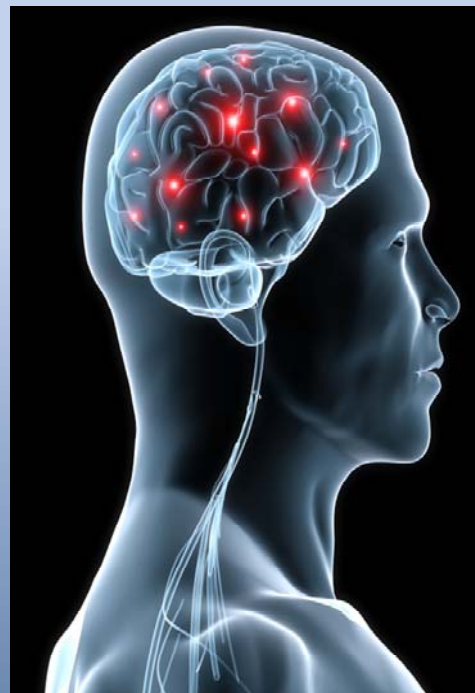




TBI Client Service Experience

[February 2012]



WELLINGTON
3 Collina Terrace
Thorndon
WELLINGTON 6011
NEW ZEALAND
Tel: +64 4 473 1061
Fax: +64 4 472 3501

AUCKLAND
11 Earle Street
Parnell
AUCKLAND 1052
NEW ZEALAND
Tel: +64 9 373 8700
Fax: +64 9 373 8704

SYDNEY
Level One, Suite 105
332-342 Oxford Street
SYDNEY NSW 2022
AUSTRALIA
Tel: +61 2 9386 1622
Fax: +61 2 9386 1633

Email: umr@umr.co.nz
Website: www.umr.co.nz
Facebook: www.facebook.com/umr.research

Table of contents

1. EXECUTIVE SUMMARY.....	3
2. INTRODUCTION	8
2.1 Background	8
2.2 Methodology.....	8
3. CURRENT SERVICES	11
3.1 About the participants	11
3.2 Services clients are receiving	12
3.2.1 Services that make a difference	12
3.2.2 Services improvements	15
3.2.3 Case manager/Support/Service coordinator.....	19
4. RETURN TO WORK SERVICES	23
4.1 Return to work (RTW) experiences.....	23
5. FUTURE SERVICES.....	26
5.1 Background	26

1. Executive summary

Objectives

To explore with clients who have Traumatic Brain Injury (TBI) their experiences of ACC services in terms of what is working well and what is not working so well.

The outcomes of this research will inform a national evidence based strategy on TBI services for more moderate to severe TBI clients aged 16 years and over.

Background to this research

Participants were very positive about having the opportunity to contribute. They had experienced a range of services encompassing experiences that were excellent to others that were not so good. The majority, however, were satisfied with services they had received.

The focus of the discussions with clients centred on current services; what services made a difference, return to work (RTW) support and what future services for clients and their families with TBI should include. There was an emphasis on exploring with clients what supports would encourage community involvement.

Supporting independence

While all had experienced a gamut of TBI rehabilitation services, including inpatient rehabilitation and community rehabilitation, it was apparent many participants were still working through grief experienced with the lost opportunities faced with a TBI. Even participants five years or more since their injury were still adjusting.

Key rehabilitation services that made a difference were those that supported independence in activities of daily living and those that supported community involvement.

Many participants valued the home support worker who enabled them to return to a semblance of normality. Being able to go shopping, do the cooking and get out and about without feeling unsafe made all the difference with a support worker to encourage and motivate.

The activities that took them out of the home, and the planning behind them, helped provide some meaning to the day. Going to the gym not only improved physical well-being but also gave structure to their day, gave them something to look forward to and also improved mental well-being.

Know me

For clients, the key message to ACC was that any future services should take into account individuality and demonstrate trust and respect. Being generalised as 'TBI' was not seen as appropriate, noting everyone is different.

Trust and respect should permeate all services. This meant that ACC would start from a basic premise of trust, that clients knew what was working well for them, that they wanted to work at meaningful work if able, and wanted to be listened to and heeded. Positive communications would support the relationship with ACC and their case manager.

Family support

Family/whānau were recognised as crucial supports for clients with their own specific needs for support. Participants suggested family needs for support should be ascertained and provided in some way. Also helpful was support to explain the impact of the TBI on the client; one suggestion was a liaison person who could work with the family and form a bridge between the client and family. This may help support family relationships that were already stretched and at breaking point.

Return to work (RTW)

Participants stressed that the majority of TBI clients wanted to contribute and work if able. Their main concerns in RTW were the need for meaningful work and work that had some links to their past experience and work. Also important was having a supportive employer who could provide a flexible work place and understood the fatigue issues and mood swings that many faced on RTW.

Sometimes the time pressure to increase hours and get back to full-time hours was detrimental and resulted in the ending of employment.

A number of participants were involved in voluntary work or supporting the work of the Brain Injury Association (BIA). For these clients, the experience was invaluable and they also viewed these activities as ‘meaningful’ and useful to the community.

Future services summary table

Participants identified a number of service improvements as well as key components for the future delivery of services and support.

Some of the service improvements mentioned were more specific relating to current service experiences whereas some of the future services components/factors identified were more the ‘ideal’ and big picture concepts.

The following table is a summary of service improvements and future services components/factors identified by participants.

KEY SERVICE	SPECIFIC SERVICE
CLIENT AND COMMUNITY SUPPORT SERVICES	
Service philosophy	<ul style="list-style-type: none"> • Having an underlying service philosophy that takes into account a person’s individuality, shows trust and respect and ‘knows’ the client • Supporting independence • Having positive communication - more what can be done than what can’t be done
Professional ACC personnel	<ul style="list-style-type: none"> • Having case managers skilled in TBI who can work across a range of complexity • Staff possessing the attributes of good case managers <ul style="list-style-type: none"> – Supportive and accessible – Honest and upfront – Can listen – Show ‘real’ understanding of their clients

KEY SERVICE	SPECIFIC SERVICE
CLIENT AND COMMUNITY SUPPORT SERVICES	
Specialists in TBI	<ul style="list-style-type: none"> • Needing to be knowledgeable about TBI and up-to-date with latest assessments, treatment and outcomes • Having access to medical assessments for TBI
Proactive medical assessments	<ul style="list-style-type: none"> • Identifying complications and issues early, and having two-yearly independent medical assessments for complex clients • Viewing the client with 'fresh eyes'
Community support	<ul style="list-style-type: none"> • Recognising support workers' value to TBI clients • Recognising community involvement adds meaning to their day, and that support workers help with this
Community rehabilitation	<ul style="list-style-type: none"> • Having community activities appropriate for people with TBI e.g. take into account fatigue, noise levels • Having more flexible rehabilitation rules that include a wider range of community rehabilitation services e.g. massage therapy • Having staff who understand TBI • Improving processes around service transitions e.g. planning for when a community service is about to end. There was some concern over short time frames for some community services/support; needs more flexibility e.g. not fixed allocated terms as some clients just starting to improve. • Having good discharge planning with community services in place
Mentor	<ul style="list-style-type: none"> • Having someone who knows TBI to encourage and support • Having someone who has been there and come through
Communication among health professionals	<ul style="list-style-type: none"> • Having good communication among health professionals, and being aware of miscommunication and the distress this causes to TBI clients • Sharing of appropriate information especially with multiple assessments e.g. clients experience assessments for equipment, their physical injuries and mental state and where these impact on other areas these should be shared this would help provide assurance that treatment is maximised • Having shared objectives and goals among all health professionals for agreed client outcomes
RTW support	<ul style="list-style-type: none"> • Having a philosophy of trust and respect • Acknowledging that clients want to work if they can and want meaningful work • Having realistic timeframes for work hours (part-time/full-time) • Providing information for employers which help employers to understand TBI and address discrimination • Address multiple injuries in the workplace e.g. clients often had physical injuries as well as a TBI • Including family/whānau in the RTW process
Information on services	<ul style="list-style-type: none"> • Information on various rehabilitation options • Information on RTW processes • Information on community activities
Public awareness raising of TBI	<ul style="list-style-type: none"> • Raising public awareness to support more positive attitudes towards people with TBI • Informing young people of hazards to help with TBI prevention

