

Thanks, Claire. I should begin with what's becoming a depressingly familiar disclaimer. As you know from what you've just heard I'm not - NOR HAVE I EVER BEEN - a clinician, an allied health practitioner, a medical researcher. I've never worked in a disability SERVICE.

My only real credential for being in this job? Look, I'm hardly representative of recoveries from severe brain injury. Though, I 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. However it was, if it was me who moved, moved on, that's really all that...QUALIFIES me talk to you today.

And in the interests of full product disclosure, to pre-empt any claims of false advertising, for those of you who were hoping to hear – as appeared in an earlier version of the conference program - about QUOTE "implementing effective accountability, transparency and disclosure processes", "establishing a robust financial model to ensure business sustainability" and "embedding strategies to stimulate income generation" UNQUOTE – truth be told, I NEVER PROMISED TO TALK ABOUT any of that. Instead what my abstract ORIGINALLY, REALLY offered was QUOTE: "how (NOT) to turn boutique lobbying into a self-sustaining business", "making an "invisible" disability visible"; "the misery olympics" and "media as megaphone". UN-QUOTE. Which, lo and behold, is now what you've got in front of you.

It's not that I'm allergic to talking about the BUSINESS of what I try and do, or about it AS A BUSINESS. It's just that SYSTEMIC disability advocacy - in the words of the Department of Social Services - advocacy that QUOTE "seeks to influence or secure positive long-term changes that remove barriers and address discriminatory practices to ensure the collective rights and interests of people with disability are upheld" - THAT kind of advocacy has a, well, deep and abiding purist streak that some, SOME would say is uncontaminated by evidencing both measurable improvements in the INDIVIDUAL lives of people with a disability let alone traction in policy.

Circumstances have changed.

And when the costs of the NDIS - AT FULL IMPLEMENTATION - are yet to be found (somehow, yesterday, Richard Madden made the missing 4, some say 5, billion dollars sound like spare) when the costs of the full Scheme are still yet to be found lobbyists, like me would be fools to think of whatever the hell it is that they do as anything other than a luxury the AUSTRALIAN TAXPAYER can't afford. This ISN'T the place, there ISN'T the time to vent my impatience, outside of – well - some/ many/ most of my colleagues need to get over it, get real and, if not ACT like a business, at least try and THINK like one. (Because there's no thinking more dangerous than that the world owes you a living.)

Having said that, it still sticks in my craw that I'm going to kick off this presentation with a market report and the, ahem, prospects for growth, in what is an ACQUIRED, and thus often a PREVENTABLE, disability (that

my real reason for being is to do myself OUT of my job). And then, I will let you in on Brain Injury Australia's, modest - and EMBRYONIC, NEW? - tripartite strategy. Its starting position, ITS reason for being, remains unchanged: that public awareness about brain injury and, thus, policy and service development lags about 20 or 30 years behind that of other disabilities. But its public education campaigns - dedicated to: the leading cause of death and disability in children who have been abused – inflicted traumatic brain injury – “TBI”, sometimes called “shaken baby syndrome”; the leading cause of traumatic brain injury – “TBI” - across the developed world, falls; people with a brain injury in the criminal justice system; “young strokes”, so called; and women, family violence and brain injury (1 woman dies every week in Australia the result of family violence. THREE women are hospitalised every week with a TBI the result of family violence) - these public education campaigns are legacy assets from the halcyon days of Australian Government recurrent funding (which ceased for Brain Injury Australia, along with 9 other "diagnostic peak" advocacy organisations representing people with intellectual disability, autism, physical and sensory disability etc. - ceased in 2015) these public education campaigns need to be cross-subsidised both by - the second and third parts of this tripartite strategy - by, ahem, monetising its constituents and by making itself indispensable to both public and private disability services and supports, by becoming THE central clearinghouse of information and gateway to nationwide referral for optimising the social and economic participation of all Australians living with brain injury, regardless of age or external cause - while, all/ at the same time, staving off the magnetic pull of providing services to INDIVIDUALS. I wouldn't be earning my keep if I didn't seize any and all opportunities to raise awareness in the here and now - on a ripples-in-the-pond basis - so will spend some time examining

the demand and supply constraints in the NDIS through the lens of what's referred to as "challenging behaviours" following brain injury.

