

Engaging the public in healthcare decision making



Faculty of Health Sciences, La Trobe University
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Acquired Brain Injury Rehabilitation Research Program

Brain Injury Rehabilitation Citizens' Jury

Final report, 2014

Reported by Associate Professor Natasha Lannin, with shared views of the participating citizens.

Project supported by La Trobe University in conjunction with Alfred Health

AlfredHealth
Occupational Therapy Department



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Brain Injury Rehabilitation Citizens' Jury

29-30 October, 2014.

Report by Associate Professor Natasha A. Lannin.

It has long been recognised that better health care policy and practice may be achieved by paying more attention to the views and experiences of health care users and indeed of all members of the community (i.e. the citizens). There are many ways to encourage citizens to share their views about health care, and one method is known as a citizens' jury. Similar in principle to a court jury, a citizens' jury in healthcare brings together a group of citizens from diverse backgrounds (conceptually representative of the broader citizenship) to consider a particular aspect of health care. Over the course of days, members of the Jury listen to expert witnesses presenting their views on the nature of the problem, raising issues as well as solutions dependent on their perspectives. Jurors are given the opportunity to question these witnesses and ask for other witnesses to appear and give their views. They then discuss as a group what they have learned and attempt to come to an agreed view on the best way forward. At the end of this process the citizens' jury findings and recommendations are made available to health service policy makers and clinicians.

Alfred Health and La Trobe University led a team of national researchers in a project to better understand the community's views and opinions related to brain injury rehabilitation. Led by Associate Professor Natasha Lannin from Alfred Health and La Trobe University, the team included experienced researchers from La Trobe University, Alfred Health, Flinders University, University of South Australia, the National Trauma Research Institute and Brain Injury Australia.

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Nicholas Rushworth, Brain Injury Australia

A citizens' jury ran on October 29th and 30th 2014, focussing on brain injury rehabilitation. Jurors were selected at random from the Melbourne population at large and invited to meet for two consecutive days at Caulfield Hospital, Melbourne to consider the topic in question.

The research project was funded jointly by La Trobe University and the Occupational Therapy Department of Alfred Health.

Prior to the commencement of the citizens' jury, the jurors were sent the following questions, which provided the focus for the two days of deliberation.

In the context of finite budgets for rehabilitation and challenges to providing optimal care to all persons with brain injuries, what considerations are important to you?

There are a number of questions that will be posed and discussed to lead you to making that final decision:

- Are there circumstances where it is acceptable to not provide rehabilitation to someone with a severe brain injury?
- Should patients be given a choice over where they are treated, by whom (the type of health professional), and what treatments they are offered?
- Should family members be considered as equal partners with the patients admitted? If YES, should some of the resources that we would otherwise spend on the patient be provided to the family members of the person with a brain injury instead?
- How can information about rehabilitation be provided and more easily communicated to people with a severe brain injury and their family?

Selection of Facilitator

To ensure a successful citizens' jury, it was important to engage a person experienced in delivery of citizens' juries to facilitate discussions over the two day event. The research team engaged Dr Annie Bolitho to advise our team and to facilitate a citizens' jury at Caulfield Hospital. The team met with Dr Bolitho in July 2014 to discuss the experts who should be invited to provide information to the jury, and the broad questions that should be posed to the jury given the study aims.

Selection of Jurors

An external agency, West Coast Field Solutions, experienced in recruiting participants to research, facilitated the random selection process. The agency provided contact details for 30 potential jurors, which were sourced from purchased publically available telephone databases, listing geographic locations in metropolitan Melbourne. The agency also provided demographic data from potential participants, collected via telephone contact, to assist in the jury selection process.

Upon expressing interest in participating, potential jurors were screened by West Coast Field Solutions to disqualify those who had experience of a brain injury, either themselves or to a family member, friend or acquaintance. Potential jurors with previous experience of brain injury may have pre-

conceived biases about the delivery of brain injury services based on their personal circumstances and it was deemed desirable to include only jurors without these preconceptions. For similar reasons, those who have worked in fields that provide them with some knowledge of brain injury were also disqualified.

Twelve jurors and three 'stand-by' jurors were selected from the shortlist of 30 potential jurors. The twelve jurors were selected based on their demographics, including gender, age, education, working status and employment type and suburb of residence as a proxy indicator for socioeconomic background, with the aim of including a broad cross section of the community.

Conduct of the Citizens' Jury

The brain injury citizens' jury was convened over two days on October 29th and 30th 2014 at Caulfield Hospital, Melbourne, where the new statewide Acquired Brain Injury Rehabilitation Service is located.

To record the citizens' jury process and report on the deliberations, discussions and outcomes, members of the research team and two invited observers remained present in the room without taking part in the discussion.

The jurors were addressed by a range of experts who had been carefully selected by the research team and were tasked with providing the jury with factual information about the Victorian statewide health system and health challenges faced by people delivering brain injury rehabilitation.

Expert presentations were given on both days, allowing for a mix of discussion and synthesis of information across the two day jury. Presentations were between 7-10 minutes long and scheduled to provide information related to the key questions. Discussions varied from facilitated question and answer panel format to small group discussions with presenters.

The expert witnesses were:

- Dr Peter Bragge: Senior Research Fellow at the National Trauma Research Institute.
- Ms Therese Morgante: disability sector consultant and policy advisor, Dyson Consulting Group.
- Mr Nick Rushworth: Executive officer of Brain Injury Australia; severe brain injury survivor.
- Mrs Cheryl Koenig: Mother; Cheryl's son Jonathan suffered a severe traumatic brain injury.
- Ms Nerida Hyett: PhD student with the Building Health Communities research program at La Trobe University, with research interests in community participation and health.
- Dr Kate Laver: Senior Occupational Therapist, working with people with stroke and brain injuries. Kate has a strong interest in understanding the gap between research and clinical practice.
- Ms Libby Callaway: Director and principal occupational therapist providing community based rehabilitation to people with acquired brain injury, and research manager of the Summer Foundation.

After the final witness presentations, the jurors began determining their responses to the posed questions. Facilitated discussions helped jurors focus on the principles they would use in determining priorities for brain injury rehabilitation.

Summaries of Presentations

Introduction to brain injury

Presenter: Dr Peter Bragge

What is a Brain Injury?

A **brain injury or Acquired Brain Injury**, oftentimes known as ABI, refers to any damage to the brain that occurs after birth. Damage can be caused by an accident or trauma, by a stroke, a brain infection, by alcohol or other drugs or by diseases of the brain like Parkinson's disease.

Brain injury is reported to affect over 600,000 Australians. Such injuries have a widespread impact in the Australian community, since those affected may experience long term or lifelong physical, cognitive, behavioural and emotional consequences with personal, family and community impact.

A person with a brain injury can experience effects from their injury for many years. The range of disabilities can affect them physically as well as affecting how they think, feel and behave, including difficulties with looking after themselves, with accessing housing, with returning to or maintaining a job, and forming or sustaining relationships.

Cost for providing initial care and long term assistance can impact greatly at both a personal and societal level.

- Brain injury is often broken down into two categories, 'traumatic' and 'non-traumatic'.
- The severity of the brain injury can be rated on a scale from 'mild' to 'extremely severe'.
- Experiencing a brain injury can impact on just about everything in a person's life, including the way they move, communicate, think and take part in their daily lives.

What is evidence based practice in Brain Injury?

Evidence based practice or EBP is defined as the thorough attempt to find and then use the best evidence to help practitioners take good decisions around the care of individual patients. The process of completing EBP involves drawing on the following areas: clinical expertise, the highest **level of evidence** and the patients' values and preferences. This process is vital in providing the best care to patients who have experienced a brain injury.

Examples:

- **Physiotherapist** doing a review of the research that is now available to design the best treatment method to assist a patient to improve their walking after a brain injury.
- **Health professionals like doctors, nurses and speech therapists**, and the organisations they work for putting in place treatment based around the '**best practice guidelines**' that have been written for brain injury.
- Health professionals doing professional development workshops or courses to broaden and deepen their skills.

What is an 'intervention' and who delivers them in brain injury rehabilitation?

