ANZASW (Aotearoa New Zealand Association of Social Workers)
Response to independent contractor working for ACC on a project asking
Three Core Questions in
Developing a National Strategy for Adults with Traumatic Brain Injury

QUESTION ONE
WHAT WORKS WELL FOR PEOPLE, AND THEIR FAMILIES, WITH MODERATE TO SEVERE TBI (SERVICES, STAFF, ACC) AND WHY IS THIS?

(1) A good **Case Manager**, is one who:

a. Listens to clients and families and treats them with respect.
b. Creates an appropriate environment to carry out interviews and assessments in a culturally appropriate, warm, empathetic and inclusive manner; with the client, their whanau/family and others who may need to be involved.
c. Provides necessary information in a timely and consistent manner e.g. sends out reminders for Medical Certificates consistently and ensures that the client has an appropriate support person to interpret written material if this is required.
d. Discusses the reports and gives a clear timeline as to when things will happen.
e. Tries to ensure that rehabilitation goals can be achieved by seeking out and using of all resources and services.
f. Is flexible and creative in finding ways through the bureaucratic systems of ACC and other organisations to meet the needs of those with TBI.
g. Has a full and comprehensive understanding of traumatic brain injury and has undertaken social work (or similar) training to degree level or higher.
h. Is proactive and will minimise any anticipated problems e.g. monitoring tax when someone is working and getting some ACC contribution.
i. Is able to assess the client's situation to exclude the possibility of family violence or elder abuse and neglect at the outset of the client/ACC relationship and monitors this over time. Understands their role is to advocate for their clients with TBI but that the advocacy is not in isolation to their family/whanau.
j. Understands that the nature of TBI means clients can be angry and that the anger may be projected at family/whanau members who support them.
k. Ensures that all Home Help, Personal Care and Attendant Caregivers and Agencies or businesses providing care and funded by ACC have staff and caregivers trained to a high degree to understand TBI and provide appropriate services to the client.
l. Ensures that ACC does not approve and fund care for a people with TBI unless that level of expertise can be demonstrated and assured by the Agency or person seeking to provide the care.
m. Does not pass the client to another case manager without an appropriate client/family/whanau meeting/hui to ensure the reason for the change is understood as much as possible by the client and their family/whanau
n. Does not use the Privacy Act to exclude family/whanau members (who may have differing views) and seeks to find ways to resolve family/whanau difficulties in a proactive manner
o. Does not use the Protection of Personal and Property Rights Act and the Family Court to exclude family members and discount their views and concerns

(2) **Return to work** trials are more successful when people with TBI have an advocate or job coach supporting them whose responsibilities include:

a. negotiating with the employer,
b. explaining TBI influences in completing job tasks
c. encourage colleagues/staff to take TBI effects into consideration
d. managing TBI factors such as the fatigue.
e. ensuring additional help is available when needed

These lessen the embarrassment for people with TBI needing who are transitioning back into employment and unable to work their usual hours,

(3) **Assessments** which:

a. assess appropriately <u>all</u> facets of the brain injury and its effects e.g. fatigue, cognitive functioning, safety from abuse and neglect
b. when these assessments consider seriously what the family report to the assessors, e.g. their ability to manage social relationships, the choice of unsafe partners, flatmates etc., the safety of the client or protected person is not compromised by the personal views of the assessor

(4) The role of the **Acute Rehab Coordinator for Moderate to Severe TBI** works well when they:

a. implement, maintain and monitor robust systems with the ACC Administrators to identify TBI admissions to hospital emergency departments and/or admissions to hospital wards and maintain the connections over time.
b. liaise closely with ACC, MDTs, regional specialist TBI unit and local TBI services for those requiring further intensive TBI Rehab.
c. are available to participate in staff education sessions about their role.
d. ensure a continuity of care within secondary services for TBI

(5)The role of the **occupational therapist** is very helpful when they:

a. visit regularly to discuss current concerns and the whole situation
b. help develop an understanding of the impact of the brain injury
c. advise how to manage living with a brain injury
d. educate employers/managers

QUESTION TWO
WHAT DOES NOT WORK SO WELL FOR PEOPLE, AND THEIR FAMILIES, WITH MODERATE TO SEVERE TBI (SERVICES, STAFF, ACC) AND WHY IS THIS?