So, for those of you who are still counting on the clouds opening, hoping for blinding flashes of revelation into business transformations, I will disappoint. But for those of you hoping to sleep, [I hope] I'll do...LIKEWISE.

Soon after I started in this job, I wanted to find out how many...CONSTITUENTS Brain Injury Australia had. I asked the Australian Bureau of Statistics for a best estimate from its most recent Survey of Disability, Ageing and Carers. They came back with 730,000 - crucially, people whose brain injury MEANS daily "activity limitations" and "participation restrictions" - so, not every standard issue/ off-the-rack Saturday afternoon concussion.

That number often surprises people. As high.

It's still likely an under-estimate, once you know that the Survey - on which both the Productivity Commission and the Disability Investment Group before it relied for scaling the NDIS - the Survey doesn't – NEVER HAS – captured QUOTE "persons living in gaols or correctional institutions" - where as many as 80 per cent of adult prisoners report brain injury. Neither does the Survey reach QUOTE "persons living in very remote areas". Only three per cent of the NATION's population live there, but nearly half of them are Aboriginal and Torres Strait Islander - whose rates

of brain injury (and it's a very rough rule of thumb) are 3 times that of the rest of the population.

AND when you think about the circumstances under which such surveys are conducted - where the respondent has to KNOW they've got a brain injury, IDENTIFY as a person with a disability, as well as one they're willing to share with complete strangers, and strangers from...GOVERNMENT: in the coy words buried in explanatory notes to the Survey; a respondent QUOTE "...may not have reported certain conditions because of the sensitive nature of the condition..." (ANOTHER, and radical, difference between the lived experience of ACQUIRED disability and CONGENITAL or DEVELOPMENTAL disability is that the former's association with embarrassment or shame - when it IS, or is perceived to be, more or less...self-inflicted. Though Australia cannot move to a national no-fault INJURY insurance scheme soon enough, don't for a moment imagine that in eliminating fault, it will eradicate...blame.)

The last time that anything approximating national TBI incidence data was collected was over 10 years ago. But I'll take a punt that the 20,000 or so hospitalisations for TBI *in 2004-05* - 2,000 to 3,000 in the moderate to severe category – the numbers wouldn't have changed that much since then, given enhancements in workplace health and safety, in motor vehicle safety design – airbags and such - random breath testing and so on.

And for as long as “they” remain compensable at common law, given the disparateness and diversity of Brain Injury Australia’s constituency – perhaps the greatest of any disability *type* – the *young* TBI remains its most, ahem, monetizable cohort. So it makes, MADE sense to...introduce to them a national-level law firm specialising in personal injury. Brain Injury Australia is proudly supported, is proud TO BE SUPPORTED by, the law firm Slater and Gordon- what, the first of the dominos to fall in a multi-year sponsorship strategy, to be followed - sooner rather than later - by financial planning, followed by funds management, followed by a Disability Employment Services provider and so on. (If any of you have any leads, can you please come and see me at morning tea?)

The largest subgroup of acquired brain injury is stroke. In 2015 there were 440,000 Australians living with the effects of stroke, along with than 50,000 new or recurrent strokes. And while the median age for stroke is around 75 years, one in every four occurs in a person aged less than 65 years. Though there is a lack of solid local trend evidence, rates of young stroke are increasing worldwide due to an increase in modifiable risk factors such as obesity, hypertension and diabetes. A recent survey of 5 million stroke hospitalisations in the United States over 10 year years found that, while rates of stroke had decreased for people aged 65 plus they had increased for those aged 45 to 64 by 5 per cent, and in those 25 to 44 by...44 per cent. The dearth of rehabilitation services and community supports fit for stroke in Australians of WORKING age is nothing short of a continuing scandal.