An **intervention** refers to a treatment, task or activity completed by health professionals to support the recovery of a patient who has experienced a brain injury. There are a huge range of treatments, tasks or activities that can be made available to brain injury survivors. All of them have been researched to different levels to indicate their effectiveness. The different health professionals that administer these interventions are: Medical services (specialists, surgeons, doctors, nurses) and allied health services (neuropsychologist, physiotherapy, occupational therapy, speech therapy, social work, dietician, podiatry).

Example 1: Medical service intervention versus allied health intervention for acute care

Medical Services	Allied Health Services: Physiotherapy
Surgery to relieve the intracranial pressure an ABI patient.	Review of a patient's ability to move to determine the safest method for the patient to get around.

Example 2: Medical service intervention versus allied health intervention for inpatient rehabilitation

Medical Services	Allied Health Services: Occupational Therapy
Provision of medication to assist with reducing the patient's pain	Provision of an upper limb exercise program to increase the patient's arm/hand movements and strength.

Example 3: Medical services intervention versus allied health intervention for outpatient rehabilitation

Medical Services	Allied Health Services: Speech Therapy
Liaise with the patients local doctor regarding the ongoing medical care that patient will require.	Provision of a communication book which includes key phrases and words to assist the patient to communicate within the community.

Which models of rehabilitation are considered 'best practice' in brain injury in 2014?

There are a variety of different models of care that a person who has experienced a brain injury could receive.

The rehabilitation path is usually dictated by local health care policy, local culture and the availability of resources. There is a lot of variation between the models of rehabilitation that are offered in different countries, in a country like Australia and between different health organisations, like Alfred Health, Peninsula Health and Western Health. There is not enough research completed which can clearly identify the model of care that results in the best outcomes for patients. The diagram below shows the model of rehabilitation that most patients who have experienced a brain injury in Australia will come into contact with; **acute care, inpatient rehabilitation, community rehabilitation and community health.**

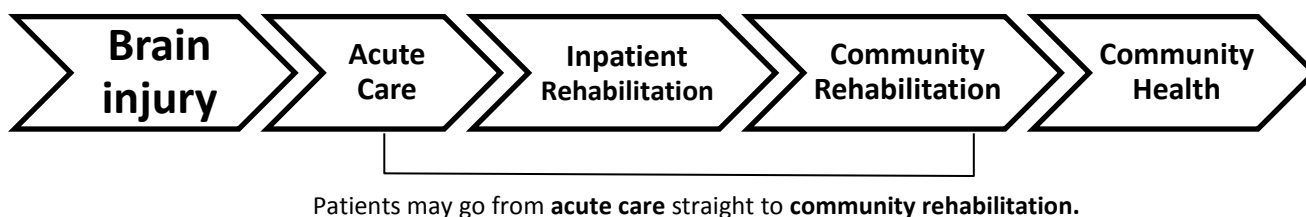


Diagram 1: Model of rehabilitation for brain injury in Australia

The table below provides more detail about the model of rehabilitation for brain injury in Australia, outlining key stages, timeframes, roles of health professionals involved, and locations.

	Acute Care	Inpatient Rehabilitation	Community Rehabilitation	Community Health
Timing	The care brain injury patients receive when they first arrive in hospital.	The care most brain injury patients receive after discharge from acute hospital.	The care most brain injury patients receive after discharge from inpatient rehabilitation. Patients can be discharged from acute services straight to home or to community rehabilitation services.	The care some brain injury patients receive after discharge from community rehabilitation.
Location	Patients receive care in an acute hospital such as The Alfred hospital, St Vincent's hospital or The Western hospital	Patients receive care in a rehabilitation facility such as Caulfield Hospital or Royal Talbot Rehabilitation Hospital	Patients receive care in the home environment or they attend centre-based therapy at a rehabilitation facility such as Caulfield hospital.	Patients receive care in the home environment or they attend centre based therapy at their local community health centre.
Patient Status	Patients are generally medically unstable	Patients are generally medically stable	Patients are generally medical stable	Patients are generally medically stable
Medical Services Involvement	Patients receive extensive medical services, which can include surgery. The aim is to give the patient the greatest chance of recovery.	A medical team completes a daily review of the patient. The aim is to ensure the patient remains medically stable and to manage any other health concerns, such as previous medical conditions, medication prescription, and ongoing assessment of recovery.	A medical team usually reviews the patient at admission to the service and provide any ongoing medical services required. The aim is to ensure the patient remains medically stable and to manage any other health concerns, such as existing health conditions or medication side effects. Patients' own GPs can also be involved in their care.	The patients' medical care is generally the responsibility of their local GP. The patient can still have contact with specialist medical services.
Allied Health Involvement	Patients receive allied health assessment and intervention. The aim is to begin the process of rehabilitation and provide recommendations regarding discharge.	Patients receive extensive allied health assessment and intervention. The aim is to provide treatment to support the patient's recovery and achievement of goals.	Patients receive ongoing allied health assessment and intervention. The aim is to continue the process of recovery and to ensure successful community participation.	Patients receive ongoing allied health assessment and intervention. The aim is to oversee any long term goals or problems the patients might have.
Length of Stay	Patients generally have a short stay (this can be from a few days to several weeks) until they are deemed medically stable.	Patients can stay for an extended period of time, from a few weeks to several months. A variety of factors influence length of stay including severity of injury, support needed for discharge, their living situation before their ABI and whether the patient is making improvements.	Patients can be involved with community services for an extended period of time. Several factors such as living situation, whether the patient still has goals to achieve and how they are coping in the community can influence this duration of contact with community rehabilitation.	Patients can be involved with community health services for extended periods of time. Factors such as whether the patients have a continued need for allied health assessment and intervention can influence this length of time.

Healthcare decision making

Presenter: Therese Morgante

Citizens Jury – Future directions for ABI (Notes from presentation):

- Dyson Consulting Group is a small, niche consulting firm, engaged in program development, evaluation, strategic planning, outcome measurement in the disability & other human service sectors such as mental health and education
- Most Dyson Consulting Group staff have also worked in the insurance industry supporting people who have acquired a disability, usually through a motor vehicle or workplace accident. My experience of people with brain injury is largely based on their engagement in community, and some of the longer term issues that can arise, rather than on the acute or clinical services/needs. When thinking about people who acquire a disability, it's important to remember that they had a life before their accident. Life – Acute – Rehab – Life again – rehabilitation is hugely important, especially in the early stages following an accident, but the focus of rehab should always be about helping people to connect to that life again. Even if a person's capacity is altered, their life, interests and roles need to be reimagined – for example; if a person can no longer manage the responsibility of working as a kindergarten teacher, can they consider working as an assistant or volunteer?
- The notion of reconnection with life is also something that needs to be a focus immediately post the acute phase and not something that is considered only in preparation for discharge. Some of the ways people in rehab are 'stopped' from reconnecting with life include:
 - o Funding rules – in Scandinavia, rehab wards are largely empty on weekends – weekend leave is arranged as soon as people are medically stable and temporary arrangements are put in place so they can go back home – in Australia, even though rehabilitation is not delivered on the weekend, people remain in hospital – in the vast majority of cases, a person's first trip home is with an occupational therapist to discuss home modifications
 - o The delay in planning for 'life' – again let me say that rehabilitation is critically important, however when it is only focussed on the clinical setting, when people are ready for discharge, there is a danger that some of their connections (for example – employment & recreation) may be lost- we all know it is much harder to build a brand new connection than it is to keep an existing one going. When working with a very competent rehabilitation unit, staff were unsure how to work with someone to fill it out as there were no questions or categories to look at a person's "function"
- Following discharge from an inpatient rehabilitation setting, many people then undergo a period of community based rehabilitation. It is important to remember that these people now have a 'disability'. In 'disability speak' the social model of disability has long replaced the 'medical model' of disability. In the social model of disability, people are not seen as 'sick' or 'requiring treatment' or 'needing to be fixed' – RATHER – they are self-determined citizens with goals and aspirations, and live their lives as full and active members of the community
- I think the challenge here, for people involved in providing essential rehabilitation for people with brain injury IS – at what point do they transition from medical/rehabilitation support to disability/social/community support?