KEY SERVICE	SPECIFIC SERVICE
FAMILY SUPPORT SERVICES	
Recognise the needs of the family	<ul style="list-style-type: none"> Assessing family needs Explaining effects of clients' TBI to family/whānau Having counselling independent of the client Transport e.g. family often provided transport for clients; had to visit clients receiving rehabilitation in other centres Financial advice e.g. family were often managing/ advising clients on the lump sum payments from ACC
Include and listen to the family	<ul style="list-style-type: none"> Trusting what the family is saying; they give another view that may provide a more rounded and realistic account of how the client is managing
Liaison person	<ul style="list-style-type: none"> Identifying a liaison person or bridge between the client and family to help explain the changes to family members including children

Recommendations to consider

Service philosophy

The development of a service philosophy in line with client's expectations that underpins all service and support components including community rehabilitation and support, RTW and support for the family.

ACC case managers/support/service coordinators

Recruitment of staff that meet the key attributes as outlined by clients:

- Knowledgeable in TBI
- Good communication skills
- Empathy towards clients with TBI.

On-going training that supports understanding of TBI clients and their families:

- Work with local clients as a resource; other clients can provide support, share similar experiences; especially if further along the road to recovery
- Identify case managers who can mentor and support case managers new to TBI services and support.

Communication training and processes

Training in:

- Verbal and written communication that supports positive communications
- Active listening skills.

Acknowledgement of the dual roles and relationships ACC staff have meeting both the needs of their clients and ACC policy, and maintaining a fine balance.

Recommendations to consider (continued):

Service development

Exploring the possibility of:

- Proactive independent medical assessments for complex clients
- More flexibility around rehabilitation support services such as massage therapy, and more flexibility around timeframes for rehabilitation
- Developing a process for service transitions (planning for when an ACC funded service will end)
- Support for families including assessment of needs.

Recognising the importance of services that support and promote return to independence.

RTW

Developing a RTW philosophy in line with client expectations and align with overall service philosophy:

- Clients want to work
- Focus on 'meaningful work' and work that links with previous experience.

Communicating with employers on the impacts of TBI on clients and the strategies to address these in the workplace.

Including family/whānau early on in discussions around RTW.

Recognising the importance of voluntary work in providing meaning to the day and also in preparation for paid work.

Public awareness of TBI

Increasing community awareness of TBI in a positive way to challenge myths around TBI:

- Consider localised community initiatives
- Address employer awareness of TBI to address perceived discrimination in the workplace.

2. Introduction

2.1 Background

In 2011, ACC commissioned research to provide input into the development of a national strategy for adults (16 years and over) with moderate to severe traumatic brain injury (TBI). It was important for ACC to explore the continuum of services and supports for clients with TBI in New Zealand as part of the development of a national strategy that would inform ACC service design, procurement, service development and measurement of moderate to severe TBI services and outcomes.

A number of research approaches will be used in the development of the national strategy including stakeholder interviews, a literature review, family/whanau interviews/group discussions and client interviews/group discussion.

This research report summarises the views and suggestions from interviews and group discussions with ACC TBI clients.

Objectives

To explore with clients who have TBI their experiences of ACC services in terms of what is working well and what is not working so well.

2.2 Methodology

Research approach

The research approach utilised a mix of small group discussions and face to face depth interviews.

Providing a mix of qualitative methods ensured that a range of participants could be involved. While some could attend a group discussion at a central community location, others were more constrained by living in rural locations. For these participants, UMR were able to meet for a face to face interview at a location agreeable to them.

There was recognition that for people with TBI involvement in group discussions can be more difficult. Consequently, the group discussions were limited to 4-6 people. In addition, participants could bring a support person to the groups. It should be noted that the support person's input was limited, as the main focus of discussions was to gain the client's viewpoint. This was managed both at recruitment time with the objectives being clearly outlined and by the group facilitator.

Research approach

Community based meeting rooms were used where possible.

The research was conducted in the following locations:

- Auckland
- Hamilton
- Wellington
- Christchurch
- Dunedin
- Invercargill.

Comment on the research approach for TBI clients

Our experience with conducting discussion groups with TBI clients was mixed.

For a small number of clients, the experience was daunting as they were meeting strangers in an unfamiliar setting to discuss their personal experiences of services and make suggestions for the way forward. Comments and voiced personal thoughts, as well as different social skill sets, meant some participants felt worried and concerned about the behaviour of others in the group.

For others, the group setting provided an opportunity to share common experiences, support others in the group with ideas and generally encourage each other in seeking appropriate services.

We note that for future group discussions with TBI clients, additional processes should be in place to mitigate the anxieties experienced by some participants. These include:

- Having an experienced facilitator, who can appropriately manage the different social skill sets exhibited by some TBI clients
- Providing the option of having a support person either in the room (but not part of the discussion) or waiting in the reception area.
- Using community based facilities with wheelchair access.
- Having transport available for each individual (sharing with strangers provided to be problematic).
- Limiting group discussions to 4-6 participants.

Providing a mixed method approach worked well with both face to face depth interviews and mini group discussions. However it should be understood there will be times where the group discussion does not work for some participants, with the facilitator being required to close the group earlier than expected or move through the lines of questioning faster to ensure participants were not too anxious.

ACC Ethics Approval

At the onset ACC Ethics Approval was obtained to conduct the research with ACC TBI clients. The ACC Ethics Committee required an opt-in process where ACC clients who wished to take part would contact ACC. This was to ensure that clients fully understood their rights to agree or decline participation in the research.

Database development

An invitation letter was sent to a selection of TBI clients in the locations for the research.

In addition ACC followed up by phone with those who had not opted in.

A database was collated by ACC of all those who opted in or agreed at the follow-up phone call. A total of 53 clients were available for recruitment initially. A second round of invitation letters to top up the database resulted in a further 53 clients agreeing to participate.

The final database (n=106) was provided to UMR for recruitment. Standard protocols were in place to protect and secure the database.

Client participation

A total of 34 clients participated in the research.

- 3 x mini groups in Auckland plus 1 support person and 2 depth interviews [N=13].
- 3 x depth interviews in Hamilton [N=3].
- 4 x depth interviews in Wellington [N=4].
- 1 x mini group in Christchurch [N=6] plus 1 support person.
- 1 x mini group in Invercargill [N=4] plus 2 support persons.
- 1 x mini group in Dunedin [N=4].

It should be noted that, while additional participants wished to take part, to meet the timeframe for the research we were unable to accommodate them all.

All participants were given a \$30 grocery voucher in recognition of their time and travel commitments.

Research was conducted from Monday 10th October to 30th November 2011.

Report structure

This report has been organised by key themes.

