

Thanks for this gratifying but not a little intimidating, invitation. There's a gratifying - but nevertheless wierd - circularity about this evening akin to Brain Injury Australia's office being just 100 metres away from the brain injury unit where I was a client a little over 15 years. (I'm a happy alumnus of the NSW Brain Injury Rehabilitation Program.) There's gratification, also, for being invited - again - inside the tent. The impression I get from the other States and Territories is that the (almost) automatic posture adopted across the gulf that often separates patients-consumers from clinicians-allied health practitioners is adversarial; the latter are thought arrogant and removed, the former/ their advocates - ratbags and whingers, consumers - thought ungrateful. It's my impression that NSW, its Brain Injury Rehabilitation Program, the Directorate has put in the most work at...building a bridge, not just to acceptance but to genuine inclusion of consumers, carers, family members.

Intimidating? I think of this as a tough, if not the tough[est] audience...on the way here this evening I was trying to think what it would feel like to speak this - apart from it being murder to write - perhaps it will be like addressing teachers at your high school reunion. I didn't really know what I would say to you, what I do know - this being my first after-dinner speech - is only a fool would stand for long between diners and their dessert. I'm determined not to detain you too long from...sweetness.

So, I want to say a little bit about what Brain Injury Australia has tried, is trying to do in recent times, then to put that in a political context by talking briefly about the push for a national disability insurance scheme, then I want to finish - since it is a 21st birthday - which I think I'm right in saying is another of our cultural imports from the US: while, the purposes of getting married, joining their armed services and so on, you're an adult at 18, but you're not a legal drinker until you turn 21. Tonight, I want to keep with tradition. If this dinner is both celebration and rite of passage...I feel not only obliged to earn my keep, but moreover entitled to stay on message as an advocate. So, in the nature of that kindly - in my case upstart - uncle at the 21st birthday party, I want to finish with some gentle admonitions derived from what Brain Injury Australia hears from consumers and family members about their experience of rehabilitation by way of some comments on hope and the imagination... And a word or two about style.

I want to start, though, with something fundamental - on which really everything that follows is based: because this is also a celebration, there is, indeed, much to celebrate about NSW's Brain Injury Rehabilitation Program. Brain Injury Australia hasn't study toured every rehabilitation facility around the country. But the experience that strikes me as being typical of brain injury is that people exit hospital and fall off the edge of a cliff. And even if there's an ambulance at the bottom of that cliff to receive them, it commonly takes the form of access to generic/ cross-disability rehabilitation services. This is especially the case in regional, rural and remote parts of the country outside of New South Wales. I spend 10 days a month in Darwin, where staff of the Northern Rehabilitation Network - it's my casual impression - have their collective fingers in a dyke stemming the waves of assaults and motor vehicle accidents. By any measure, even when you adjust for its relatively small population, its age profile or the vast distances that Territorians travel, as soon as you add in alcohol and other drug-related brain injury, ABI prevalence rates in the Northern Territory would easily challenge, or be, the nation's highest. I wouldn't have a clue what brain-injury specific rehabilitation services might be available 1500kms south in Alice Springs - where prevalence is perhaps again higher than at the Top End - or points in between...but any best guess is it can't be more than threadbare.

I am not intimately familiar with the history of your 21 years. I am sure that the Brain Injury Rehabilitation Program has suffered its share of the slings and arrows of outrageous state government budgeting. But as a result of the Program's retention - and defence - of its specialty statewide, the people of New South Wales are, almost doubtless, singularly blessed.