Family experience

Presenter: Cheryl Koenig

“The 18th May, 1997 is permanently etched in my mind... It was a lovely autumn Sunday. A day spent at home doing ordinary things. We were a typical middle-class family with our own business and I was then the blissful mother of two very active boys, 10 and 12. Jonathan, the eldest, could play 3 musical instruments, had innate agility, and was at the top of his class academically. The 18th May 1997 was the day he was hit by a speeding car whilst crossing the road to come home.

I was there within minutes and found him lying crumpled like a rag doll on the road. I knew immediately it was serious. There was an enormous amount of thick, dark-red blood oozing from his nose and mouth. He was on his right side and his eyes were open. After a few minutes, he suddenly vomited, and it was then that I began to get truly frightened because his breathing became laboured and his eyes glazed over. I knew I was losing him...

That was 17 years ago, but when I go there in my mind, it feels like yesterday. To be honest, I had never really heard of the term TBI. Oh yes, I had definitely heard the term ‘head injury’ thrown around on the news – especially to do with MVAs – but I naively envisioned a ‘head injury’ as something perhaps involving some bleeding at best, or at worst, a fractured skull. I had no idea what the implications of an ‘extremely-severe-TBI’ meant – but I very quickly learnt.

Initially Jonathan had a Glasgow Coma Score of 3 and we were told many times over the ensuing weeks in Intensive Care – from nursing staff to neurosurgeon – not to expect him to live through the night.

During the first 3 weeks all we could do was sit helplessly by his side as he clung to life on a ventilator and watch with horror as numbers plummeted and alarms shrilled. We thought our prayers were finally answered as he defied the odds to survive. Only then were we confronted with the daunting realisation that not one muscle in his entire body functioned; his eyes were fixed to the right, he couldn’t move, talk, or even swallow – his head hung forward and dribble poured from his mouth. When he was pronounced ‘medically stable’, with that came overwhelming feelings of relief; but what we didn’t know then was that we were in for a marathon – years and years of intensive daily therapy.

Based on statistical outcome measures for brain injury, as Jonathan was in a coma for approximately six weeks, and worse, in post-traumatic-amnesia (PTA) for about ten months, we were told he may never walk, talk or ever eat again, and we were given a very definite poor long-term prognosis. At the 1-month mark, the neurosurgeon said: “I am not sure what, if any function, he will ever regain”. You never forget words like that...it was like the falling guillotine, severing what little hope we had left in our already crushed hearts.

I realise that clinicians are reluctant to give anyone ‘false hope’, due to so many unpredictable factors, however I believe there needs to be a distinction between ‘false hope’ and ‘false promises’ – and families need to be given credibility for understanding the difference.

We live just under an hour’s drive from the Children’s hospital that Jonathan was in for 5 months. During the first month, my husband and I didn’t leave the hospital grounds, sleeping wherever we could find a couple of chairs, or later, a spare bed. Once he was moved to the Neuro-ward, therapies

slowly began; my husband began going home at night to be with our 10y.o. son – who had been shunted between relatives – and I stayed day and night, sleeping then in the parent’s room of the same ward. At about the 2 or 3 month mark, therapies were dramatically reduced, and when asked why, we were told by the rehab specialist that it was because our son was not a ‘fast-tracking patient’ – meaning therapists were required to work on people who could turn beds over more quickly. So at about that time, we began bringing him home for long weekends – against medical advice. We sourced out private therapists and paid for them to come to our home and devise a programme for us to follow. It was an extremely expensive and exhaustive exercise, but well worth it.

Were we treated as equal partners in his rehabilitation? Definitely not. For example: at around 5 weeks, when he began responding to commands, it was only to my voice. Yet I was not given any creditability in this regard, unless a clinician was actually present. I think if you opened his file, within the margins would read: “Unrealistic Mother”. Regardless, like a lioness fighting for her cub, I eventually forced my way into therapy sessions and decision making processes.

After five months in hospital we went home permanently. Yes it was ‘home’ – but we very soon realised that home would never be the same again. Life would never be the same again. We threw ourselves into the mammoth task of rehabilitating our son. For most of the first year at home we had no time at all to deal with feelings of grief or loss.

We continued to utilise the outpatients clinic for another year, but often after 1 ½ hours in peak hour traffic – usually with Jonathan vomiting from motion sickness – on arrival therapy appointments were often cancelled. Generally, therapy was haphazard, and not as intensive as it needed to be, with no repour initiated with us nor Jonathan and hence no due consideration of the family’s goals. So we were forced to look elsewhere. As he was only 14, he was too young for Sydney metropolitan BIUs. Fortunately, in my research, I discovered the hi-mobility training program at Epworth Hospital (designed by Gavin Williams PhD, under Prof John Olver) and Jonathan was accepted there as a client. We began travelling from Sydney to Melbourne every school holidays for 2 weeks of intensive rehab, with Gavin instructing us what to do with him at home in-between visits (this still continues today, and Jonathan still continues to make small gains).

As Jonathan’s condition improved he gradually resumed his place in the community, returning to his former high school and participating in more activities outside the family home. With this progress came the realisation that for us to survive and function in the community as a family, we had to find a new foothold in a very different world to the one we had previously enjoyed. This was a world filled with adversity, inequity and unexpected confrontations and hurdles. A society that still today regrettably averts its eyes and closes its ears to the plight of people with brain injury. We not only had to accept that precious dreams had been lost, but on top of that we also had to deal with the attitudes of the ignorant. The largest burden came not from the 6-hours-a day of home-based therapy programme, nor from the countless hours of physical care that Jonathan required; instead it came from the weight of insensitive remarks and preconceived notions of others, including clinicians.

For several years following the accident life was a huge challenge for our little family. It changed the whole dynamic of the family: e.g. there was a role reversal for our younger son, who took the mantle of ‘older brother’. My husband’s father, who was then 70, had been running our family business, but eventually we closed it down. For me, the change was pervasive and overwhelming, partly because I was reluctant to relinquish my attachment to the ‘perfect’ life we had once shared.

Today, however, I have accepted this new reality. We are once again a happy family having adapted, albeit slowly, to our new lives. From a personal perspective, I have grown as a direct result of caring for my son and dealing with his residual disabilities on a day to day basis. Yes, I am a 'Carer'; though my role has changed over the years in parallel with Jonathan's needs. I wear many hats, as do most people who find themselves in the role of Carer. At home I am his physical trainer, speech therapist, social secretary, tutor, counsellor, personal-care attendant etc. Outside the home I have been his aide in education courses, but remain, by and large his navigator and assistant – both literally and figuratively.

*Our biggest challenge, or main aim, was to restore as much function and mobility to Jonathan, so that he could successfully participate within the community – as we see **that** as the OVERAL MARKER OF SUCCESS. Consequently, he now has a very full and active life: he not only can walk well, but can run, snow ski, play piano 1-handed, is learning to drive, and works in 4 part-time jobs 5 days a week."*

Personal experience

Presenter: Nick Rushworth

"Thank you. Coming here this morning, it dawned on me: if YOU'RE a "citizens' jury", and brain injury rehabilitation is on trial, I'd be the star witness for the prosecution.

Maybe I'm dreaming.

Whatever I am, I don't want to let the side down. But while my...victim impact statement is almost entirely...by way of contrast, I'm hardly representative of recovery from severe brain injury, I do have some glimpses of what LIVING with a brain injury is like. But perhaps it's more in the nature of having a brain injury as a kind of housemate, a former housemate- one who moved out, and moved on, or perhaps I did, I can't always tell. However it happened, in the way of housemates, my brain injury left a few things behind - half-empty cartons of milk in the fridge, odd socks, a pot plant or two. Less lost property than mementos. Reminders. Reminders of what living, STILL living, with a brain injury might have been like if he'd stayed. I hope that makes sense.

In order for me to prosecute a case on behalf of patients, of consumers – my constituents - everything else, ALMOST everything else, comes down to the use of the imagination. By imagination, I don't mean of the staring-out-the-window, daydreaming of a desert island kind, but something much more instrumental; the ability to transplant yourself in imagination into something of the life circumstances of somebody else. Somebody you've just met - in, perhaps, a therapeutic role, a human services, a humane role - and on first look someone with whom it would appear you have nothing in common, to evoke something of the world from whence they came, as both a first principle and a starting point, and as the foundation for (quickly) building rapport. I trust that this might make me a passable eyewitness to the experience of others.