It should be noted that while qualitative research can be used to identify a range of issues and assess the intensity with which views are held, quantitative research is necessary to establish with certainty the extent to which views expressed are held throughout the wider TBI population.

3. Current Services

3.1 About the participants

- Wide range of social, family, employment backgrounds
- Recent injury vs. longer term
- Keen for ACC to be involved rather than backseat role

I also had to come to terms with the change in my personality myself which was probably the hardest thing to do, is to come to terms with how you've changed yourself as a person. It's been five years for me now and I'm still learning.

TBI clients are a diverse group

■ **Wide range of background**

Participants came from a wide range of backgrounds with varying levels of family/whānau support. Some had very active family members who provided both family support as well as advocating for services. Others were more independent of family and were working through support services for themselves.

Participation in employment was mixed. Some participants were employed while others were formerly employed and since their TBI had been in and out of work. Some participants had lived with their TBI since birth and had never been employed. A few were participating in some training in preparation for employment.

It was notable that some young people stated they knew nothing different having had their injury since birth or at a very young age, and so were getting on with life as they knew it.

Nonetheless many other participants were still grieving for their former self and the changed opportunities from injuries sustained many decades ago. These clients still talked longingly of how life was and the things that were not possible now and the difficulties they faced in gaining employment and filling their days.

■ **Recent injury versus longer term injury**

Many participants in the groups and depth interviews had their injury many years ago (15 - 20 years), so found it hard to recall what ACC services they were receiving, as many no longer receive many services.

Others had more recent injuries and more intensive relationships with ACC and so were able to contribute more to the group discussions.

■ **More involvement**

It was apparent that for TBI clients, ACC was a large part of their lives. Some had grown up with their TBI and consequently with ACC.

Clients were positive about the contribution they could make to the research and the need for ACC to be actively involved in their lives rather than in the background. This was not to say that ACC should be controlling their lives, but rather ACC should recognise the importance that the support and services provided made to increasing independence for TBI clients.

3.2 Services clients are receiving

- Full range of inpatient and community rehabilitation services
- Specialist TBI rehabilitation

■ *Current services*

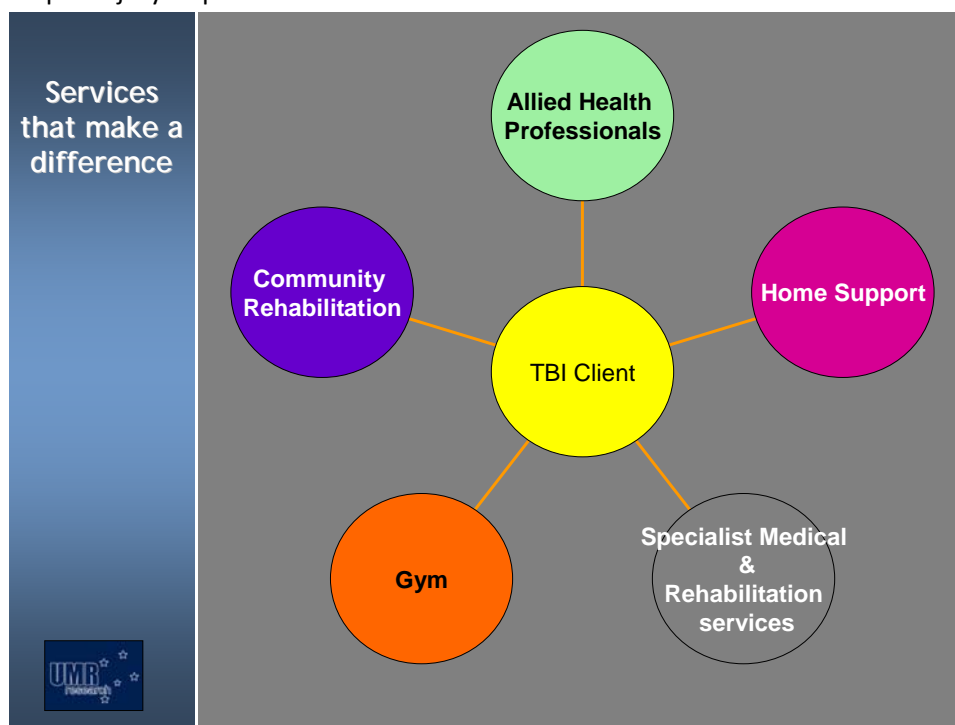
Clients identified the full range of inpatient and community rehabilitation services they were receiving.

These included specialist TBI rehabilitation health professionals and services such as ISIS Centre, Burwood, Cavit ABI, as well as specific disciplines in neuropsychology, occupational therapy, speech language therapy and physiotherapy.

Home support services including support workers were also mentioned frequently.

3.2.1 Services that make a difference

A number of key services were identified by clients as making a difference in their lives. These services were the ones that helped them to regain and maintain independence, and more importantly get them to a point as close to pre-injury as possible.



Allied health professionals

Allied Health Professionals:

- Psychologist
- Occupational therapist
- Physiotherapist
- Speech Language therapist

It was getting back on my feet and support. If you're alone and trying to deal with this sort of injury, it's really difficult to try and organise your day as I found, and just keep things ticking over so you don't stagnate and find yourself all alone or anything and not sure where to take the next step.

■ **Psychologist**

For many TBI clients, the psychologist was a critical health professional. The psychologist provided insight into how the TBI was affecting them post-injury and helped them through the grieving process. Some valued the time to talk through the issues, while others also viewed the psychologist a bit like a mentor.

■ **Occupational therapist**

Getting back to daily routines was crucial for TBI clients and they particularly valued the support and services from the occupational therapist. The occupational therapist provided both motivation and strategies to help structure and organise the day, while acknowledging the impact of the TBI on daily tasks. Also important were strategies suggested by occupational therapists for managing the fatigue issues that plagued clients.

Many clients found it hard to fill their days especially with employment, education and training options more limited in the early days of their injury (and for some an ongoing issue).

The occupational therapist was also recognised for advising on possible day activities as well as providing support to find work.

■ **Physiotherapist**

Keeping mobile and physically active were important for independent daily living, with the physiotherapist playing a key part in maintaining and regaining mobility.

Participants were also quick to affirm the importance of physical activity in improving their brain function.

■ **Speech language therapist**

Also acknowledged as important was the role of the speech language therapist in addressing speech impediments and supporting communication needs as a result of the TBI.

TBI medical specialists and rehabilitation services:

- Neurosurgeon/neurologist
- Psychiatrist
- Specialist rehabilitation services

ISIS was pretty good for me, mostly. I'm pretty sure they are pretty knowledgeable about head injuries and what I was going through.

[Organisation Name] is the one that's made a difference to me because for the first year of my injury I didn't get any help. Then after a year later I got [Organisation Name] and I've had them for about eight or nine months. They've been a great help. I need to find something to occupy my time a bit more positively. That's what's doing my head in, yeah. I like to be occupied. I'm used to working. I'm not used to sitting around doing nothing or watching silly DVDs or something like that.

Community services included:

- Support person
- Gym
- Community rehabilitation services

Medical specialists and rehabilitation services

■ *Neurosurgeon/Neurologist*

There was great respect for the medical specialists' opinions. Participants acknowledged they were in uncharted territory so relied on the medical specialist's knowledge and expertise in TBI.

■ *Psychiatrist*

Again, there was respect for the psychiatrists' opinions especially regarding support for mental issues arising from the TBI.

