who are supporting their family/whānau member in an Family / whanau would like to see more planning for the future, with them and the person with a TBI.

Some older parents reported feeling afraid of what would happen to their dependent person if something happened to them (e.g. illness, death). They would like ACC to recognise this and help them contingency plan and plan for the future.

get her to let him go back to work

I can't last forever, I am over 70 now. What will happen to him when I am gone? Why can't we start planning with ACC now?

What is going to happen when mum and dad have passed on? They are getting older. Will I be left to pick up the pieces?..... It (the TBI) has ruined my life already. It has been [30 years of] hell

It was hard to know how to parent; suddenly their dad had behaviours we had to work with, yet they were not allowed to do. It has really confused them no matter what I told them

Our case manager is fantastic. She always returns calls and is there for us

The case managers change all the time. We have to go in to battle all over again

❖ Working with ACC

There were mixed views on how ACC works and questioning of what is ACC's true intent. Most felt like ACC just wanted them off the books and wanted rid of people who were difficult, for example those with TBI.

Some had previous or current experience with what they termed "good" case managers and some could recall "outstanding" case managers. They reported that a good case manager returns calls, is proactive and assists with meaningful rehabilitation activity and goals. Importantly, they listen well.

Overwhelmingly the turnover of case managers was an issue for people. Some felt that ACC just changes the case managers to stop them getting to know the person well and therefore wanting to help them.

Common examples given of working with case managers who weren't so good included that they don't return calls, they don't understand TBI and they don't take the time to really hear what the person is saying. Some reported feeling that the case managers were "hostile" or feeling like they had to "battle for everything".

❖ Future

The key changes clients and their family/whānau want to see for the future for improved service delivery and outcomes are:

- information, listening and communication at all levels
- better involvement and respect of the clients and family/whānau
- more training and general education in TBI for health professionals, ACC staff, themselves and the general public
- ability to meet face to face with the ACC case manager, e.g. not have a case manager in a different part of the country
- someone to help the person with a TBI and the family/whānau understand the system, provide continuity between different parts of the system and link them up with local services and supports, e.g. have a coordinator who is not ACC to assist with transition, information and seeking supports (some say the BIA or HIA are doing some of this already)
- better use of skilled multi disciplinary teams
- recognise this group as a long term claim group and don't treat them the same way as for short term, e.g. the three monthly need for medical certificates, reduce the number of unnecessary

Get quality assessments. The last assessor wrote "She can ride a bike"; well yes, 10 years ago she could but she can't now. Why did she write this? ACC then believes this and we have to battle again

assessments that don't change anything and increase the number of skilled assessors so when assessments are done they are useful for ACC and the person with a TBI

- recognise the family/whānau and fund support groups for family/whānau and separately for the people with TBI
- access to better quality independent assessments
- ACC to return calls and to listen so services can be tailored and flexible
- ACC to not terminate supports without notice or other supports being in place

3.7 Maori specific feedback

- Success and issues for Maori, same as for non Maori
- Key to listen and see people in their own context
- What supports do whanau need
- Build trust

Of the family/whānau interviewed only three proactively self identified as Maori.

Of the other stakeholders interviewed three were specifically targeted for their involvement and overview of issues for Maori, across a range of parts of the system and / or the size of the Maori population they support. Two are providers and one is a researcher.

As a general conclusion the successes and issues for Maori have some specific cultural requirements but also many of the same themes and needs as for non Maori.

The key thing is for people to be listened to and seen in their own context. One person noted that ACC should have a Maori strategy to guide their work.