I had my "scrape" in February, 1996.

Two weeks in hospital (which included putting my right leg, and the right side of my face back together and re-attaching a severed ear. The forces involved were such that I had a fracture of the entire circumference of my skull. My sister told me that, from looking at the scans, it was as if its bottom half was wearing the top half like a cap.

Three weeks in rehabilitation.

And then back at work by August.

Which makes it all sound like a bit of a diversion, an escapade. I'm sure I thought of myself as lucky. My thinking has matured since then.

I've never believed in fate. Nowadays, I don't much believe in LUCK either. As I can remember a famous sporting coach once saying; that HIS team, HIS players "make their own luck". In this same way, I've come to believe, instead, in systems, in structures - whether they're governments, they're publicly-funded services, the economies, the businesses that those services depend on for money. And I believe in communities, in families. Don't mistake me, I'm sure an individual's - whatever you choose to call it - their drive, their determination are still crucial, perhaps indispensable, to recovery from any injury, any adversity.

But because I was on my way to work – in New South Wales – I was covered by worker's compensation.

And I got hit in the right place - when I think about the parts of the United States, Ireland, and the parts of Australia that I've ridden my bicycle where it could have been so different. I was minutes by ambulance to a major metropolitan hospital.

And I had private health insurance. Although I wasn't really in any position to exercise my rights to, what, a private room, my choice of doctor. But, my family were. You see, my father is a brain surgeon. My mother and my sister are doctors also.

While I have been asked today to reflect on my experience of this time in hospital, I didn't, WOULDN'T have had a clue. I spent most of the time sleepwalking through the loopy fog of what's called post-traumatic amnesia - a delirium the result of trauma to the head that cuts you loose of any reliable hold on time, place, person. And when I wasn't there, I couldn't, CAN'T really account for anything of what I did, let alone what I thought, or - perish the thought - what I said. But one of the many luxuries of occupying the high ground of an exceptional recovery is I get to choose what I remember, and forget from what's left. So, once I'd retrieved my sound mind, one of the first things I did was request a copy of my medical record.

I DO know that my family hand-picked my care, and unlike the ~ 99% of the individuals and families I represent in my role within Brain Injury Australia, where very often the first time they hear the words "brain injury" is upon entering hospital to visit their injured loved one - my family knew brain injury backwards, frontwards, sideways and, crucially, were directly involved in my care almost at equality with the staff of the hospital. For instance, I was the standard issue head trauma patient - agitated, aggressive, clearly a flight risk and in need of both physical and pharmacological restraint. My family was able to engage in the highest level discussion - and debate - with the hospital's psychiatrist about the kind and amount of anti-psychotics and sedation I was being administered so as not to impede my recovery from brain injury.

This is one of those screamingly obvious life lessons you can only TRULY learn in the crucible of going through something like rehabilitation and recovery from brain injury- that all of us live and operate in the world armed with and protected by the stories we can tell about ourselves. In my case, an innocent bicyclist hit by not one, but two, cars. (Double victimhood. And double heroism. The heroism of the physical. I was barely post-prime of life, in the peak of fitness. And...I was on my way to work, to a job). And protected by my LIFE story - all those accidents of birth, birthplace, of family, and of a person not just born but created. Look, my purchase on the memory of that time in my life ain't crash hot - and I don't deny that thinking from this distance in time can distort things. But I still reckon the greatest part of the reason for my recovery IS my life story - the kind of formed, created and supported person - supported by family, by communities of friends and work colleagues - the person I was BEFORE I hit the cars. And all the relative advantages they bestowed, BESTOW that I took with me into - and through - my brain injury.

On a subject like brain injury where there's so many known unknowns, and unknown unknowns, there's ONE truth that can bear re-stating here: that brain injury - like other disabilities - tracks social-locational disadvantage.

Those people at the greatest risk of a brain injury are drawn from exactly the same populations as those at risk of ANY injury - from backgrounds of low income, low levels of education, high levels of unemployment, poor housing and so on. This might bring it home: half of my hometown Sydney, half of its metropolitan area's young, risk-taking, severe traumatic brain injuries - the motor vehicle accidents, the assaults - HALF occur between the, what, longitudes of Parramatta and Penrith. I'm no bleeding heart but many, perhaps the majority, of Brain Injury Australia's constituents were already born behind society's eight ball. Their brain injury also - mostly- serves to add, and add significantly,

to their disadvantage. And call me quaint but in a broader culture of creeping competitive individualism - of sink or swim, with some safety nets - I just don't reckon that society's capacity for "overcoming" its quantum of resilience (of rebounding from adverse events, from trauma) gets shared around equally. Shared around equally between individuals, nor shared around equally between communities.

These are, in summary, the findings of local longitudinal surveys into the outcomes of severe traumatic brain injury:

- *9 in 10 return to care of their family;*
- *the average costs of care are around \$100,000 per year;*
- *only 40 per cent of people living with severe traumatic brain injury are employed 5 years post-injury;*
- *of all people with a disability, they have the second lowest representation in employment;*
- *over half of all marriages involving a partner with a severe traumatic brain injury dissolve within 6 years of injury;*
- *half report they have lost friends, have become socially isolated since their injury;*
- *they run a 60% likelihood of major mental illness during the course of their lifetime; and*
- *1 in 5 will attempt suicide.*

Traumatic brain injury is more often than not a "prime of life" disability occurring right at that point of a person's life (3 in every 4 a male [person], a MAN'S, a YOUNG man's, a BOY's entry into adult life, and of maximal expression of independence from the constraints of a too-long childhood - in leaving home, adventuring in the world of gap years or work, of embarking on further study. And AS often it's an infinitesimal moment, an instant, of - nothing more, or less - than inattention, than undue risk - their own, somebody else's - that moment, that instant divides their life in two. For many, for most people living with a severe brain injury they describe it as THE watershed event of their life - where everything changes, when nothing after will ever be the same as before. (A watershed's a line, a strip of land that separates two bodies of water – two lakes, two rivers.) I think it's fair to say that what most people profoundly disabled by their brain injury feel most keenly is having been cut adrift of their past - in concrete terms, that they cannot do, or think, or feel as they once did.

And when I "train" people in brain injury, what I invariably ask of them is to reach for any and all continuities with their client's, their customer's past, try and tap any wellsprings of work, diversions, interests, pre-injury pastimes and passions – as a means of breaching that watershed.

You'd be surprised by how uninterested many professionals who work in brain injury seem to be in excavating what person the person in front of them was BEFORE their injury. There is, believe me, nothing more re-disabling than being thought nothing more or less than the sum total of your injuries.

Thank you."

Consumer Participation in Healthcare

Presented by Ms Nerida Hyett; Written by Dr Sophie Hill and Ms Nerida Hyett

What is consumer participation?

Consumer participation is the intentional involvement of individual service users, or potential service users, in the planning and delivery of healthcare, and service development initiatives.

The Australian Government defines patient and consumer participation as a *partnership* between healthcare service users and their families, and health practitioners and managers. The definition adopted by the Victorian Government is:

“Participation occurs when consumers, carers and community members are meaningfully involved in decision making about health policy and planning, care and treatment, and the wellbeing of themselves and the community. It is about having your say, thinking about why you believe in your view, and listening to the views and ideas of others. In working together, decisions may include a range of perspectives.” (Department of Human Services Victoria, 2011, p. 2)

Consumers may adopt different roles (Hill & Draper, 2011), including:

- As an *individual*, a person can be involved in making decisions about their health, treatment options and management of illness, or on behalf of a dependent
- Being a person who *shares* a health interest or health condition with a group of others who are similarly affected, an individual could work with others to develop and provide information and support
- As a member of the public or a health advocate, a consumer can be part of *civic* dialogue about health, to raise awareness and influence government policy, professional agendas, research, health service delivery and governance

Box 1. Examples of consumer participation

Consumer participation can include:

- Filling out a consumer feedback survey after visiting an allied health practitioner
- Attending a focus group to inform the development of a new health program
- Reading and discussing health information materials with your doctor in relation to a new health diagnosis
- Working with a treatment provider to develop an illness management plan
- Using an electronic personal health information record to manage care plans with multiple service providers
- Using a health providers social media site to provide feedback or contribute to discussion

Rationale for consumer participation

Consumer participation in healthcare has a range of benefits and is expected to lead to more accessible and acceptable health services, and improve health and quality of life of consumers (Crawford et al., 2002)

Historically, consumer participation was identified by the World Health Organization as a democratic right, stating “*people have the right and duty to participate individually and collectively in the planning and implementation of their health care*” (World Health Organization and UNICEF, 1978)

Australian Government policy requires consumer participation in the planning and design, and monitoring and evaluation of healthcare (Australian Commission on Safety and Quality in Healthcare, 2011, 2013), which is supported by international health authorities including the World Health Organization and the World Bank.