■ *ISIS, Cavit ABI, Burwood*

Participants, while valuing the input of the specialist rehabilitation services, had mixed views on the quality and services they received.

Some found the services excellent, while others had a more love/hate relationship with these service providers.

We should note that for many clients, their priority and goal was to leave the inpatient facility and get home so any obstacles in their way were not always welcomed. Furthermore, clients as mentioned earlier were going through a grieving process which made initial rehabilitation more fraught.

Home support

Of the home support that clients were receiving, the bulk of comments were on the value of the support person who enabled them to get on with everyday activities. Getting back to normal, everyday activities such as shopping for groceries, coping with cooking and cleaning etc were made possible through the presence and guidance of a support person.

Importantly, the support person played a role in encouraging and supporting community involvement and socialisation.

Gym

Another key rehabilitation service in the community was the ability to attend gym sessions. For many clients the gym sessions both provided physical rehabilitation and, for some, meaning and structure to their day. It was something to look forward to with the gym programme itself a positive experience.

Participants were keen to reinforce the spin-off benefits of gym attendance that included socialisation and improved brain activity.

Community rehabilitation

Brain injury support people have groups. [What is it that helps you when you go along to one of those groups?] You hear a lot of stuff that pertains to yourself which makes you understand "hey, I've got that too" which you don't find walking around the shops or anything. Stupid things, little things. You can be there to help somebody that's going through a rough time too so it's sort of give and take, and I think if you can give, that's really good for you, for yourself.

While some participants were not using or had not used any community rehabilitation services, it was abundantly clear that many clients found these services very useful and again reiterated the importance of having some structure and meaning to their day.

Community rehabilitation services mentioned included:

- Challenge Trust
- Stewart Centre
- Dunedin Training Centre
- Brain Injury Support Groups.

Those clients who had or currently used these services confirmed that the staff really understood TBI, which ensured they felt supported and encouraged when they attended. Learning off others with TBI was a bonus.

3.2.2 Service improvements

Support and planning for when ACC funded community services end:

- Cost effective alternatives
- Understanding the impact and sense of loss when these services end

Service transitions

■ *Community rehabilitation*

Participants commented that while they valued the regular, structured services such as physiotherapy, gym attendance, swimming etc, they were often left stranded when the period covered by ACC came to an end. Routines were established and there was meaning to the day as well as concrete rehabilitation, all which contributed to their well-being. When this abruptly ended, clients were often left feeling bereft.

Often, they were just starting to improve when ACC funded services were completed.

While some were able to pick up the costs of this and chose to do so, many others found this more problematic.

What would be helpful were earlier discussions to explore alternatives and plan for when ACC funded services came to end.

Also, some understanding of the impact of the loss of attendance and supporting clients through the process would be beneficial.

■ *Transitions to home*

Participants also reiterated the importance of good discharge planning and ensuring there was a good transition from hospital to home with community rehabilitation services in place. The main concerns were regarding discharge home before support services were in place. Some also found it difficult adjusting from the 24 hour support in place to coming home to mainly family and community support.

More flexible rehabilitation service rules

At the moment when you apply for something, they give you like six visits. If they could realise that things aren't fixed that fast and we do have quite serious issues sometimes and like if you sprain your ankle or something then six visits is enough, but you only get the six visits and then you have to review it at the end and then apply for more, and things like that.

ACC restrictions impacted on rehabilitation outcomes for some clients.

These clients were looking for additional rehabilitation services not currently funded by ACC. This was mainly regarding rehabilitation services that were less than main-stream such as massage therapy. It was noted that acupuncture was now funded.

In addition, there was some concern expressed that ACC timeframes for rehabilitation were too tight and more flexibility would be helpful. Having fixed terms meant that community rehabilitation sometimes ended just when clients were beginning to benefit. These clients got anxious when these community rehabilitation services were drawing to an end.

Positive communication

Other service improvements include:

- More flexible rehabilitation service rules
- Positive communication
- Communication among health professionals
- Two yearly medical assessment

The power of communication and positive communication was reinforced. Participants requested more trust and respect from ACC which would be reflected in the style of communications and demonstrated in positive discussions on service planning and needs. Importantly discussions could focus more on what could be put in place by way of services and support rather than what could not be done.

Discussions and communications should also display understanding of the client's point of view and recognise that they are the ones living with TBI - their experiences should count.

Communication among health professionals

Some participants had stories to tell of miscommunication and noted that conflicting messages were very distressing especially for TBI clients who were finding it more difficult to process information anyway.

They also voiced concerns that not all information and assessment reports were shared with key health professionals involved in their support and service provision.

They reinforced the need that with multiple assessments and health professionals involved, it was important that health professionals collaborated and shared information to ensure treatment was maximised and that all were working to similar goals and objectives.

Two yearly medical assessment

A few clients suggested that ACC be more proactive in providing assessments and services rather than waiting for the client to regress.

One suggestion was to have an independent medical assessment every two years, which might identify potential issues which could be addressed before things began to deteriorate. The aim of the independent medical assessment was to have this completed by someone outside the current specialist rehabilitation team and who might view the client with 'fresh' eyes.

In the long run, this might save ACC money and also be positive for clients. Clients benefited by an independent review that acknowledged their need for ongoing rehabilitation and expectations of improvement. ACC also has the opportunity to view the client in a different light and possibly address potential issues earlier.

Case Study 1: Showing respect ... Communication ... Professionalism

Lizzie is generally very happy with the service she has received from ACC over the years, but criticized the lack of tact and diplomacy (respect) some staff have shown.

Meet Lizzie *¹

Lizzie is 59. She had her accident 10 years ago which has left her fatigued, with memory loss and an inability to concentrate for any length of time. Lizzie also suffers from epilepsy and hypoglycaemia; her Dilantin(²) levels are at present unstable and she is currently unable to drive. Lizzie usually lives with her husband (her children have left home), but he recently had a stroke and is being cared for by relatives as Lizzie is unable to cope.

Lizzie previously had a busy job with lots of responsibilities in an advertising agency and still feels the loss keenly. She is now working as a cleaner as this has flexible hours, allows her to rest and does not require much mental input.

Showing a lack of respect ...

Lizzie's main criticism of ACC is that on occasion she has not been treated with respect, though she does not believe this would be condoned by ACC and that *"the person sitting behind the desk is not reflective of ACC"*. Lizzie gave a number of examples where she feels her privacy, independence or intelligence have been undermined:

- Messages containing private information have been left on Lizzie's answering machine ... *"and nobody knows I am on ACC but they will ring and leave a message on the answer phone, this is ACC we need to talk about your earnings or something and everyone in the house can hear"*.
- Lizzie was upset when ACC gave private information about her husband's gambling to her employer ... *"nobody at work knew until ACC told them"* and she feels she lost her job after her case manager told them *"I would never be as good as I was"*.
- Lizzie feels she has been treated in a patronising way by some occupational therapists ... *"They would give you four blocks or something and tell you to put them together and then say good girl, good girl and I would think oh I am an adult"*. She has also been disappointed to see the same approach used during her husband's stroke rehabilitation.

In summary, Lizzie is keen to see that systems are in place and protocols enforced which protect a client's privacy and ensure they are treated as intelligent adults despite their injury.

¹ NB: pseudonyms are used throughout

² Anti-epileptic drug

3.2.3 Case manager/Support/Service coordinator³

Background

Participants experienced a range of case manager experiences ranging from the good to the not so good. Generally, most were able to recall those who had provided a stand-out service.

What makes a good case manager for TBI clients?