(6) When **Case Managers:**

a. Indicate to a client that they will discuss a situation with their psychologist (or other professional) and say they will "get back to the client". If there is no time limit given for this, clients wait in some instances for months for a reply (yet their entitlements can be cut very swiftly!)
b. Treat the clients in medical categories rather than people with a TBI. Clients can feel they are made to be liars or not trying to improve; e.g. a client being asked to complete a "Psychological Test for Malingerers", which felt very degrading.
c. Have no appreciation of the client as a member of the community and no understanding or liaison with the community services which seek to support those with TBI
d. Have no understanding of the vulnerability of people with TBI in community settings.
e. Are unaware of the incidence of and dynamics of family violence as it affects those with TBI
f. Do not understand how to organise and participate in whanau hui/family meetings and to create safe environments for this to occur.
g. Appear to listen to concerns raised in relation to the client with TBI, yet fail to follow up, return calls or seek more information
h. Do not liaise with, involve and ensure accountability from the client's GP in terms of the relationship between the client's general medical health and wellbeing and the medical matters related to the traumatic brain injury i.e. a holistic approach to the client which takes into account other aspects of health e.g. cervical screening, adverse effects on TBI recuperation of prescribing medication for co-morbid conditions,

(7) When people with TBI are being **transferred between services** the interface from secondary to primary health services is so important, but there is not:

a. Clear information provided,
b. Clarification of roles and responsibilities to prevent duplication for the patient, with their family/whanau.
c. A Coordinator who integrates well within the Multidisciplinary Team (MDT) throughout the patient journey.
d. The service from the Rehab Coordinator that was so necessary and effective in the past, but is no longer provided.

(8) If the original **Medical Certificate** does not document "Brain Injury" because it was not picked up, it is a time consuming process to have it recognised and included at a later date. A person may have multiple injuries and the broken bones are the most obvious so there needs to be education about assessing for and filling in the TBI information on the medical certificate at the time of injury. The correct terminology is helpful e.g. 'post-concussion syndrome' not just 'concussion'.

(9) **Generic letters** sent out can be very stressful for people with TBI. The clients may focus on one aspect .e.g. their entitlement can be cut if they do not attend the assessments. They may not be able to read and follow the whole letter in its context.

(10) Choice of **Assessors** can be difficult as clients seem to be told who they have to see. Sometimes this involves going to another city. Even within one city can be difficult when assessments can be over 3 sessions and require the client to travel on 3 consecutive mornings. Given that fatigue is one central feature of TBI, such appointment planning appears to disregard such crucial effects of TBI.

(11) The **assessments** must assess the *Brain Injury and its effects*. Many of the standard tests do not seem to be able to assess TBI effects such as: fatigue, decision making, managing social relationships in workplace settings.

(12) Although the ACC regulations allow **taping of assessment sessions,** this can be difficult. Some Assessors refuse to allow it to happen. They agree to do the taping but have the right to turn it off when they want, and will say that they will provide the client with a transcript of the assessment. Many clients with a TBI have poor memory and/or cannot read and find these situations very stressful so cannot remember what took place.

(13) Many clients have been devastated by the negative personal material in **assessment reports** and they do not seem to have the opportunity to discuss this with the Assessor. It would be more helpful if the Assessor had to meet the client (and where appropriate and safe, their family/whanau) to present their report and justify their conclusions.

(14) Whilst the client should be able to choose who to have as a **support person at an assessment**, that person should not automatically be a caregiver. If the views of caregivers are considered necessary, they should be sought separately from the client interview/assessment and should be with a brain-injury trained caregiver supervisor present.

(15) When **return to work** is encouraged too soon; often it is because the long term impact of the TBI has not been understood and no recognition given to the ongoing effects of TBI.

(16) Moderate to severe TBI can have life-long effects. Once **ACC assistance stops**, people with TBI can feel totally alone without any support, which can be scary and isolating. Seeking out advice from people who are knowledgable about TBI is challenging for people with TBI, particularly once they have been discharged from rehabilitation/support services as these were usually their information and support sources.

QUESTION THREE
IF THERE WERE THREE (OR FIVE) THINGS TO BE IMPROVED / CHANGED AS A PRIORITY FOR THE FUTURE, WHAT WOULD THEY BE?

- Attendance of all professionals concerned from ACC and health agencies at MDT meetings to discuss and collaborate collectively about the client management and rehabilitation.
- Incorporate regular education for staff at hospital/community emergency departments and appropriate resource available to give the patient, family/whanau with a referral and feedback process.
- Maori Health role to support Te Taha Tinana, Te Taha Wairua, Te Taha Hinengaro, Te Taha Whanau and work in partnership with the whanau/family and other professionals.
- Social work(or similar) trained and educated Case Managers with a sound knowledge of the effects of Brain Injuries, an understanding that the people with TBI are part of a family/whanau and that the work of the case manager must, of necessity, involve the whole family/whanau, irrespective of the provisions of the PPPR Act.
- Assessments that assess the effects of the Brain Injury within a holistic medical/psychosocial, whanau/family and community framework, taking into account family and social connectedness, community and appropriate GP support, the exclusion of family violence and any other form of abuse or neglect by any person or persons. Assessors must be prepared to discuss their conclusions with the clients.
- For clients returning to work, it is vital to provide more support in the transition to work stage to enhance better long term employment outcomes.
- Professionals who are interacting with and give advice/information to clients with TBI should give the same information to family/whanau to relieve the pressure of the client with TBI to be in the ‘messenger’ role.