ACC needs an internal ACC Maori Strategy to drive cultural understanding etc

Can't see the TBI or the person with the TBI as separate to the rest of the

❖ Cultural specific

- learn and understand culture specific aspects for that whānau (i.e. different iwi or whānau may have different needs, some however are basic – e.g. don't touch on the head)
- ACC and services need cultural competency driven by the whānau knowledge and needs
- understanding the meaning of wellbeing for Maori is holistic and all inclusive

❖ Same as for others

whānau

Look at the whānau goals alongside the person's goals (in relation to the TBI

Be values driven not dollars driven

- being client centered which means also whanau centered (i.e. listening, working in the context of that whanau, making rehabilitation goals meaningful to them). Take a partnership approach to overall “wellbeing”.
- Maori need to take control of their own development (i.e. whānau specific and rehabilitation goals meaningful to that whānau and situation)
- consider what supports the whānau might need (e.g. counselling, supports re information access)
- help people navigate their own communities to identify what supports (paid and non paid) are available (i.e. a coordination role that knows the local community well)
- build trust between all parties (i.e. open communication, listen with honesty, respect that particular whanau and their cultural desires)
- give information to the person and their whānau re TBI and what to expect, in language that they can understand (i.e. not in clinical based language, maybe in Maori)

Part Two: Specific parts of the continuum / system

3.8 Acute: Ambulance, emergency department, trauma services, ICU and acute wards

- Development of protocols and guidelines for ambulance and retrieval services
- National Trauma Network under establishment
- Data and quality of care both need to be improved
- Coordination of services is important

❖ Ambulance services

Ambulance services provide pre-hospital emergency care and include:

- land and air ambulance services
- emergency ambulance communications centre that:
 - receives and triages 111 calls
 - monitors availability of ambulance services
 - selects and dispatches appropriate services and
 - provides ongoing communication and support
- patient transfer services
- event or commercial services

There is no one national ambulance service. However all services are coordinated and dispatched by one communications service and all services work to one national service specification, standards, clinical guidelines and protocols.

The services are supported by a relatively new (2008) National Ambulance Support Office (NASO⁵) which is jointly funded by Health and ACC and sits in the National Health Board Structure in the Ministry of Health. The NASO coordinates funding from main agencies that fund ambulance services and they foster nationally consistent direction for New Zealand ambulance services. There is a 2008 national ambulance and paramedic strategy⁶.

There are three key types of organisations that make up national coverage:

1. St John's Ambulance – road transport everywhere except Wellington region
2. Wellington Free Ambulance
3. A variety of local community determined and led air ambulance services (i.e. Trust structures who fundraise for and own helicopters for emergency retrieval and other services e.g. search and rescue)

Ambulance services have about 4,000 people working for them nationally of

which 1,500 (38%) are paid and the rest, 2,500 (62%) are volunteers.

❖ Emergency department services

Emergency departments are located in public hospitals. Each department interfaces closely with ambulance services.

❖ Trauma centres / systems

Trauma systems cover road side care including transport and recovery, in hospital acute care and rehabilitation. Trauma services can be categorized in to four levels of service delivery. The highest level providers 24/7 care to the most complex patients and in New Zealand these are located at⁷:

- Auckland
- Hamilton
- Wellington
- Christchurch

The next level services are located at:

- Waitemata
- Counties Manakau
- Mid Central
- Dunedin

There is a national trauma network under establishment which will give New Zealand the opportunity and ability to have a more coordinated and quality based approach to trauma services. However the Ministry of Health noted this is at a very early stage. Also there are plans in the future to develop a national trauma guideline, protocols for retrieval transport and improve trauma data collection and usage.

❖ Intensive Care Unit (ICU) and acute wards

People with TBI may end up in ICU when the TBI is severe or there are multiple and severe injuries. The person with a TBI is typically discharged from ICU to an acute ward. They can also be transferred from an emergency department to an acute ward if appropriate.

Feedback across the services is summarised in the following table.