A good case manager is:

- Supportive and accessible
- Honest and upfront
- Can listen
- Show 'real' understanding of their clients

[What makes a good case manager for you then?] Somebody who gets in touch with you and tells you who they are, they're your case manager, or your old one telling you that they're changing, or bothering to even communicate with you at all.

Participants were asked to consider what would be the ideal attributes for a case manager working with TBI clients.

■ *Supportive*

Participants wanted their case manager to be supportive and available when they required. In particular they wanted to know they could talk issues or concerns over with their case manager in a supportive environment.

A supportive case manager was one who could be contacted and who was responsive by email, phone or face to face. For some, this included a visit at the local ACC Branch office.

A number of participants commented this was more difficult when their support coordinator was not located in the same city.

■ *Honest and upfront*

Honesty was particularly valued. It was important that case managers were straight up and 'told it like it was', rather than making promises that couldn't be met. Participants appreciated being told what ACC could do and also what clients were responsible for in a positive manner, rather than in the negative.

■ *Listens to clients*

Listening to the clients' viewpoints was a real skill and usually demonstrated by the ability to deliver appropriate services and supports to clients. Participants were at pains to point out it was their experiences that should be taken into account regarding how and what services would be helpful, especially once they were in their community rehabilitation phase and striving for independence.

³ Read case manager to mean case manager/ support coordinator/ service coordinator

Case Study 2: Listen to the client ...

Mike feels that in the past ACC have not listened to him nor taken the suggestions or comments he has made seriously. He hopes this research will be a forum for ACC to prove otherwise, to recognise that brain injured people are the best people to talk and listen to about brain injuries.

Meet Mike ^{*4}

Mike is 43 years old. He had his accident 23 years ago, when he was 20. He initially lived with his Mother in [City], but moved to [Town] when he was able to cope alone. He has bought and renovated his own property, which he is very proud of. He lives alone, but has a busy social life; dancing and keeping fit and attending Brain Injury Association (BIA) meetings in [City] once a week.

Mike is a trained carpenter who had served his apprenticeship before his accident. He now has two part time jobs as an 'odd job' man at two local childcare centres which ACC helped him to secure. He *"absolutely loves"* his jobs; they are flexible and allow him to use his carpentry skills in a constructive way.

Listen to Mike...

Mike had a number of issues to discuss during the interview - he wanted his views and experiences acknowledged and valued and not *"rubbished"* on account of him not being as quick or having such a good memory as other people. Mike wanted to be heard on the following topics:

- The importance of knowledgeable (specialist) staff ... *"ACC have got to get their case managers assigned to people who know about head injuries and brain damage ... because some of them wouldn't have a clue from a slice of bread"*. Mike has had many case managers over the years and has been disappointed with the lack of empathy or knowledge some have demonstrated.
- Viewing brain injuries as a long term (life time) injury ... *"I am 23 years down the track and I am still going through this psychological help all the time."* Mike feels there is still an expectation, even after all these years, he should be able to cope with a full time job.
- Improved communication ... *"Inform the Brain Injury Association Liaison Officer about meetings that are coming up."* Mike often forgets what has been discussed at meetings, so prefers to have an advocate from the BIA present. However, they cannot organise this if notice is too short. Alternatively, he tapes meetings (including this one) so he can be sure he has raised the points he planned to raise and that his *"take out"* of the meeting is what was said.
- Treating people as individuals ... *"Get ACC to treat the problem that brain injured people have rather than trying to tick the boxes and get them off their book"* ... as Mike feels there is a tendency to treat all brain injury Clients all the same. He also feels case managers should *"actually read Clients' files ... to get an idea of what stage he is at and what treatments he has had"* to avoid going over old ground.
- Increased funding for support groups ... *"Another one is getting ACC to help fund the Brain Injury Association"*. Mike has found the help and support of the BIA invaluable and feels they are not given enough credit by ACC.

In summary, Mike wants ACC to treat him as an intelligent adult by listening to and valuing his comments and opinions.

⁴ NB: pseudonyms are used throughout

A good case manager is one that's there to assist and guide you through, when things get tough and help you through the process. A bad case manager will sit back and let you do all the work. The new case manager I've got, they tried to get me here to do part-time work and I've kept myself ready to do voluntary work for brain injury, but with my new case manager he said "now about this part-time work" and I said "no, I'm already doing part-time work with the brain injury" and he said "okay, we'll cross that off then."

The main concerns with case managers were:

- The high turnover
- Dual role and relationship
- Varying quality

■ **'Real' understanding**

Critically for participants, a good case manager was one who showed real understanding of a client's needs and situation.

This required the case manager to read the client file and know the client history, especially before assessment meetings and family meetings. It was very apparent when a case manager had not read the client file through the inappropriate and irrelevant comments and suggestions that were made.

Real understanding was evidenced by:

- Not being talked down to
- Showing trust and respect for the client's experiences and point of view
- Not being demanding and directive
- Empathising with the client's TBI injury as best they could (without actually living it).

Concerns

■ **Dual role and relationship**

Participants were concerned with the dual role their case manager played both as a support to them with their rehabilitation and at the same time was an ACC employee required to follow ACC policies and implement policy changes. Different situations meant the relationship could be compromised unless good communication and understanding were in place between the client and case manager.

Situations where relationships were endangered included structural changes with resultant changes of case manager (even though the client was getting on well with the case manager). One structural change referred to by clients was the establishment of the National Serious Injury Service which for some clients has meant additional travel requirements to see their support coordinator who is not in the same town as them.

And ACC policy (real or perceived) requiring case managers to reduce the number of ACC clients and to 'get everyone off the books'.

■ **Staff turnover**

Participants were well aware of the issues around staff turnover. Ideally participants would like case managers to stay with them for at least two years.

Being informed of any change would be a minimum requirement and importantly having the new case manager introduce themselves as soon as possible. Ideally the first contact and introduction would be face to face.

■ *Varying quality*

While at pains to talk about the experiences they had with case managers who were supportive and had made a difference in their lives, it was apparent that over the course of their injury the longer term clients had experienced a range of case manager service of varying quality e.g. poor communication, poor understanding of TBI through to those who were highly competent.

3.2.4 Service planning

Service planning was being conducted. The key people involved included:

- Inpatient rehabilitation service e.g. Cavit ABI
- Family/friends
- Assessor/occupational therapist (someone independent of ACC and the family)
- Case manager
- Sometimes the client's general practitioner.

It was also interesting to note that a few clients, unprompted, also mentioned the Lifetime Rehabilitation Plan (LTRP). These clients were those with more complex needs.


They found the LTRP helpful to cover off all aspects of their support and rehabilitation with input from a range of people.

Those with a Support Plan found these helpful, although they mentioned there needed to be caution in the development of goals and objectives as sometimes 'big' ideas can set up a client to fail. There needed to be some balance between aspirational goals and realistic goals.

4. Return to work services

4.1 Return to work (RTW) experiences

Return to Work



- The underlying premise and philosophy around RTW should be that 'clients want to RTW'.
- Also important is showing understanding of the effect of the TBI on future employment; especially fatigue and safety issues.
- Key factors for supporting RTW include:
 - Meaningful work
 - Work that has a link with former employment/ interests
 - Explaining the process and each component in the RTW support that ACC works through
 - Part-time work is more doable/ flexible work.

What is working well?