What are the benefits of consumer participation?

Potential benefits of consumer participation include:

Improved delivery of health information to consumers

- Interventions that help people acquire adequate health information during clinical consultations can increase question-asking and discussion during consultations, and improve patient satisfaction with care provided (Kinnersley et al., 2007).

Improved communication of health information by providers

- Consumer participation can improve the quality of communication between health practitioners and consumers, which is likely to improve health outcomes (Oliver-Baxter & Bywood, 2013)

Increased evidence-informed choice and shared decision making

- Consumer participation interventions that improve informed consent consistently improve patient knowledge and satisfaction with treatment decision-making (Kinnersley et al., 2013)

More capable patient-centred health practitioners

- Interventions to promote patient-centred care within clinical consultations were effective across studies in transferring patient-centred skills to providers, which makes them more capable of responding to the patients personal health needs (Dwamena et al., 2012)

Increased health service responsiveness and performance

- Consumer input provides different and complementary perspectives to views of health providers. Consumer perspectives are a valuable source of information for the design and delivery of healthcare services for both individuals and families, and whole communities
- Consumer participation can increase the accountability, transparency and responsiveness of public health services

- Involving consumers in developing patient information materials can improve the clarity and relevance of materials, and can improve people’s knowledge without increasing their anxiety about medical procedures (Nilsen, Myrhaug, Johansen, Oliver, & Oxman, 2006)

Positive experiences of consumer participation are described by participants, for example:

- Participants of the Cochrane Consumer Collaboration described benefits of *“Make information about evidence based health care more accessible. Learn and keep up to date, either with research about a specific condition or with evidence based health care. Contribute to the development of evidence based health care.”* (Horey, 2010).
- A review by Attree et al. (2011) described positive benefits experienced by participants including *“physical and emotional health and well-being, self-confidence, self-esteem, social relationships and individual empowerment”*. Feeling empowered was linked to feelings of being useful to others, feeling in control of events, being able to express ideas and having an awareness of individual rights.

What are the challenges of consumer participation?

At the individual level:

- Health professionals face many demands and challenges that might prevent use of consumer participation practices, such as the inclusion of consumers, carers, and families in collaborative care planning
- Common misperceptions are that consumers have little health knowledge to offer, or from the consumers perspective, that their input will not be used by their provider
- People of different ages, cultural groups, and people with disabilities require different mechanisms to effectively engage, and using only single mechanisms or inaccessible methods might exclude valuable consumer insights

At the health service level:

- So far, there is a lack of ‘gold standard’ evidence that demonstrates the impact of consumer involvement on patient outcomes (Nilsen et al., 2006)
- Sustainability of consumer participation practices can be compromised if insufficient supports are in place by management (Horey, 2010)
- Participation with consumer groups and advocates can sometimes lead to unintentional negative consequences such as stress, exhaustion and burn out because of over-consultation or volunteering-related fatigue (Attree et al., 2011)
- Budgets and lack of flexibility in service delivery can limit implementation of consumer ideas (Freeman et al., 2014)
- There can be systemic or bureaucratic barriers to sharing decision-making power with consumers, for example, policy and legislation that criminalises specific health practices and choices (Freeman et al., 2014)

How are consumers involved?

- Consumers can be involved via in-person or online methods
- Consumers can be involved through consultations to elicit their views or through collaborative processes with groups of consumers to allow debate
- The purpose and methods used for consumer participation vary from information provision and seeking feedback (e.g. consumer feedback survey), to shared decision-making, or initiatives where consumers are given full program control (e.g. Aboriginal Community Controlled Health Services)
- Participation can be a single event, or repeated events, with an individual health service provider, or with a group of consumers and/or providers
- Individuals or groups might be convened especially for a consultation, or established consumer organisations might be consulted for input on consumer experience (Nilsen et al., 2006)

Box 2. Final statement on consumer participation

Final statement

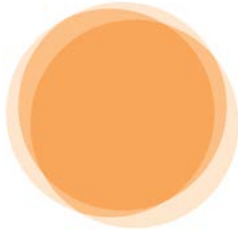
Consumer participation ensures that individuals, families, and communities have access to essential health information, to enable them to fully participate in their treatment with health service providers. In addition, consumer participation can provide valuable input in health service improvement initiatives. Research demonstrates that consumer participation can improve health outcomes for individuals and families, and the broader community.

Consumers are involved in the spirit of collaboration, to provide their experience, opinion, or advice on the health issue, which is in their interest personally, or because of a greater community issue or need. Consumer participation initiatives seek out a diversity of consumer views and experiences. Participation can be facilitated in many ways, however primarily involves listening to consumers, encouraging them to ask questions and seeking their feedback.

Community based brain injury rehabilitation

Presenter: Libby Callaway

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MONASH University
Medicine, Nursing and Health Sciences

Today I have been asked to talk to you about the importance of outcomes in rehabilitation and potential impact for community living. Specifically I have been asked to focus on the experiences and complexities of rehabilitation - what works, what doesn't work, funding, and timeframes for engagement in the rehabilitation process.

Michelle's story

To do this, firstly I am going to introduce you to Michelle. Michelle is like many of the people who may come through the new ABI unit at Caulfield ... a unit that has been designed for people who sustain the most severe brain injuries and would have traditionally not been deemed eligible for rehabilitation.



Michelle was 19 years old, had just completed VCE and secured entry to University to study teaching when she suffered an extremely severe asthma attack and stopped breathing for over 40 minutes, causing a lack of oxygen to the brain and severe ABI.

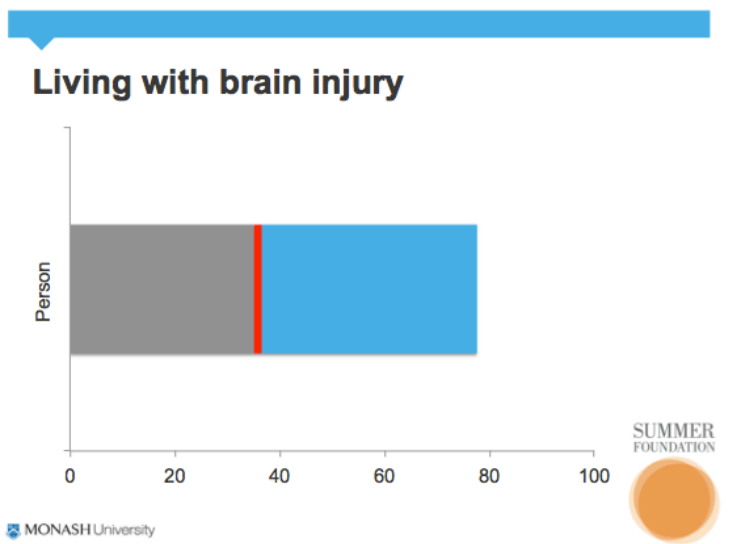
After two weeks in hospital, Michelle's parents were told to look for an aged care nursing home for their daughter, as she was not deemed able to benefit from rehabilitation. Michelle lived in aged care for the next 18 months, until she moved back to the family home.

Over the next five years, Michelle learned to eat, toilet, talk and walk again. She began to work on the skills of showering and dressing, cooking and shopping. Over time, she was able to speak with a level of clarity that allowed her to begin volunteering with young children at a local primary school, and with intensive physical rehabilitation she developed the fine motor control to start making her own gift cards for sale at markets.