Table 2 Summary of Acute Services Feedback

Topic	Comments
1. Data	- Data collection and accuracy needs to be improved in order to allow for better knowledge

	<p>of what is occurring but also benchmarking, quality control and quality improvement</p> <ul style="list-style-type: none"> - Ambulance is trying to implement an electronic data collection and reporting system. This would allow for real time pre-information to ED and also photos of the scene for context and more information, with improved accuracy, as the system would have prompts and forced fields to populate. A current barrier to this is the cost but they are still planning to proceed. - Need to agree common data descriptions and codes
2. Quality of care	<ul style="list-style-type: none"> - Need highest quality of care from point of injury, including pre-hospital - Ambulance can have a person for hours before getting to hospital; what is best clinical practice for people with TBI? - Quality of outcomes needs to be measured; it is not currently - Practice is currently variable across the system; there needs to be more clinical leadership for an evidence based and quality approach - Paramedics in New Zealand have a range of levels of training and only a few have the highest level where intubation can be done. There is evidence to show that intubation when there is the presence of severe brain injury, is vital for good outcomes
3. National Trauma System	<ul style="list-style-type: none"> - Development of a national system is underway but not yet developed - This includes protocols, guidelines, networks etc where all 17 Trauma Clinical Directors have input
4. Ambulance	<ul style="list-style-type: none"> - New nationally agreed and consistent clinical “standing orders” for all ambulance service paramedics are being rolled out over 2011/2012 - Air ambulance “Dispatch and Request” guidelines are being introduced soon and will be available

	<p>for sector consultation in 2012 via NASO</p> <ul style="list-style-type: none"> - Also in 2012 a “clinical desk” model will be established in ambulance communication centres to provide experienced clinical advice and support for triage and dispatch decisions, as well as advice to personnel in the field - Ambulance services are training more paramedics to be able to do intubation as this can be a very important procedure for people with TBI
<p>5. Retrieval type: road or air?</p>	<ul style="list-style-type: none"> - Helicopters at times can take longer than road, depending on terrain, distance, ability to fly directly to a hospital or having additional land transfer as well - The air dispatch protocols that are in development will provide algorithms for determining whether air or road is the most appropriate option - Note that as helicopters are under the ownership of local Trusts, there is currently no ability to influence what type or size of helicopter is purchased. There are basically two groups of helicopters in New Zealand for emergency retrieval: <ol style="list-style-type: none"> 1. Those that are large enough to accommodate the patient and the paramedic team (who can move around the patient as required for assessment and treatment), separate the patient from the pilot (in case of behavioural issues etc) and allow for flying directly to hospitals (e.g. two engine helicopters are the only ones allowed to fly over built up areas) 2. Those that are smaller, one engine and don't allow for separation of patient from the pilot and don't allow for paramedics to move around the patient to access their head (i.e. they sit on the side) - There is no national “Destination Policy” to guide decisions on where to take the person. For example which hospital should be the destination hospital in which situation, and which hospitals to bypass, and why. E.g. bypass Rotorua in favour of

	<p>Waikato if x, y or z condition exists, or bypass Hutt and go to Wellington if x, y or z condition exists.</p> <ul style="list-style-type: none"> - Some regions e.g. Coromandel, do have local protocols. NASO is encouraging DHBs to develop regional destination policies - NASO is encouraging DHB's to develop regional destination policies
6. Coordination	<ul style="list-style-type: none"> - There used to be an ACC person based onsite at the hospital - This role assisted with ACC based data collection, systems and processes and speed things up as well as supporting people - Some stakeholders report that losing this role (approximately in the early 2000's) has increased the hospital based length of stay by up to 10 days for some people - The new trial Acute Rehabilitation Coordinator (ARC) in Auckland is reported to be having a very positive impact on early detection of TBI, information, support of family/whānau, relationship between ACC and the services, improved transition planning and transitions. All of this is believed to be reducing the length of stay in acute hospitals - Evidence supports reduced length of stay for improved outcomes for TBI and having coordination to support discharge planning and transition can speed things up

3.9 Inpatient and community based residential rehabilitation

❖ Overview

It was difficult to get an objective national view of what might be working well

- Early rehabilitation is vital
- Transition(s) between services is an issue
- No agreement on how many services to have
- Expert services are important

If we know who the ACC case manager is we will invite them to the discharge meeting, but often it is difficult to know who it is

If the service is experienced and knows what they are doing and they truly are client centered, which means listening to and working with whānau as well, then the whānau will feel comfortable with the service, no matter where it is located

or not, due to natural tensions between providers who may compete for contracts.