Working well:

- ➔ Graduated RTW
- ➔ Supportive case manager
- ➔ Supportive employer

■ **Graduated RTW process**

Having a graduated RTW process worked well for those clients who had experienced it. The recognition that TBI clients cannot return to full-time work very quickly was appreciated. There was also confirmation that, for many clients, part-time work was more 'achievable'

■ **Supportive case manager**

A supportive case manager who would work with the client and also with their employer was important. The case manager could provide valuable encouragement and a sounding board when issues arose at work.

■ **Supportive employer**

Those clients who had supportive employers had smoother RTW experiences. Issues around part-time work were usually followed up and were more able to be addressed by these employers. These issues included flexible work hours, rearranging hours of work to best suit the client's 'best time' for working and accepting that clients will have 'off' days.

.. I think it helps a lot when work want me, they still want me. I suppose if they didn't want me back then it could have been a bit of a different ball game. I've had a very, very supportive employer and ACC have said that quite a bit and other clients that the employers weren't as helpful as the one I've got.

The common elements for supportive employers' was that their line of work meant they did not rely on specific time and product requirements or they could provide alternative job roles within the workplace that met the needs of TBI clients.

Improvements

Suggested improvements were:

- ➔ Acknowledge that most clients want to work if they can
- ➔ Clear explanations of the RTW process (step by step)
- ➔ Identifying meaningful work
- ➔ Show understanding of the effect of the TBI on RTW opportunities
- ➔ Supporting employers to understand TBI
- ➔ Include family where appropriate

■ ***Acknowledge that most people will want to work if they can***

Participants pointed out that the majority of clients wanted to work if they were able rather than the converse. Accordingly they stated strongly that the underlying premise and philosophy around RTW should be that 'clients want to RTW' and that they want to contribute.

By acknowledging that clients want to work, the case manager would be building the foundations on a positive framework when working with clients on RTW.

■ ***Understanding the RTW process***

Clients need be informed and clear explanations of the RTW process provided. For some clients, it was apparent they were confused over some of the steps, with some assessors adding to the confusion by commenting on the order of how things were being approached e.g. *'I should have seen you later or earlier or I wonder why I am seeing you now?'*

Some of the process steps and support clients felt required clarification were:

- Assessment for work readiness
- Job training or retraining
- What help is available from ACC to find work?
- What support is available?
- What do clients need to pay for themselves?

■ ***Meaningful work***

Participants spoke of the need to find 'meaningful' work; it did not need to be the same as what they done previously but links to previous work were important. For instance, those who had a practical outdoors job may find it difficult to manage in an office environment.

There were a number of participants who found the change from a lifetime of physical outdoors occupation to only potentially indoors work opportunities particularly difficult, as their injury made returning to an outdoors job very difficult; especially if expected to last the full day.

It's got to be what you want to do and you're enjoying doing it. Most people with head injuries have an attention deficit problem and if you're not happy, your mind's gone somewhere else. So you've got to find something you want to do.

■ **Understanding the effects of the TBI on RTW**

[So you've still got lots of fatigue issues now?] Yeah. That's one of the reasons I can't go back to work. I'm just unreliable ... I went out of employment from 19 to 25 so that's six years out of employment.... you know, if I could actually stay awake all day and be competent, you stick me straight back into the workforce now, I'm probably not going to be able to handle it anyway.

Fatigue is a big issue for TBI clients and while they may 'look okay' they know they cannot last the distance. Some found that once they started to manage better at work there was pressure to increase hours too quickly, resulting in relapses and sometimes the ending of employment.

■ **Employer understanding**

Participants were aware they made unreliable employees and could pose safety issues at work. They could also experience mood swings making things difficult for themselves, their employer and workmates.

Being able to work flexible hours, part-time hours and choosing the times of the day when they were most productive all helped.

Employers needed to be made aware of the issues and also the positive steps that needed to be put in place to ensure an employee with TBI could manage better at work.

Some participants suggested that a step in the right direction would be addressing employer discrimination in the workplace towards people with TBI. The lack of understanding of disabilities, including TBI, meant clients did not feel they got a fair deal when seeking employment or retaining their job.

■ **Include the family/whānau**

There was recognition that in the early stage of the injury it was often the family/whānau who supported the client and who were with the client when they were focused on recovery and rehabilitation. During this time, it was especially important that family were included in discussion on RTW.

■ **Value of voluntary work**

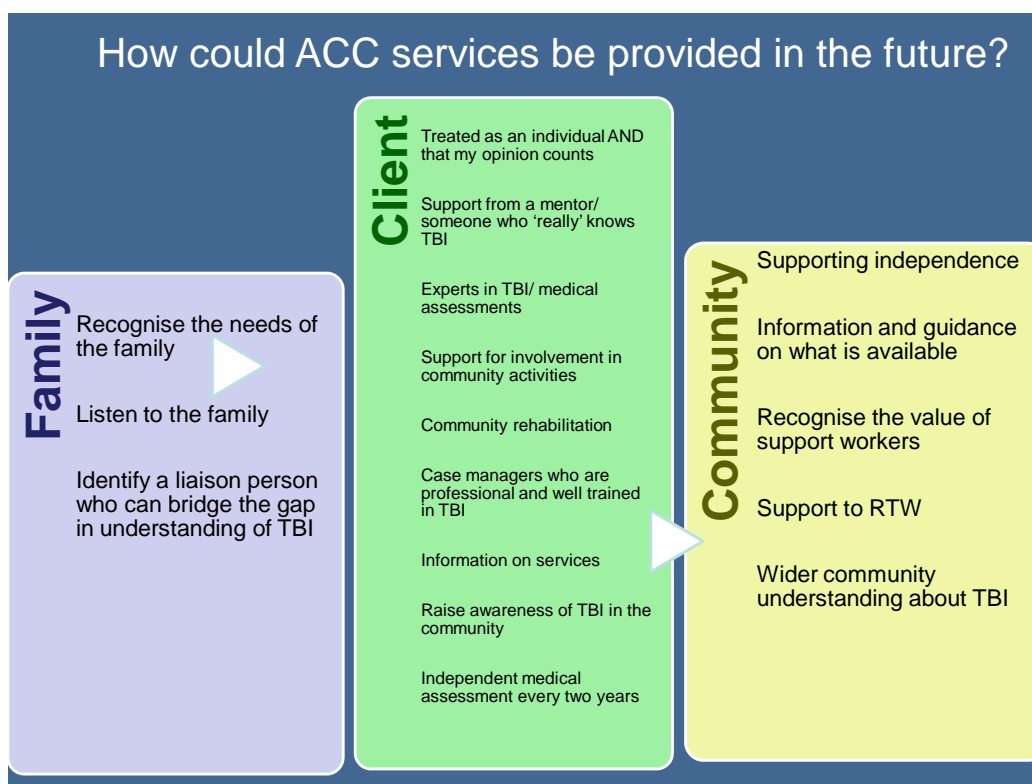
A number of participants were involved in voluntary work in the community including for the Brain Injury Association. These clients were very positive about the value of what they were doing for themselves as well as for the wider community. As well as providing work skills and structure to their day, the involvement in voluntary work supported mental well-being.

5. Future services

5.1 Background

To explore how future services for TBI clients could look, participants in the groups were asked to think about what services would be important for them, what was needed for them to be more involved in their communities of interest, and services for their families. We then worked together as a group and developed key components on the whiteboard.

The following is a summary of the collective suggestions from all groups and interviews. Where relevant we also refer back to the suggested improvements made earlier in previous sections.