Now 12 years since her brain injury, Michelle has set a new goal – she aims to develop the skills and establish flexible supports and the use of technology to allow her to move from her parents' home next door to a rental property of her own. Michelle is excited to take this next step towards her new life of independent adulthood.

A lifetime approach to rehabilitation following ABI

As you have heard from Michelle and will see from the graph on the Powerpoint slide provided, rehabilitation for people with ABI is a lifetime process and the inpatient rehab experience is such a small component of their lifetime recovery. People experiencing neurotrauma are usually in mid 20s, whereas people who experience stroke are on average in their mid 40's. People with extremely severe ABI may experience an inpatient rehabilitation stay of up to 18 months (indicated by the small red part of this bar graph). However, the life expectancy of person with ABI is on average comparative to people living without neurological disability, +/- 7 years. So people will often live for a longer period of time with their ABI than without it and the funding and resources put into recovery must be factored around that.



We must therefore ensure rehabilitation is designed to build skills for a lifetime and that community rehabilitation can be timed and funded to deliver responsive bursts or targeted input as necessary over time as circumstances change. Government and the community has a responsibility in this process – we need to pursue and provide well planned and located housing, transport, work and education that may be accessible for people with ABI.

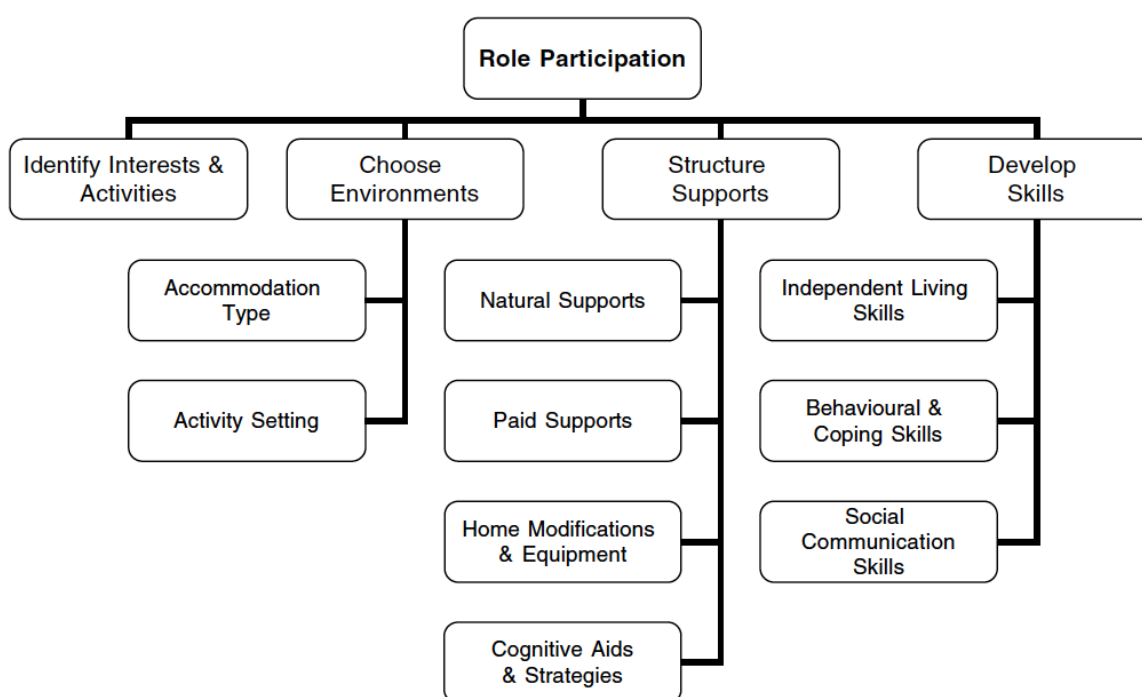
Our group’s past research has provided clear evidence – with a long term approach and community-based or contextualized rehabilitation targeted at skill development in the areas that underpin life roles (like working, being a family member, participating in hobbies), increased participation in home and community life can be achieved by people with severe ABI, even many years post injury.

Following on from this, our colleagues in NSW have demonstrated that family functioning and distress in relatives is not predicted directly from the severity of the person’s brain injury. Rather, psychological distress in families was mediated by the degree of community participation achieved by their relative with brain injury, particularly in relation to everyday activities and independent living skills. Higher levels of distress have been identified in families when their relative with a brain injury was socially isolated, had few activities outside the family home, and had minimal leisure interests. There is a need for a stronger rehabilitative emphasis on home, social and work-life participation of the person with ABI, and the inclusion and support of families as well as the person in the rehabilitation process.

If you think about your own life, your time and daily activities are structured around the things that are important to you, or necessary to allow you to have the means to participate in those things important to you – you may be a parent, a partner, a worker, a friend, a caregiver to a child or elderly parent, or a passionate enthusiast in a particularly hobby area. Michelle is rebuilding a life with a focus on her valued meaningful life role, a life that is deemed “good” by her.

The Community Approach to Participation

I am now going to talk to you about what our research and clinical work has shown are the key elements of well-designed community rehabilitation through our model, the Community Approach to Participation.



Winkler, Sloan & Callaway, 2009

The first step in well designed rehabilitation is to work out those roles that are of importance to a particular person, and the interests and activities that underpin these roles, and then work with the

person and their support network to set goals that relate to those areas of their life. The person and their support network must be absolutely central to rehabilitation planning.

The next step is to look at the skills that the person will require to participate in those valued roles and focus rehabilitation efforts in those areas. Rehabilitation interventions like walking re-training by physiotherapists, cognitive communication strategies developed by speech pathologists, and hand therapy and living skills training by an occupational therapist must be driven by evidence-based practice and linked to the person's goals for role participation within a coordinated and interdisciplinary rehabilitation program.

Then consider the type and amount of support that may be needed to develop skills to participate. This is where assistive technology can be extremely useful to build independence, autonomy and participation. Community-based, slow stream rehabilitation programs that grade the support provided over time, as people test and built skills, are imperative. A key goal of rehabilitation should be for the therapist and their assistants to make themselves redundant in the person's life as that person builds natural supports, new roles and a sense of choice and control.

The final step in a Community Approach to Participation Rehabilitation Model is to consider the environment in which the activities and roles are undertaken – what social connections and community links can be built through participation?

Finally...

Every moment of every single day is an opportunity to learn something new – rehabilitation needs to be contextualised and timely, include some calculated risk taking, and focus on the participation goals of the person and their support network as a starting point.

A rehabilitation effort that maintains or enhances social networks, builds home, community and work life participation, and assists the person to develop skills to return to the maximum level of functioning and participation they can, is required.

Successful rehabilitation should be measured by the ability to assist a person to operate with the maximum level of independence and autonomy, maintain family and social networks, and build a life that they see as being “a good life”.

Thank you.

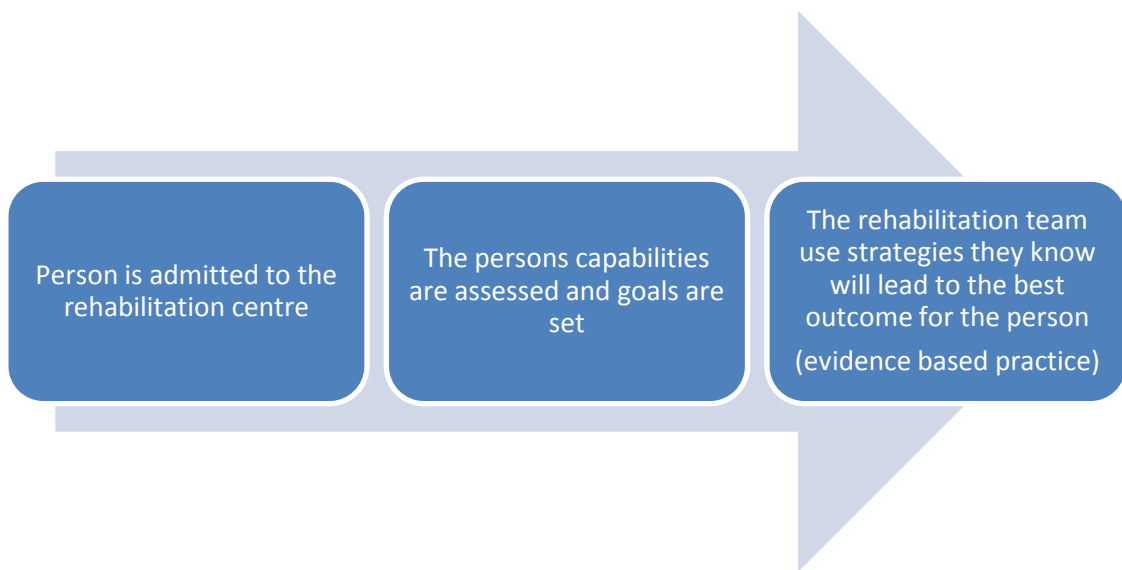
Evidenced based brain injury rehabilitation

Presenter: Dr Kate Laver

Uncertainty in health care: Challenges in providing evidence based care

All patients should receive care that is been proven to be effective and is delivered by skilled rehabilitation professionals. Patients should receive a high standard of care, regardless of location. For example, people living in rural areas should receive the same care as those living in metropolitan areas.