Services are currently located in Auckland, Wellington, Christchurch and Dunedin.

❖ Early rehabilitation

In line with the evidence all services agreed that early rehabilitation (i.e. while still in the acute setting), involving family/whānau, and using a multi disciplinary approach provides better medium to long term outcomes. This was also true for providing client centered services that based rehabilitation goals on what is important to the person with TBI and their family/whānau. Noting that, at times, these priorities might vary between the person and their family/whānau.

❖ Concerns

The greatest concerns were at times of transitions from their services. Issues were mainly around:

- lack of effective communication
- not being able to access the right services for the person
- variation in quality of ongoing supports and services
- relatively consistent concerns with gaps in vocational rehabilitation options post inpatient or residential rehabilitation
- not being able to get ACC or other providers involved early enough
- not being able to follow up or have ongoing outpatient clinics, as these are not in the contracts

They all offer the ability for discharged clients to telephone if they have concerns.

❖ Geographic location and number of residential rehabilitation services

One question posed by a limited number of stakeholders in the mid and upper

North Island, was how many residential rehabilitation services might be needed. Currently for example there is one in Auckland and people from the Waikato have to travel there.

There was no consensus about how to balance the need for a critical mass / volume to attract and retain experienced staff and build infrastructure, therefore an improved likelihood of better outcomes, versus the need for family/whānau to travel and the person to be out of their local community. Opinions varied from within and between services, family/whānau and researchers.

The most common response was that in the context of the New Zealand environment and relatively sparse population, that one service for the mid to far north is probably appropriate, especially when considering the need to attract and retain experienced staff and have an affordable and sustainable service.

Family/whānau in other parts of the country also have to travel, e.g. to Dunedin or Christchurch or Wellington, from quite wide catchments. The key response when they were asked about travel was that they preferred to receive a good expert service, but that they need more financial support up front from ACC for travel and accommodation when necessary.

3.10 Community rehabilitation and ongoing supports

For the purposes of this report community rehabilitation and ongoing supports are defined as all ongoing rehabilitation and supports in the community, post intensive interventions. These would typically last for the first six months or more, post injury. Note this includes vocational and return to work supports as well.

The people interviewed for this group all had the same concerns and ideas of what works well as reported earlier in this report. The only difference was there was some specific additional clinical input from specific groups about the need for:

- auditory screening for all people with a TBI
- optical screening for some people with a TBI
- the need for more TBI specific speech language therapy

3.11 General practice – primary care

Engagement from primary care was difficult to obtain. Those who did respond reported the need to have easy access to information on TBI and the pathway locally they can use, i.e. where to refer to.

There was no specific primary care nursing stakeholder input.

Part Three: Additional common themes

3.12 Coordination

❖ Overview

- ➔ Help with coordination of services is needed
- ➔ Coordination will improve transitions
- ➔ Inpatient and community both important
- ➔ Focus on relationships, knowledge and access

Support and help with coordination (facilitation, broker, case management are all other terms that have been used to describe coordination) across the continuum was a very strong theme both in the interviews and in the evidence. Through the interviews rationale, roles and functions as well as desired skill sets for a “coordinator” were tested.

For those who were familiar with the Acute Rehabilitation Coordinator (ARC) role (based in an inpatient setting in two areas where there is a trial currently running) they likened the need for a community based coordinator role to that. This role may not be required as much for NSIS clients as it was reported their case managers do some of the coordination role.

The coordination role appears similar to the previously trialed Post Acute Rehabilitation Coordinator (PARC) role. But it requires more role definition and clarity. ACC branch staff familiar with the previous PARC role reported that they were disappointed when the PARC role went, as they found it very useful. This was not the same for national serious injury staff.

Analysis of the feedback for coordination roles showed that there is a distinct and separate need for an inpatient role and a community based role.

One question posed to some stakeholders was, if up skilling of ACC staff in TBI was undertaken, would there still be such a need for the community coordination role? Most thought that it would reduce the need for everyone to have access to a coordinator, but that there is still a divide between the role of the ACC claims manager and a person who works in and knows the local community and what non ACC funded or social supports might be able to help the person or their family/whānau.