That's like trying to stereotype a gender, like what a girl's like. Everyone is different. It comes down to the individual. You need to almost have some - one person who maybe knows the basics of a head injury and just a few things ... a few attributes that do work with it, but then everything's got to be custom-made to a certain individual, like you can't stereotype anything for a head injury.

That's a really good way to put it. It's got to be custom-made for each person.

Like if they stereotype a few attributes to go with a head injury and then put them on me and you, it's possibly not going to work because we're completely different people.

I found that once I got transferred to this long-term injury unit. I've had the same case manager for two years and she's met me and she knows my file. Like the rest of them don't bother to read it because they know they're not going to have you for very long, but she knows me and knows all that stuff. Because it's such a small unit, they don't have heaps of change around. So having a specialised unit like that has been really helpful.

Future services should include:

- The underpinning philosophy in service planning and delivery should take into account a person's individuality and not generalise all TBI clients as the same.
- Services that support independence especially the everyday tasks that people need to do.
- Supportive organisations that provide practical advice and support.

■ **Be treated as an individual**

Participants reiterated that they were all individuals with their own personalities. It was important that those working with TBI clients did not generalise and 'lump' all TBI clients together as one group.

Being treated as an individual meant:

- ACC was supportive of their opinions and that their opinions were valued
- ACC was positive in their dealings with them, giving support and encouragement for clients to reach their full potential.
- ACC took the time to ask clients what services would work best for them and then following through on these suggestions
- Customised service and support received from ACC.

A number of participants mentioned unprompted the improvement in ACC service received once they were part of the National Serious Injury Service.

They felt with this unit that there was more consistency of service with support coordinators demonstrating professional and knowledgeable service.

■ **Supporting independence**

Knowing TBI clients were grieving for the past lives, it was crucial that clients had the support necessary to return to independence. Some participants spoke of being able to look after themselves with support from their support worker, occupational therapist and physiotherapist. Having services like 'meals on ice' made a huge difference for one participant.

Physical limitations and communication difficulties all made community involvement more difficult and, again, participants wanted support to address these 'somehow'. They did not have all the answers and so relied on their case manager and other health professionals as well as family to help them through this stage of rehabilitation.

Again critical to community involvement was access to supportive organisations who could provide practical support and demonstrate an understanding of TBI. Among those mentioned were the Brain Injury Association which organized support groups, disability sports groups, Dunedin Training Centre and Cavit ABI.

Case Study 3: Being treated as an individual ...

Nick has been “*stoked with the service*” he has received from ACC and how his ‘team’ have worked together to ensure his rehabilitation programme is relevant and useful for him in his everyday life and takes account of the needs of him and his family.

Meet Nick ^{*5}

Nick is 39 and had his accident nearly two years ago in January 2010. He lives on a farm five minutes drive from a small NZ town. He is married with two primary school aged children. At the time of the accident, Nick was working as a lecturer in farming studies and running a small farm. Since the accident he has been unable to return to his job as a lecturer and, due to a slight speech impediment, doubts he will do so. Instead, he is focusing all his time and energy on developing a self sustaining organic pig farm.

Treating Nick as an individual ...

After his accident, Nick worked with a range of specialists to manage his rehabilitation. He commented ... *“I have been very impressed with how they have handled my accident; they have all been very helpful”*. Nick felt that his opinion counted and *“when I have had something worthwhile to say they have actually listened and physically got on with what I have hopefully expressed to them”*.

They were interested in Nick’s life and how he was getting along, taking things at his pace and not rushing nor pushing him. Nick remarked: *“They were both bloody good, you just sit there and have a chat for the first ten minutes having a cuppa and then you get to work after that”*.

Nick was impressed with how his Occupational Therapist and Physiotherapist prescribed activities and exercises that he could do during his working day because, as Nick admitted ... *“if she had left me with chores I would never do on the farm I would probably never get around to doing them”*.

“The OT was bloody good she left me with stuff that was related to farming because obviously that is what I do so I might be undoing a nut, because it was the right side of my body that was affected majorly in the accident. So she might perhaps leave me a nut and bolt and say unscrew that nut off that bolt.”

“Again she leaves me with physical exercises to get on with when she is not present. And again it is farming related. In the morning I feed the pigs and get up and milk 10 cows and so while the cups are on the cows I physically have to use my right arm... and when the cows are being milked I am doing some squat exercises and she has got me doing some lunge exercises to get my balance in my right leg.”

Nick has also been very appreciative of how ACC have sought to recognise the needs of his wife and family. They understood that his and his family’s wellbeing were intrinsically linked and suggested games and activities he could do with his sons to help his rehabilitation e.g. Jenga for his fine motor skills and memory games.

⁵ NB: pseudonyms are used throughout

■ *Having a mentor/someone who knows TBI*

Future services should include:

- Having access to a mentor who comes from a similar background and who has experienced TBI to support the client to understand the change in life circumstances AND to motivate and encourage

Participants suggested having a support person or mentor who had lived with TBI and who had experienced the system, the life changes and come through the other side to support the TBI client especially once they were living back in the community.

The mentor could help the person understand the change in life circumstances from a position of having been there too. It would be important for the mentor to come from a similar background and life experience to the TBI client. Also helpful would be the ability to motivate the TBI client post-injury and to discern between being pushed and being encouraged.

■ *Access to experts in TBI medical assessment*

Future services should include:

- Expert medical specialists in TBI and assessments are available. Look to include proactive independent medical assessments.

Participants expected that medical specialists experienced in TBI would be available. They wanted to know that the medical specialists they were seeing were knowledgeable about TBI and were up-to-date with the latest assessments, treatment and outcomes. One example given was knowing to check for Alzheimer's Disease and recognise the link to TBI.

As well, they should be supported by access to medical assessments such as MRI scans to identify TBI. Having more independent assessments being made available with the suggestion for a proactive medical assessment every two years again mentioned.

(See Section 3.2.2)

■ *Community support*

Future services should include:

- Recognition of the value of support workers
- Recognition of the importance of community activities and the support needed to participate in these e.g. support worker, transport

To be involved in the community and participate as best they could, the support worker was a critical service. The support worker could enable TBI clients to maintain independence and also encouraged and enabled the person to participate more. Being safe was a key concern for many participants and having a support worker in the home and also when out and about was really helpful for some participants.

Transport support to get around and access community activities were also mentioned e.g. taxis, public transport.

In addition, there needed to be recognition of the importance of daily activities and the meaning they gave to the day; hence the need for a support worker, especially in the early days of community living.

■ **Community rehabilitation**

As mentioned above, having community activities and support to access these can make a big difference to daily living for TBI clients. Community activities that were suitable for people with TBI were mentioned. These included a gym that could provide a quieter space and rehabilitation services such as Cavit ABI and ISIS.

Future services should include:

- ➔ Access to both formal and informal TBI community rehabilitation support services including gym, specialist community rehabilitation and TBI community support groups

In addition, community rehabilitation support services with staff who really understood TBI provided a very useful service for some clients. (See also Section 3.2.1)

Participants also thought ACC could support and encourage clients to take a course and 'use your brain'. Some participants/support people recalled the Lifetime Rehabilitation Plan as a useful tool to get clients and ACC to think longer term and also identify the supports needed.