Where alcohol and other drug-related brain injury the result of CHRONIC ABUSE - rather than, say, Fetal Alcohol Spectrum Disorder or hypoxic/

anoxic injury (where the supply of oxygen to the brain is depleted or stopped due to, for example, an overdose) - where chronic brain injury, GENERALLY - is going to fit and sit in the Scheme remains unclear to me, at this stage of the...rollout, at least. Likewise for people with the DISABILITY for whom the relationship to their INJURY isn't a direct, isn't a linear, one. The Scheme is going to be challenged by Post-Concussion Syndrome and what the literature demeans as QUOTE the "miserable minority" living with the lingering effects of so-called "mild" TBI.

Australia is blessed (if you can call it that) with the some of the best, and longest, longitudinal surveys of the outcomes from the several thousand severe TBIs sustained each year in Australia, funded - no real surprises here, and I'll come back to that - by compulsory third party motor vehicle and workplace accident compensation schemes. Their findings, in brief, are as follows. As many as 9 in 10 moderate to severe TBIs will return to the care of their family; their average costs of care are over \$100,000 per year; only 40 per cent of people living with severe TBI are employed 5 years post-injury; of all people with a disability, they have the second lowest representation in employment; half report they have lost friends, have become socially isolated since their injury; they run a 60 per cent likelihood of a major mental illness during the course of their lifetime; half of all marriages involving a partner with a severe TBI dissolve within 6 years of injury; and 1 in 5 will attempt suicide.

Take anything from that grim catalogue and I reckon it'll make for a safe marker of unmet need. Yet, at the time I made my request to the Australian Bureau of Statistics, only? 16,000 people with a brain injury (out of a total of 310,000) were using a National Disability Agreement-funded service.

Only 21,000 (out of 820,000) were receiving the Disability Support Pension. Only 2,200 people with a brain injury (out of 160,000) were using Disability Employment Services (and, while the TOTAL number of participants in Disability Employment Services has INCREASED 7 per cent since 2011, those with a brain injury have FALLEN by 10 per cent).

Brain Injury Australia's core representational-political challenge remains to solve the puzzle of high prevalence (relative to other disabilities) matched by apparent high unmet need, confounded by low service and income and other support uptake. At the risk of gross stereotyping, a potentially very large number of Brain Injury Australia's constituents comprise men AND women, sometimes in their 40s or 50s, living in their pyjamas being cared for, more often than not, by...mum. (...What gets me out of bed in the morning is making the highly rarefied work that I do as relevant as possible to THEM, and to gain some, ANY, traction in making the wider world beyond THAT person's bedroom, outside their front door, as understanding of brain injury, and thus as...welcoming, as possible.)

Among the range of answers to that puzzle – and, sorry, I think this as uncontroversial as it's bleedingly obvious – is that brain injury is an ACQUIRED disability and, for the majority of those 2 to 3 thousand severe TBIs, it is also a PRIME OF LIFE disability, occurring right at that point of entry into adult life, and everything that promises: the maximal expression of independence from the constraints of a too-long childhood - leaving home, adventuring in the world of gap years or work, of embarking on further study and so on. 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 people living with a severe TBI they describe it as THE watershed event of their life; where everything changes, when nothing after will ever be the same as before. What many? most? people profoundly disabled by their brain injury feel most keenly is having been cut adrift of both their past, and ITS imagined future, marooning them on an alienating, and seemingly fixed, present - in concrete terms; that they cannot do, or think, or feel as they once did. (Key to the training that Brain Injury Australia offers to disability services is cultivating the ability to trade places, in imagination, with a client with an ACQUIRED disability, how to QUICKLY build rapport, and retain hope, REALISTIC hope, for as long as possible.)

And here's a tip for you - the nearest I'll bring you to a BUSINESS STRATEGY - if I've learnt anything from my years in this job (again, hardly a revelation, but rather just tripping over the bleeding obvious) there is a whole world of work, sorry, of OPPORTUNITIES for disability services, AT THE TOP OF THE CLIFF THAT LOOKS OVER what's often for a person with a brain injury, what's often going to be a life-long struggle to come to terms with the disability. At the TOP of the cliff. BEFORE, for the 9 in every 10 who return to the care of their family, before for many, a literal EM-BEDNESS sets in.