The ideal rehabilitation process:



Evidence based practice is regarded as the highest quality care in rehabilitation. Evidence based practice is based on the combination of individual clinical expertise, patient values and expectations and best external evidence as per the following diagram.



In clinical practice, care is not always evidence based. The care provided depends on the resources, culture and care processes of the rehabilitation facility and the knowledge, skills and beliefs of the rehabilitation professionals.

Rehabilitation professionals make decisions about the care they provide based on:

- On the job training
- University training
- Clinical supervision and mentoring
- Ongoing professional development
- New research findings
- Clinical guidelines

Problems arise when:

- There is a lack of research to guide practice
- There is research available but the proven treatments are not provided in practice. This may be due to a combination of factors, such as
 - (1) the health professional may not have the knowledge or skills to deliver the treatment,
 - (2) the organisation may not have the facilities or equipment to deliver the treatment,
 - (3) the treatment may not be liked by patients

What should patients and their families expect?

- That rehabilitation professionals are trained and able to provide proven treatments
- That care is consistent across rehabilitation facilities
- Improved communication regarding treatment. What is the best way to increase transparency so that patients and families can be sure they are receiving the highest quality of care?

Outcomes of Deliberations

The jury over two days had the opportunity to discuss and critically analyse the information provided to them and formed some high level opinions and recommendations responding to the questions posed for deliberation.



Jurors were especially interested in the role of the family in the rehabilitation process and sought to understand the nature of ongoing rehabilitation through the lifespan of a person who experiences a brain injury.

The following passages have been produced and endorsed by members of the jury working in collaboration with the jury facilitator and are summarised from the transcripts of discussions held during the jury.

Views within the jury varied, however key themes emerged to the overarching question of:

In the context of finite budgets for rehabilitation and challenges to providing optimal care to all persons with brain injuries, what considerations are important to you?

1. Consumer based focus

The jury were of the view that brain injury rehabilitation needs to be tailored to patients' current and future requirements. They acknowledge that the current provision of inpatient rehabilitation is provided to patients immediately following acute care, however the jury determined that this may not be the optimal time for an individual to receive intense rehabilitation. The jury recommended that flexibility be built into the health care system to allow patients to access facilities and resources at the time it is more beneficial to their circumstances, which may be influenced by their motivation level, physical state, external support or other personal factors.

The jury felt patient focused care, also known as patient centred care, is of great importance. Allowing patients to set their own goals would enhance the rehabilitation process and outcomes for the person with a brain injury. The jury advised that goal setting is proven to achieve results (based on an expert witness presentation), yet when it is overlooked, leads to consumer dissatisfaction and disengagement. Advocating for patient-led goal setting is proven to decrease the anxiety of the

patient about the recovery process and increases accountability and responsiveness to therapy. The jury did not believe that there were “unrealistic goals” raised by patients, but rather that it is likely that such a comment indicates that the clinical team involved haven’t tried to understand the goals of a patient or their family.

The jury discussed that patient focused care also means acknowledging the person that the patient was before their brain injury, their hopes for returning to that pre-injury life, and committing to working alongside the patient and their family to work towards that goal. The jury recommended clinicians should take the time to determine a patient’s pre-injury professional and social role, with the primary aim of rehabilitation being the returning a patient to their pre-injury identity and social role as much as is feasible. Health professionals should consider as many factors of relevance as possible in determining an appropriate rehabilitation plan. Retaining hope after such a catastrophic injury was seen to be very important, and having clinicians understand who the patient was *before* their brain injury and their pre-injury life may assist with having a goal to work towards and to retain hope during the long rehabilitation process.

Finally it was felt by the jury that patients, where possible, should be given choices about where they receive rehabilitation care, by whom they are treated and what specific goals they wish to achieve from treatment. The jurors perceived that the current system did not permit choice, and this was thought to potentially limit the possible outcomes from rehabilitation

2. Long term process

The jury proposed that rehabilitation needs to be considered as a lifelong process, spanning the duration of the patients’ life. As such, treatment plans from the earliest stages should include considerations of discharge, community support and a return of activity participation in the community. The jury highlighted the important consideration that a person with a brain injury will still have an average life expectancy and, with injury often sustained early in life, 75% of people living with a brain injury are under 65 years of age.

The jury noted that, with the unpredictable nature of brain injury recovery, providing a definitive prognosis in the early stages of treatment is not appropriate and may in fact upset patients and their families and reduce hope for a long-term life living in the community. However, the uncertainty of no diagnosis may also be detrimental for the patient and family. Therefore it is important for staff to ask what information would be most helpful for the family and to explore different ways of communicating prognosis pathways to meet the specific needs of the patient and family.

The jury acknowledged that rehabilitation may not always yield linear improvements and that plateaus may occur. The jury felt that a plateau in recovery does not necessarily mean that a patient has achieved their full extent of rehabilitation and that regular assessments for the duration of the patient’s life are important.

The jury reinforced the important role family can contribute in the life long process of rehabilitation, as they reflected that in the current system, patient care after hospitalisation is assumed to be the responsibility of the patient’s family.

3. Access to services

The jury felt strongly that there needs to be equitable access to services regardless of the government funding stream. Current Victorian services lack equity in access for people living in outer metropolitan areas, the country, those who sustain their ABI from non-transport accident causes (i.e. those not covered by the Transport Accident Commission) and those who are from various socially marginalised groups. Given that health is funded by government in one form or another (state health, Department of Health, WorkCover, Transport Accident Commission), the lack of consistent access to services across different funding streams did not seem reasonable to the jury.

4. Family participation

The jury developed recommendations related to families of the person with a brain injury that they are included and supported as much as possible, giving priority to the brain injured person's wishes when known. Where possible, it was felt that the patient should be able to determine how much family involvement there is at any time point along the continuum of recovery.

Specific recommendations were that the family should be given as much information as possible during the initial stages and support and acknowledgement of the trauma they as family members experience. The jury considered the option of a single contact person or case manager to provide a continual point of information, especially during the early phases of treatment.

It was felt that counselling may need to be provided to family members both in the initial phases of care and at critical time points related to the pressures and demands placed upon the family and that financial counselling may also be warranted, depending on the impact that an acquired brain injury has on the family's financial circumstances.

The jury requested that families are considered as equal partners in the rehabilitation process. However, they stipulated that families should not be seen as the default carer. Discharge planning should also include support for families to explore access to community carer supports to ensure a continuity of not only the patient's care, but the family's ability to provide care. Using existing community carer supports will decrease duplication in the healthcare system and reduce the demand on inpatient family services.

The jury supported the idea that communication was an important aspect of the rehabilitation process, especially in the phase when the person with a brain injury is spending more time in the community. The jury felt strongly that communication of the rehabilitation approaches and education of the family who will be providing some of the rehabilitation is integral to achieve a good outcome.