Some felt that what the serious injury case managers do now is part of what this role would do in the community and others felt it was what support agencies already do.

❖ Functions

The inpatient role would be to undertake what the ARC is doing now but with a greater focus on the family/ whānau:

- building relationships
- work across and with the various departments and wards, supporting early detection of TBI
- coordinate data collection and information
- improve quality of data collection and input
- work with the family/whānau to provide TBI specific information early
- assist with discharge planning and coordination
- link with the next stage of rehabilitation providers
- strong link with ACC case managers
- adds value to the hospital via being an additional resource on the multi disciplinary team

The community coordination / mentor role is seen as necessary to assist some people and their family/whānau with:

- building relationships
- ongoing information
- linking people up with social supports and non funded ACC services; i.e. knowing their community intimately
- to be an ongoing contact point if things start to go wrong, or a person's needs change
- a strong link with ACC case managers
- oversight of the continuum of rehabilitation over time and over various services or inputs

❖ Skill sets

For both inpatient and community roles it was seen that the core skill sets included:

- to be a senior person, for credibility with health professionals
- ability to build relationships and work across a range of organisations
- client centered – listen to and work with people and their family/whānau
- ability to problem solve, be innovative and have difficult conversations with a wide range of people

- have credibility in a range of settings
- know the local community
- skilled / knowledge in TBI
- ability to share information and educate people in TBI

In addition for the inpatient role a strong clinical background (e.g. nursing) was seen as important to help build the credibility and be able to work with the multi-disciplinary teams.

❖ Employer

Who should employ coordinators was also a question put to some stakeholders. All but one said the coordinator role needs to be independent of providers.

Some thought they could be employed by ACC and others didn't, due to the potential conflict between claims management and coordination and support. In summary, there was no consensus but impartiality was seen as important.

3.13 Outcome predictor factors

- ➔ Need better long term predictor tools
- ➔ Improve outcomes with most appropriate services and supports
- ➔ Pre and post injury factors can assist predictors

There was a lot of comment from all groups of stakeholders on how the current use of Glasgow Coma Scale (GCS) and Post Trauma Amnesia (PTA) are useful for immediate and short term predictor of need and outcome, but not for medium or longer term. The most common example given was a person with a GCS of say eight (or even lower) could fully recover or may not progress well at all.

When asked what people thought would be better predictors, there are a range of factors that should be taken in to consideration. This was informed by the published evidence. For example for those who are more likely to have poorer outcomes the predictors are at pre injury:

- lower socio economic backgrounds
- poor interpersonal skills
- having pre-existing conditions
- not so strong family/whānau supports and / or other social networks

Post injury a predictor for stronger rehabilitation outcomes is when the

person can be discharged back in to their pre injury home and continues to have strong family/whānau supports.

There was some input that there are better tools than the GCS and PTA. However upon enquiry it seems these are still in development and have not yet been validated, especially in the New Zealand context.

3.14 Data, benchmarking and monitoring

- Data is important for planning and quality control
- Need to improve the collection and robustness of data

There is general agreement from stakeholders that the data collected on TBI in New Zealand is not robust. The reported exception that the NSIS has been improving their data set over recent years. There were reports of inaccuracies and inconsistencies, including not having consistent data definitions so there is a lack of comparability and benchmarking possible.

It is agreed by the stakeholders, supported by evidence, that it is important to have a good data set to support planning, develop baselines, undertake benchmarking and for monitoring of services.

Having consistent data definitions and consistent collection processes was seen as important. As was “measuring the right things”. Other factors mentioned for improving data in the future were:

- have a long term approach
- invest in developing a web based “continuous client based” data system, where all information regarding the TBI is available on the system , including assessments etc, so the client doesn’t need to repeat their story. This would also mean providers may not have to repeat tests, if the results are available to them, meaning a more streamlined service for the client and a more cost effective system for ACC
- have a national database
- invest in ensuring accurate data input

3.15 Applied Research

Several people commented on the need for more applied research. This is in

- More applied research is needed
- Develop a TBI Research Agenda

line with the 2006 NZGG Guideline recommendations.