Brain Injury Australia is the "peak of peaks". It sits at the apex of a very small triangle of State and Territory Member Organisations. Many of them, in turn, have their own members comprising people with an ABI, family members and carers. Some are sole person operations in what's called "systemic" advocacy - lobbying for policy change. Others are service providers with larger staffs and larger budgets. Brain Injury Australia's remit is in systemic advocacy. My impression of what it tries to do - and I hope this sounds less grandiose, than...just grand - is making this invisible disability visible, with constituencies, with populations. Brain Injury Australia always tries to retain a keen sense of needing to serve a constituency. Married to that, in my mind - without wanting to get precious about it - is that the Australian taxpayer pays my wage. Neither do I want to come over sounding like the head of the local chapter of the Tea Party Movement - but to paraphrase the rallying cry of the American Revolution; there can be "no taxation without representation". The following statement probably applies to all disability advocacy organisations based on a membership model, but I suspect the question of how representative disability advocacy organisations are is a little more, well, acute with brain injury: Brain Injury Australia's constituency is broader than its Member Organisations, broader again than the members of its Member Organisations, broader certainly than the people who know we even exist.

I think it's reasonable to say that the traditional focus of brain injury advocacy has been that "prime of life" traumatic brain injury - the young man, sometimes the young woman and the motor vehicle accident, the workplace accident...Brain Injury Australia has tried - in its modest, journeyman-like fashion - to exercise some leadership with its Member Organisations by making visible some relatively under-represented constituents, whom they may not see as clients - for being too young, too old, or just outside the disability services system altogether. This has taken the form of policy papers it prepares - as part of its funding agreement with the Australian Government's Department of Families, Housing, Community Services and Indigenous Affairs, FAHCSIA. Brain Injury Australia's policy papers have been well-researched and well-argued but they've also been destined to gather dust in a filing cabinet somewhere in Canberra. What Brain Injury Australia has tried to do in recent times is to turn their subject matter into attractive prospects for advocacy and awareness-raising (about brain injury in general). For instance, last year's paper was devoted to very young children and inflicted traumatic brain injury - one potentially large subgroup of which is traditionally referred to as "shaken baby syndrome" - the leading cause of death and disability in children who have been abused. The paper argued two key points: firstly, those inflicted brain injuries in children that come - that need to come - to medical attention, that are detected and diagnosed in hospital - during the last 5 years more than 70 children have been hospitalised with inflicted traumatic brain injury in NSW - represent the 'tip of an iceberg'. Secondly, if the "community incidence" of this kind of physical abuse is (much) higher than what's represented in hospital admissions, what are the potential long-term consequences of repetitive, sub-clinical head trauma in young children. Here, Brain Injury Australia was relying on - and I think it's fair to say - that no one in the neurosciences

has established the minimum thresholds of force above which you can do long-lasting, if not permanent, damage to a young child's developing brain.

Perhaps similar questions about minimum thresholds of force arise with the fragile ageing brain, which is why the previous year's paper was devoted to the leading cause of traumatic brain injury throughout the developed world – accounting for around 2 in every 5 hospital admissions for TBI in Australia - falls. This is not because more teenagers have decided to take drunken dives from balconies at the 2 a.m. On a Saturday, but because of the ageing of the population. Australians aged 85 years and over – the fastest growing segment of Australia's population – now have not only the highest rates of falls and falls injury, but TBI and TBI death rates. And while the age-standardised rates of falls-related head injuries are rising while those for hip fracture are falling, Brain Injury Australia's pretty comprehensive scan of the nation's burgeoning falls prevention program literature didn't locate a single mention of head or brain injury as falls risk. And maybe I'm being unfair to the nation's falls prevention practitioners and geriatricians, but in the case of former, it was impossible to get them interested and with the latter; their stereotype of an older person who sustains a brain injury from a fall is someone demented – or dementing – in residential aged care. And the prevailing attitude; "what's a little head injury on top of their Alzheimer's?" Hence the reference to minimum thresholds - what might be a "mild" head injury for an 18 year-old will be much more than that for someone in their 80s.