Brain Injury Australia fields about 300 inquiries by email and phone a year. It's 1-800 number diverts to my mobile. A good percentage of the calls can't wait on the typical "information and referral" response time, but hang on an emergency service - often an ageing carer whose son's or daughter's behaviours are now life-threatening to self, to others/ to the caller. And they've just fathomed that the son's or daughter's

incandescent, and unprovoked, rages only really emerged after THAT motor vehicle accident, THAT workplace fall, THAT assault - 10, 15 or longer years ago. It's just that nobody...made the connection. Until now. Until near enough to too late.

"Challenging behaviours" - sometimes referred to as "behaviours of concern" - these behaviours include hair-trigger impulsivity, irritability, verbal - sometimes physical - aggression, as well as social-sexual disinhibition. One of the design flaws of the human head is THE parts of the brain most vulnerable to the most common kind of head injury, a CLOSED head injury - where the brain is forced forwards, backwards or rotates inside the skull - are the very SAME parts of the brain responsible for its EXECUTIVE functions - reasoning, problem-solving, and planning as well as all the regulation of emotions, of behaviours, that make for the bedrock of polite, of civil, society. Survey work recently completed by New South Wales' Brain Injury Rehabilitation Directorate (in the interests of full disclosure, I serve on the Directorate's Executive) the Directorate found over half of both adult and paediatric samples screened positively for such behaviours upon discharge. (Work carried out by the Transport Accident Commission - the "TAC" - in Victoria found the same proportions.) The Directorate also found a positive relationship between INJURY severity and the severity of subsequent BEHAVIOURS. THE BEHAVIOURS CAN ALSO WORSEN OVER TIME (hence the kind of crisis calls that Brain Injury Australia receives). From those longitudinal surveys I mentioned earlier, for 2 in every 3 people who behave in such ways – especially where insight into the behaviours and their effects is also limited by damage to their brain and they have limited, or no, control over, combined with lack of memory of, them – this is reported by them, their carers, their

family members as being THE MOST DISABLING aspect of their brain injury.

To give you some of idea of what these behaviours can...look like, one of Brain Injury Australia's constituents is slowly bringing his masturbation in public under control. Another regularly risks limb and life to lock her daughter in a purpose-built windowless room of her house lined with mattresses until she...settles down. Both are on first name terms with the police.

What constitutes the MANAGEMENT of these behaviours can be THE MOST COSTLY aspect of brain injury for third party insurers. The TAC's "Independence Branch" manages the claims of clients with severe TBI and spinal cord injury and, while they make up only 3 per cent of the TAC's claims, they represent two-thirds of outstanding liabilities. Current approaches to..."behaviours of concern" in TAC clients are primarily focused on risk management and supervision, largely through the use of attendant carers. The Branch's ANNUAL expenditure attributable to managing behaviours across 625 severe TBI clients is around \$8 million - over one-fifth of the annual expenditure on the group, and 10 per of overall Branch expenditure on both client groups. So, it still surprises me - and comes as grave disappointment to callers in crisis – that genuine INTERVENTIONS in behaviour are so thin on the ground, and that the behaviour management of default looks like glorified baby-sitting. Some constituents, I'm sure, are left thinking (after they hang up from, ON me); hang on, TBI isn't the Ebola virus, some, what, emerging phenomenon, some new disease vector. But not only are specialist services in this area sparse to non-existent, the evidence base for what works and what

doesn't - let alone "best practise" standards - is still at the foundational stage. Which is why the TAC, through Monash University's Institute of Safety, Compensation and Recovery Research, is spending \$3 million to conduct the world's first randomised controlled trial of what's called Positive Behaviour Support for adults with a TBI living in the community (again, in the interests of full disclosure, I serve as the consumer representative on the trial's Steering Committee).