■ **Well trained and professional ACC personnel**

Critically important for participants were well trained and professional ACC case managers. Above all else there was a need for case managers who were skilled and focused on brain injury and had the ability to work with a range of complexity of TBI clients. This would be demonstrated by case managers who could:

Future services should include:

- ➔ ACC case managers experienced in TBI across a range of complexities and demonstrate understanding of TBI in their dealings with clients

- Provide good explanations
- Show understanding of TBI
- Show patience, especially when supporting people back into the workforce.
- Get it right first time (demonstrating the case manager had read the file, knew the client and what they were discussing and recommending)

(See also Section 3.2.4 on 'good case manager')

■ **Information on services available**

Future services should include:

- ➔ Information on the services and support available including rehabilitation options and community safe places
- ➔ Clarifying the RTW steps, especially the assessment process
- ➔ Referrals and encouragement to attend community activities

Rehabilitation options

Participants suggested that they needed to be made aware of the services and support available, both for supporting RTW and also rehabilitation options.

RTW processes

As mentioned earlier, some participants were confused about the RTW steps and processes and wanted more clarity around the assessment process for RTW.

Community activities

To support participation in local communities, participants needed information and guidance on what was available and also how to access these. For a number of TBI clients, being safe was an important criterion for participation. They wanted to know about safe places and activities and how to get about safely. Referrals and encouragement to attend would also help.

■ *Raise awareness about TBI in the community/address attitudes towards TBI*

Future services should include:

- Awareness-raising among the wider community including young people and employers to increase understanding of TBI impacts, including a prevention message

While not strongly voiced there were a number of participants who were concerned with the lack of knowledge and understanding of TBI impacts on people. While they may 'look okay', they were easily fatigued, had mood swings and required flexible work places. Flexible work places would have the ability to have hours to suit the client's best times for work and also adapt to times when the client was too fatigued for work for example.

Awareness raising could also have a prevention component to support prevention of TBI among young people such as showing the general public the potential danger of some activities and actions that contribute to a TBI.

Participants essentially wanted more widespread community understanding so that they were not made to 'feel like criminals' and, conversely, were treated with respect.

Some participants mentioned the mental health awareness campaign and Brain Injury Awareness week; however it should be noted that not all participants were keen on a widespread general public communications campaign.

■ *Support to RTW*

Future services should include:

- Support to RTW which covers; information to employers, finding meaningful work, addressing multiple injury requirements at the workplace, being realistic about hours at work

Participants strongly stated their commitment to RTW if able. The critical factor for TBI clients was that ACC needed to understand that clients cannot be pressured into work too soon. This would only lead to a possible failure further down the track. Being realistic was critically important.

Also addressing the client's multiple injuries (TBI clients often had physical injuries as well as the TBI) was required for successful RTW, as was supporting and informing employers on TBI impacts.

Trying to understand from the client's viewpoint the work process, how that was affecting them and what supports were required would be helpful.

Help and support to find meaningful, interesting and positive work was also mentioned.

Future services for family/whānau

■ *Recognise the needs of the family*

Future services should include:

- Acknowledgement of the role family play in supporting the TBI client. This should include practical support to the family and knowledge sharing on the effects of TBI

Participants welcomed the opportunity to give suggestions how their families could be supported better. Paramount was the recognition that family support was vital and for this support to be effective, families needed to understand the impact of the TBI on the client.

Firstly, participants suggested that there should be assessment of a family's needs at the onset - the critical question to ask was 'are you coping alright?' There should not be an assumption that family can do everything, and there should be acknowledgement of the support family were providing. This could be formally in client support plans, financial support for transport and other costs incurred in supporting the client as well as verbal acknowledgement from the case manager or support coordinator.

Secondly, ACC needed to explain the effects of the TBI on the client to family members and friends as this was often difficult for the TBI client themselves to articulate.

Support for family included:

- Family counselling and support independent of the client
- Transport costs acknowledged as families were often visiting clients or transporting them to rehabilitation treatment
- Financial advice so that they can support the client to make good decisions especially regarding lump sum payments

It was also important to recognise that family are a large part of client's lives so family need to be kept informed throughout about treatment and rehabilitation goals and options.

■ *Listen to the family*

Future services should include:

- Include the family and listen to their viewpoint when adjusting support and services

In acknowledging the role of family it was important to also listen to the family and trust the family's point of view. Often family were able to give a more realistic account of how things were working. One example given was terminating support too quickly without consulting the family.

Case Study 4: Involve the family ...

Dave's wife feels very strongly that ACC do not recognise the level of help and support that partners provide. She knows from experience that the stress can cause the break up of marriages and that Clients *"are left to try and sort things out for themselves"*.

Meet Dave *⁶

Dave is 56 years old. He had his accident 16 years ago when he was living in [City]. He moved to [Town] about 11 years ago. He lives with his wife, who has a professional full time job and who is also his primary caregiver. Dave has two grown up children who visit regularly.

Dave was a senior civil servant at the time of his accident and also had a lifestyle block where he planned to grow nut trees to support their retirement. He had a *"perfect memory"* and was looking forward to an affluent and relaxed retirement. His accident has left him with a very poor memory, poor concentration and very little stamina. He has his driving license and a part time job which give him a small measure of independence. However, he acknowledges the job is more *"as a favour"* and that he is *"not a valued employee"*; Dave worries what will happen when they do not need him anymore. He is interested in plants and horticulture but cannot study due to his poor memory and concentration and does not have the stamina for a labour intensive job.

During the course of the interview Dave often forgot the gist of our conversation; he repeated some things and contradicted others.

Dave asked if his wife could be involved in the research and she telephoned and spoke to the researcher after the interview.

Listen to Dave's wife

Dave's wife (Alison) contradicted a couple of things Dave said:

Dave said he had *"never met his current case manager"*. His wife said *"he has been more proactive than any they had had in the past and was the first one to have come out and meet Dave"*/*"Current Case Manage is excellent ... seems to have a better understanding of Dave's condition"*.

Dave said he keeps busy *"looking after the garden and taking the dog out"*. Alison commented: *"Dave will tell you he does the garden and takes the dog out. Now look around my garden; when were the lawns last cut? He took the dog out about a year ago. He tells you these things because these are what he thinks he should be doing. People with TBI's live in a fantasy world and I don't think the people at ACC always understand that."*

Alison was concerned that some case managers were not fully trained for dealing with brain injured people and they lacked experience and judgement that just because ... *"they look normal and talk normal, it does not mean that all is well. They should not take things at face value"*.

Alison wanted case managers to visit Clients in their own homes ... *"also to make surprise visits. It is too easy to make everything alright on the phone. People can pretend for an hour"*.

She felt ACC needed to have more *"realistic expectations of what Dave is capable of"* and to *"look at Dave as a family man and how his injury has impacted on me and the children. There is still very little acknowledgement of the pain and stress that family members experience."*

In summary, Alison feels that while it is important that Dave is treated like the intelligent grown man he is, his brain injury has left him needing ongoing support from her and that she should be consulted in any decisions or planning made on Dave's behalf.

⁶ NB: pseudonyms are used throughout

Future services should include:

- Identifying a liaison person to help bridge the knowledge gap on the effects of the TBI on the client

I guess there would be like someone to liaise with your family and your friends about the changes you're going to go through, and how mood swings affect people because that's a really big thing on the people that are close to us, and it's really hard to ask for help. I know I can't. And having kids, that's a really big thing because they really don't understand what goes on inside.

■ ***Identify a liaison person/bridge between the client and family***

Participants knew that they could be difficult to live with and considered a liaison person to explain the changes the 'client' was going through to family would be helpful. It was important to support families who were already under stress from the accident and often were at breaking point.

Family included not only parents, spouse/partner but also children. It was noted that children also needed to be included in communication around the impacts of the TBI on the client.