The focus of this year's policy paper is the criminal justice system. It's hard to imagine a constituency more invisible, more "out of sight" than the nation's 30,000 prisoners. But while no Australian prison, no juvenile detention facility screens - and there's a whole other presentation buried underneath this one on screening questions, screening tools, assessment tools and the like - no jurisdiction screens specifically for brain injury (though some may refer prisoners for further assessment should they openly disclose their disability) and only two (South Australia and the Australian Capital Territory) ask about histories of head injury at reception – brain injury in adult corrections is by no means is brain injury under-...researched. Somewhere, sometime, someone in corrections or in health policy deciphered a...relationship between brain injury and behaviour, offending behaviour, offending, re-offending and re-incarceration. Of perhaps all jurisdictions, ABI among prisoners in New South Wales has been the most studied - for instance, I think I am right in saying that each of Justice Health's Inmate Health and Young People in Custody Health surveys have included questions about offenders' experience of head injury with loss of consciousness.

What follows constitutes, little doubt, rubbery-to-vague indices of disability...however/ i'll persist: more than half of all male, and more than a third of the female detainees who participated in 2009's NSW Inmate Health Survey detailed histories of "head injury resulting in unconsciousness". Around 1 in every 10 of the 1000 prisoners surveyed reported the "time unconscious for [their] most severe head injury" lasted "between 30 minutes and 24 hours" while 7% said it lasted "24 hours or more". Almost 1 in every 3 male, and 1 in every 5 female, prisoners recalled more than one head injury with loss of consciousness over the course of their lifetime. More than 1 in every 10 male (and 1 in every 20 female) prisoners reported five or more head injuries with loss of consciousness. Three-quarters of the sample reported "neuropsychiatric sequelae" and for a third of, these problems remained unresolved. 15% of men and 12% of women reported their most severe head injury "resulted in a skull fracture". A quarter of the men and nearly one-fifth of women reported they had intracranial bleeding as a result of their "most severe head injury" and almost one in every

four of Survey's respondents with a history of head injury resulting in a loss of consciousness "reported that they had had tests or scans that confirmed they had brain damage as a result of their head injury."

As strikingly, I think, high as these TBI proportions might appear (and if you don't bring a TBI with you to prison - assault was the most common conviction in sentencing - there's a better than even chance you'll get one while you're there - a pilot study of attendance at prison health clinics in NSW found assault was the second most common reason). And since we are talking just TBI, these proportions are likely still conservative estimates of ABI prevalence in prisons, especially once you factor in alcohol and other drug abuse. So, in the best of all possible worlds, you'd imagine...that the potential high levels of - to use the relevant jargon - of "criminogenic need" in this prisoner group, at high risk of re-offending and re-incarceration, would merit access to programs of "offender rehabilitation", even that a "criminogenic needs" assessment would translate, would be "operationalised" into programs specific to those neurobehavioural needs. Of all the justifications for a policy encompassing program provision in this area, saving the Australian taxpayer - with prisoner numbers rising at 5% per annum - over \$200 in net direct costs per prisoner per day would be motivation enough. As part of the preparation of the paper, Brain Injury Australia approached the departments of juvenile justice and adult corrective services in each jurisdiction - and, it will perhaps/ probably come as no surprise - we were unable to identify any program - with the broadest capture of what might constitute "offender rehabilitation" - for which prisoners with an ABI were directly eligible, let alone that positively included. In NSW, as in every other jurisdiction where offender rehabilitation is offered, what programs are available almost exclusively target prisoners with an intellectual disability or mental illness. Access for prisoners with an ABI to programs run solely by Statewide Disability Services of Corrective Services or in conjunction/ partnership with Ageing, Disability and Home Care is limited to those who also have an intellectual disability or borderline intellectual impairment and in the case of the latter programs, only if their brain injury was acquired before their 18th birthday.