There is currently a large three year TBI research study underway in the Waikato, led by the University of Auckland⁸. This is not due to report till the end of 2012, however is likely to make recommendation on future research topics. It is looking at the frequency and type of head injury and how the head injury affects people and their family/whānau.

It would be useful to have a nationally focused TBI Research Agenda that lists priority topics for funding. This would need to be nationally coordinated by a joint ACC, stakeholder and academic group.

No specific applied research topics were given as a priority to invest in, during the interviews.

3.16 Service continuum and quality of services

- Quality of services is linked to outcomes
- Improving quality of services is seen as a priority by stakeholders
- ACC procurement practices can assist quality improvement

A significant number of stakeholders reported that at times there is a lack of the right range of services to refer to or a lack of TBI expertise in the services, and with some ACC Branch advisors.

Quality of services and the delivery of outcomes is linked to how providers are delivering to the contract they have with ACC and the levels of expertise they have. Currently there is little to no monitoring of outcomes (e.g. benchmarking) or accountability to the contracts. Stakeholders felt this should improve as a priority, across the continuum of services.

It was reported that there needs to be more collaboration within ACC when identifying, purchasing and implementing services to better understand what services are required. This includes the level of TBI expertise and knowledge in the services.

3.17 Better use of expert resources

- A formal Centre of Excellence is not the favoured approach
- An Expert Network Approach is preferred

At the initial TBI project stakeholder workshop in June 2011 there was a lot of discussion on the role of future expert centres to support other services or areas. Throughout the interviews this was raised again in terms of specialist services.

When tested most stakeholders did not want a formal separate “Centre of Excellence”, as it may attract skilled workforce away from services and also cost more.

Rather what was preferred was a system or a network where experts could

formally and informally support peers in other services and / or other geographic areas. Examples given included telephone support, video conference support and visiting (both undertaking clinics and to talk with staff to problem solve), both on a planned and an ad hoc basis. This does happen in some areas by default now, but not in a coordinated or recognised way. To enable this service to occur well, there would need to be a contractual and financial recognition of the scope and time commitment expectations.

3.18 Use of Technology

➤ Opportunities for developing some tele-rehabilitation and other use of IT

The role of technology in TBI outcomes for the future was mentioned by some stakeholders. An article sent to the interviewer by a stakeholder noted the use of hand held technology (e.g. blackberry phones) to remind people with TBI about tasks (e.g. taking medication, putting out the rubbish). It showed some success with the use of that technology.

The advancement of technology for telemedicine was raised several times as an option for investigating for tele-rehabilitation. Tele-medicine is typically used for two reasons. First as a clinical option when personnel or services are not available locally and secondly for peer, or expert, support and advice to colleagues or services.

Some of the rehabilitation and trauma experts interviewed for this project agreed that technology should be investigated for tele-rehabilitation. There was some caution from some allied support disciplines that this may not work for them until technology is improved. For example being able to check the appropriateness of eye contact, as this is more difficult on screen.

3.19 Internal to ACC

➤ TBI training for ACC staff
➤ Increase quality of services
➤ Change of focus to encourage improved working with medium to longer term clients

As previously mentioned this included staff from ACC corporate, branches, the return to independence service and the national serious injury service.

The messages and themes from the interviews were common across all the meetings.

The top themes included:

- staff wanting education and more knowledge on TBI, especially for branch and return to independence service staff
- wanting higher quality and a more flexible range of services to be able to refer to that also understand TBI
- change in focus for working with this population that is longer term

rehabilitation and slower back to work

A solution to the knowledge issue was to have a subset of specialised staff in each branch, trained in TBI, with changed KPIs and peer supported / mentored by a NSIS staff member who in turn is expert in TBI.

The rest of the ACC feedback has been incorporated into the main body of this findings report.

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