5. Advocacy

The jury recognised that not every patient with a brain injury has a family or significant other to advocate on their behalf. It was acknowledged that for the average person, knowledge of the hospital and rehabilitation processes, the impact and possible outcomes of the injury / illness, and of the process of care is lacking, and therefore that families need an advocate within the hospital system to

ensure that they are able to understand, process and be an active partner in their family member's care. The importance of having access to a social worker or disability advocate throughout their rehabilitation was highlighted as a significant need for a person with a brain injury.

6. Public education

The jury acknowledged their own increased knowledge of brain injury rehabilitation through their participation in the citizens' jury. They felt the information would be more generally relevant and suggested targeted campaigns about prevention for those most at risk (young males) and generally raising awareness of the effects of brain injury and the cost to the community. The jury felt public education programs could raise the profile of existing support services and contribute to the awareness of reintegration of patients recovering from brain injuries into their local and social networks.

The jury also considered the need for an online 'one stop shop' for information and resource links about acquired brain injury.

In response to the subsidiary questions posed to the jury, the responses are described below:

Question	Response from Citizens' Jury
Are there circumstances where it is acceptable to not provide rehabilitation to someone with a severe brain injury?	Qualified yes but the decision should be related to quality of life considerations, not funding
Should patients be given a choice over where they are treated, by whom (the type of health professional), and what treatments they are offered?	Unanimous yes
Should family members be considered as equal partners with the patients admitted? If YES, should some of the resources that we would otherwise spend on the patient be provided to the family members of the person with a brain injury instead?	It would depend on family circumstances When yes, resources should certainly be provided to family; possibly on a trial basis with review built in
How can information about rehabilitation be provided and more easily communicated to people with a severe brain injury and their family?	Information should be available in a number of formats, both at a community level, the level of the hospital / service, as well as at an individual patient level. The personal stories heard within the citizens' jury were considered to be valuable. Access to a video which clarified the Australian rehabilitation process may assist.



Other matters discussed

- **The recruitment and retention of highly skilled staff in brain injury rehabilitation is critical.** Patients and their families should be able to be certain that the staff they are working with are suitably skilled and understand evidence-based practice. The jurors acknowledged that if they were to put themselves into the same position as families entering the rehabilitation system for the first time, they would *assume* that all treatments and rehabilitation provided would be of the highest possible effectiveness, that everyone would be assumed to know what they were doing. Jurors expressed disappointment that there is research available but the proven treatments from this research are not always provided to everyone who would benefit in practice.
- **Rehabilitation should extend to all time spent as an inpatient.** Patients and their families should be able to receive specialist rehabilitation therapies on the weekend. Jurors were disappointed to learn that in the Australian system, people remain in hospital on weekends but do not receive a rehabilitation program. Consideration could be made to models in other countries where flexible arrangements on weekends allow patients to spend time out of the rehabilitation facilities.
- **The physical environment.** The initial inpatient phase of rehabilitation was highlighted by the jury for consideration of the physical environmental within which the patients reside. The jury recommended further funding towards updating and modernising inpatient rehabilitation facilities to be aesthetically pleasing and pleasant to live in.

Possible strategies to address key areas of concern

The Jury submitted suggestions to address the problems it identified. These included:

- **ABI Prevention and health promotion to the general public:** acquired brain injury prevention education could be provided to target populations, such as young men aged 30 years and under. Further, there should be high quality education and advertising about what a brain injury is, how the general public can support community members living with brain injury, as well as brain injury prevention strategies.
- **Advocacy:** The appointment of a knowledgeable professional as the Brain Injury Rehabilitation Ombudsman would allow Victorians to have a single point of contact for advice about best evidence, to raise concerns about their own rehabilitation, and to seek support for family members who are unsure about brain injury or the services they are receiving.

Appendix: Biographies

Dr Peter Bragge



Peter Bragge is a Senior Research Fellow at the National Trauma Research Institute. The mission and the goals of the National Trauma Research Institute (NTRI) are focussed on reducing death and disability, and improving the quality of life of survivors of traumatic injury. Understanding traumatic brain injury, and its medical effects, are key to better healthcare and enhancing this knowledge is a goal for the NTRI.

Dr Bragge leads the NTRI Forum program [<http://www.ntriforum.org.au/>], which aims to improve the care of spinal cord and brain injury by bringing together key stakeholders in priority areas of care.

Therese Morgante



Therese Morgante is a consultant in the disability sector providing both direct support services to people with a disability, and policy advice to the Victorian Government. Therese has previously worked at the Victorian Transport Accident Commission and as a senior manager within Disability Services, Victoria. The focus of her work during this time was the development of policy and guidelines to support people with a disability to access the disability service system, and to build the capacity of people with a disability and disability service providers to develop and implement individualised plans. She has experience in resource modelling and

understanding the impact of government funding decisions on health policy and service provision.

Nick Rushworth



Nick Rushworth is Executive Officer of Brain Injury Australia - the national peak acquired brain injury (ABI) advocacy organisation representing the needs of people with an ABI, their families and carers. He was also President of the Brain Injury Association of New South Wales between 2004 and 2008. In 1996, armed with a bicycle, Nick attacked two cars. The cars won, but Nick's recovery from a severe traumatic brain injury was exceptional. Before joining Brain Injury Australia, Nick worked for the Northern Territory Government setting up their new "Office of Disability". Formerly a producer with the Nine Television Network's "Sunday" program and ABC Radio National, Nick's journalism has won a number of awards, including a Silver World Medal at the New York Festival, a National Press Club and TV Week Logie Award.

Cheryl Koenig, OAM



At the age of just 12 years old, Cheryl's son Jonathan was involved in a horrific car accident and suffered an extremely severe traumatic brain injury. Jonathan was in a coma for six weeks and given very little chance of survival. Doctors predicted that if he did survive he would be unable to walk or talk ever again. Jonathan went on to complete his HSC and a TAFE course and is currently learning to drive.

Cheryl has written about her remarkable son in '*Paper Cranes: A Mother's Story of Hope, Courage and Determination*' which chronicles her family's journey through despair, denial and anger, to eventual acceptance and healing. This is her third book, having already written two books in a voluntary capacity for NSW Health Agency for Clinical Innovation. Cheryl volunteers much of her free time assisting in development of government policy and services in the health care arena, as well as a huge commitment to fundraising. She has been a guest speaker at various Medical Conferences; Rotary & other Community Groups; Carer Support Groups and/or Disability Groups; including training days for clinical networks or those who work in the disability arena.

Nerida Hyett



Nerida Hyett is a full time PhD student with the Building Healthy Communities research program at La Trobe University. Her research interests are in community participation and health, and how health services can be improved by including communities in the design and implementation of programs. Nerida has published research on how to facilitate community participation initiatives with rural populations, and effective strategies for engaging communities with healthcare, such as via social media. She has presented preliminary findings from her doctoral study at international conferences including Canada and Japan. Nerida also has clinical healthcare experience as an occupational therapist working in youth mental health and substance misuse, community health and health promotion.

Dr Kate Laver



Dr Kate Laver is an occupational therapist with over 10 years of experience working with people with stroke and brain injuries. She has worked in senior roles in hospital settings (both acute and rehabilitation) and home and clinic based rehabilitation settings. Kate has conducted systematic reviews of research and has a strong interest in understanding the gap between research and clinical practice, how we can support clinicians to provide evidence-based care, and in developing clinical practice guidelines.

Libby Callaway



Libby is a registered occupational therapist, having worked for over 20 years in the field of neurological rehabilitation in Australia and the USA. For the last 15 years, she has been the director and principal occupational therapist in a community based practice providing rehabilitation services to people with acquired brain and spinal cord injury. In addition to this clinical work, Libby is the research manager at the Summer Foundation, an organisation working to address the issue of young people living in nursing homes. Libby is also a lecturer in the OT department at Monash University and is completing a PhD on community integration outcomes following neurotrauma.

Libby currently leads a program of research on models of housing and support for people with acquired disabilities for the Institute for Safety, Compensation, and Recovery Research, and has published in a range of peer-reviewed journals. The work of Libby and her colleagues, including their model of community based rehabilitation following ABI – the Community Approach to Participation – has been acknowledged internationally within a casebook of exemplary evidence-informed programs that foster community participation after acquired brain injury, published by the Ontario Neurotrauma Foundation.