In its submission to the Productivity Commission's inquiry into long-term disability care and support, Brain Injury Australia acknowledged the commitment written into the Inquiry's Issues Paper to extend the support of any proposed social insurance scheme to some of these invisible populations who, well, languish on the outskirts of service provision. But it also pointed out the faulty presupposition that seems to predetermine the Inquiry's [entire] thinking: that people with a disability somehow comprise a coherent population who know both their disability and their needs arising from it and can not only express those needs, but pursue them for the purposes of receiving disability services and support (including advocacy). [I find it both astonishing - and frustrating - that the most recent Australian Bureau of Statistics Survey of Ageing, Disability and Carers, one of the fundamental drivers of disability policy and research for years to come - even with the injection of an extra \$6.5 million from the nation's Community and Disability Services Ministers to boost its sampling - DIDN'T include Australia's 30,000 prisoners. Neither did it capture remote parts of Australia, where Aboriginal and Torres Strait Islanders are concentrated. Their rates of brain injury are around 3 times that of the rest of the population.

Brain Injury Australia welcomes the commitment to systemic advocacy contained in the National Disability Strategy. And for as long as Brain Injury Australia is included in that commitment, we will continue with what we think of as the real guts of our work; building awareness of a disability that lags around 20 to 30 years behind that of others, especially

within those "invisible" populations, where their brain injury might be undiagnosed, or unknown. Certainly, to bring them into any new scheme of "disability care and support". Some of the most powerful – and sobering - words I've read on this kind of "work" comes from Michael Ignatieff's 1984 book "The Needs of Strangers": "there are people who have had to survive on so little for so long in our society that their needs have withered away to barest necessity. Is it wrong to raise their expectations, to give them a sense of the things they have gone without?...Any politics which wants to improve the conditions of their lives has to speak for needs which they themselves may not be able to articulate. That is why politics is such a dangerous business: to mobilise a majority for change you must raise expectations and create needs which leap beyond the confines of existing reality. To create needs is to create discontent, and to invite disillusionment. It is to play with lives and hopes. The only safeguard in this dangerous game is the democratic requirement of informed consent. One has no right to speak for needs which those one represents cannot intelligibly recognise as their own."

If Brain Injury Australia is successful in this work with "invisible" populations, will governments fear the floodgates opening? Will they begin to draw in the fences around eligibility and assessment for any new scheme (for what the Productivity Commission reckons is the 360,000 Australians with "severe" to "profound" disability)? I haven't had the time to read the 800 pages of the Commission's two volume draft report (who has?) And I know that the architecture of any proposed disability insurance scheme is "work-in-progress" but I did get a chance to keyword search the draft report for references to alcohol and other substance-abuse related disability, including brain injury. And while I got the sense that the geography of any proposed scheme might extend to the heroin overdose with hypoxic brain injury, and to the early teenage petrol sniffer, it was nowhere near as clear to me whether the abuser of a cask of tawny port every night for the last 20 years would be...eligible (and their numbers can only really be guesstimated). And I also know the last time a disability insurance scheme was floated - during the Whitlam years - it was sunk in part by the disability sector's infighting about who'd be in or out - at the moment, one of the pitched battles inside the sector is whether chronic disease should be, or not.

Brain Injury Australia's real point in drawing attention to these "invisible" populations isn't to risk the certain death of a disability insurance scheme a second time around, but rather to suggest that if governments are seriously serious about social inclusion there are some political realities that, I believe, the disability sector needs to face. There 's a whole other presentation I'd love to give on the idiosyncrasies of how Australians perceive risk, and how they do or don't insure against it - whether it's [of] flooding, climate change or disability - but if the politics of the reception of a \$1.8 billion Queensland flood levy and an UNPRICED carbon price/ carbon tax/ great big new tax are anything to go by, getting a 12 and a half billion - that's an additional \$6.3 billion on top of the current disability spend - getting a 12 and a half billion national disability insurance scheme legislated so that it's funding is quarantined from the whims of changing governments - whether whether the new scheme is funded by some manner of legislated "National Disability Insurance Premium Fund", or by some GST-style arrangement with the State and Territory governments or a levy on marginal tax rates - is going to be a political enterprise with a degree of difficulty on a par with raising the Titanic with tweezers.

This is not intended as rain on anyone's parade...but if it isn't already, the disability sector should brace itself for the next round - not sure how many rounds they've been, perhaps this is the...12th? - of welfare-to-work reforms (starting with the tightened work requirements for the Disability Support Pension included in Tuesday night's budget) . And even though it's 18 months out from the next election – to quote Bob Dylan "you don't need a weatherman to know which way the wind blows"; with not-so-heavily coded political speech about the welfare "kindness that kills", the need for governments to be "firm to be fair", the QUOTE "benefits and dignity of work", and this, its logical corollary, from this from Wayne Swan's on budget speech - ; "at the core of this Budget are the firm convictions that our economy doesn't have a single person to waste and that a wealthy country like ours has no excuse to leave people behind." And whether it's an ever-tightening labour market or someone's election promise to return the budget to surplus by 2012-2013, politicians are already picking what they think of as electoral winners - the \$13 billion DSP (the Commonwealth's fifth biggest spend) and the 230,000 long-term unemployed are already on the hit list. And whether it's the politics of the dog whistle or downward envy, I can almost hear the whispers adjudicating the "deserving" from "undeserving" disabled, beginning perhaps with drug users/ substance abusers.

I warned you I'd round up - playing the kindly upstart uncle I referred to at the beginning - I just wanted to talk briefly about...hope and the imagination. Imagination: because in the 7 years i've worked in this sector, initially as a volunteer, in the last 3 years in a paid capacity, i've become convinced that anyone involved in the "human services" business – my business and, I think, your business - has to at least try and transplant themselves in imagination into the circumstances of their client, their customer, or their patient or their patient's family - as both a first principle and a starting point. Brain Injury Australia doesn't hope to turn you ALL into de facto counsellors or social workers. I've never worked in rehabilitation, but I wanted to share one recent contact from a "constituent". (Importantly, it isn't an experience of the NSW Brain Injury Rehabilitation Program, though it's a NSW "story"). But it IS right in that gap between what "we" try and say 'v' what we sometimes hear professionals who work in rehabilitation and allied areas say.

I had someone contact me late last year who'd - in effect - had a horse fall on her, around a year earlier. Certainly a severe TBI. She'd been able to afford her own rehabilitation specialist, someone very senior, very experienced, experienced in brain injury, someone you'd imagine would be, well, up on the latest evidence (from, say, brain injury outcome studies - again, with which Australia is well-blessed). When asked what kind of recovery she could expect and how long it would last - common enough questions, you'd imagine - he told her that she could, quote, "bake a cake" in time for the second anniversary of her accident and the way she was that day would be the way she'd remain for the rest of her life. Again, someone very senior, very experienced, experienced in brain injury, someone you'd imagine would be, well, acquainted with traumatic brain injury as a disability that often occurs in the prime of a person's life, precisely at that point of entry to "adult" life - as was the case with this young woman - and everything that promises, someone to whom, you'd imagine, experience had taught a light touch on such statements, a human, a humane touch, someone who'd learnt to transplant himself, in imagination, into the circumstances of someone trying to imagine what it would be like to come to terms with their recovery coming to an end, [let alone the injury itself]. Even if the second anniversary business was true -

what are two years anyway, give or take a minute, an hour, a day, a week, a month - even if the second anniversary business was true (and likely there are recoveries from brain injury that lie inside the bell curve and there are outliers) would anyone - their imagination bypassed, or otherwise - consider saying it at all - even out of the most pressing need to inject realism into a client's prospects of recovery, as reverse psychology, as some perverse incentive to the client to "try" even harder in recovery - let alone in that way. Without...style. I should state the obvious. I didn't witness the exchange. But I've heard about the dispensing of the "two-year" myth - to consumers, to family members - I've heard about it often enough that the truth, or at least the verifiability, of such exchanges takes on an...iterative quality; their truthfulness grows with repetition. (Admittedly most of dispensing comes with a little more...hair on it than was the case with this young woman.)

Having said all that, I couldn't front a crowd more expert in the vagaries of memory, especially post-traumatic memory, than this one. And, I imagine, somewhere someone has done the (definitive) research into how much - the 3%, 4% of the "bad news" or the "good news" - people take away with them from the deep and long crucible of such life-transforming events as these. And, given the context of said events, can anyone really control, misinterpretation-proof what might be informed opinion, provisional prognosis? Well no. But it's been my experience that what's taken from these...statements are hastily stored by consumers and their families, taken out regularly, dusted off, re-examined, held up to the light of recovery and recovery measured against it - in the hope that the statements will proven wrong, or right.

Though it mightn't sound like it, I've given hope some thought over the last few weeks to the notion, and place of, hope in rehabilitation. And while I am not sure that the nation's brain injury rehabilitation units should be in the business of dispensing hope - that's probably not their role - I am sure that they shouldn't resemble the hell of the Italian poet Dante's Divine Comedy - written in the 14th century - with "abandon hope, all ye who enter here" inscribed over their front doors. The very first time that many, perhaps most, family members hear the expression "brain injury" is upon entering a rehabilitation unit to visit their son or daughter, sister, brother, mother, father. For families in this situation, it wouldn't - I imagine - take them long to enter the first of Elisabeth Kübler-Ross' five stages of grief; denial - not my son, not my daughter.... Brain injury rehabilitation units must seem like black boxes, with all the mysteriousness and hierarchy of a Catholic mass. And if your point of reference is the hospital of television, clinicians and allied health staff their high priests and priestesses, god-like in their wisdom.

I wonder what it would be like for any of you to say (perhaps you do, and regularly, already) - given the uncertainty about outcomes from brain injury at so early a point in stabilization, let alone recovery - to say that I/ you am unsure, even that I/ "we" don't know [what to expect, what to hope for]. And what it would be like for a family member - who wants, no, expects - since hope is at once the desire of something combined with the expectation of obtaining it - what it would be like for that family member who expects nothing less than their loved one to be restored to them the same person they were before they got in the car that March morning - what it would be like to be ...counselled in patience (in an age of the quick fix, the miracle cure). Counselled in patience, and nothing more. While I don't think that brain injury rehabilitation units should be in the business of dispensing hope, let alone false hopes,

forlorn hopes or hopes that promise triumph over experience, neither - it seems to me - should they be curtailing hope, even if the intention - however sincere - is to inject...realism. From time to time, Brain Injury Australia will hear from a consumer or a family member that they were told - within a few days, a few weeks of injury - that they or their loved one would not/ never be able to do x or y.

I've got some limited, and pale, experience of this a little closer to home: the results of my second neuropsychological assessment as part of return-to-work rehabilitation. The standardized tests found that my Performance IQ had "declined significantly", that my "attention, concentration and memory" were "significantly impaired", and that my "academic potential" would be "significantly compromised". This, for someone working full-time as a journalist, in postgraduate study part-time, and coming from a family of intellectual over-achievers - rendered, I thought/ I still think, dumber, permanently. I can, I think I can remember - during the loopy fog of that time - individual days, sometimes minutes or seconds when I thought I was stepping up in recovery, that damaged synapses were re-firing or that new ones had swung operation. This day was my dead reckoning. However the neuropsychologist was - and his report was professional and detailed - I've always reconstructed him in memory as wearing a labcoat, perhaps with a stethoscope slung around his neck. And....this is important, I feel; when I choose to remember...I've never really forgiven him for letting not me - but the next someone like me, or the next or the next, someone with perhaps fewer...resources - simply take this kind of report and walk off into the sunset. It is, I believe, no exaggeration to liken it to saying; here's a hand grenade. I want you to hold it for me while I take out the pin. Now goodbye and good luck. I think he walked me through the report. I can't remember whether he offered me any counselling to go with it. I can't remember him offering me any hope. I was reminded that no one escape a brain injury severe enough to make you eligible for admission to the Brain Injury Rehabilitation Program, no one escapes that kind of brain injury...unscathed. Some people have glass jaws. I retain my glass IQ. And i'll always wonder whether this speech tried a little too hard to be too smart by half.