Look, while I don't want to be taken as detracting from a main message by peddling extremes, there are some seemingly insuperable supply and demand challenges to the quasi-market of the NDIS for people with a brain injury. In Australia, GEOGRAPHY is destiny. The NDIS' "trial site" in the Northern Territory – where one-third of the Territory's population is Aboriginal and Torres Strait Islander, compared with 4 per cent or less in the rest of the country – its "trial site" was the Barkly region, an area 40 per cent bigger than...Victoria.

(Brain Injury Australia recently conducted some training for Centrelink. They couldn't, or wouldn't, pay for it in cash. So I asked for data: people in receipt of the Disability Support Pension with a brain injury as their "grant reason", disaggregated by Local Government Area.)

The Barkly's a, what, cluster of people with a brain injury. 544 people - or 1 in every 15 residents of the Barkly - are on a DSP. And for 68 of those - or 1 in 8 - the "grant reason" was a brain injury. And while I certainly don't imagine that access to the DSP *ipso facto* confers eligibility for "Tier 3" participation in the NDIS – AND, according to the Territory's bilateral agreement with the Commonwealth, the "trial site" was expected to cover

QUOTE “approximately 150 people from 2014” – still, how far away, IN BOTH PLACE AND TIME, will MORE THAN ONE – to make meaningful the CHOICE in “choice and control” – how far away will evidence-based, AND culturally relevant, behavioural INTERVENTIONS be for Scheme participants in the Barkly with a brain injury?

On the DEMAND side, if the international AND local evidence from self-directed/ individualised funding schemes is anything to go by, uptake by people with a brain injury will be both low and late. As at the end of March this year, only? just? 600 of the National Disability Insurance Scheme’s 25,000 approved plans were for people with a brain injury. Of the 2,500 TAC clients eligible for its new Individualised Funding service, around 3 in every 4 would have a brain injury. As at April last year the service had attracted only? 31 clients, of which 3 in every 4 have a SPINAL CORD INJURY.

I don’t mean to rain on anyone’s parade, but Brain Injury Australia’s fundamental reservations about the NDIS remain unchanged since the bill for its establishment was drafted. THAT an individualised funding scheme, wrapped in “choice and control”, packaged in human rights, or in obligations under international conventions is simply lost on anyone trying to put back together the pieces of their...broken life. And THAT, while some people with a brain injury will be able to navigate its new quasi-market as easily as the disability services system of old, many will not. Specifically, Brain Injury Australia suspects that few people with a brain injury that makes them eligible for the Scheme are going to be able to readily transform themselves from the PASSIVE CUSTOMERS of disability services of tradition into active RETAILERS of their funding.

(Remember that the Scheme's, what, aspirational target is for 30 per cent of Scheme participants to be self-managing.)

Without an enabling infrastructure to do so. That infrastructure still isn't in place, I believe, for what the Scheme refers to as "hard to reach populations". AS disappointing is what appears to me to be the Scheme's backpedalling – as part of its Information, Linkages and Capacity-Building supports – is a backpedalling on funding outreach efforts. Scheme philosophy remains, it seems, simply; BUILD IT, AND THEY WILL COME. Brain injury – like many other disabilities – tracks social-locational disadvantage: that those people at the greatest risk of a brain injury are drawn from 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. To bring it...home – half of the greater Sydney metropolitan area's young, risk-taking, severe traumatic brain injuries occur between the longitudes of...Parramatta and Penrith. And, I think - in these cost-conscious times - whether the SCHEME wants the likes of Brain Injury Australia to beat a path for participants, whether, indeed, it wants PARTICIPANTS whose costs-per-plan are going to be higher than the Scheme average – I think it's fair to say these remain open questions.

If you've ever gone into a supermarket on a forlorn search for your preferred toothpaste, you would have been confronted with the blinding kaleidoscope of choices. Disability supports aren't toothpaste. But, as I think some of the NDIS's architects imagine it, imagine what – using the jargon of microeconomics - utility maximisation; gaining the greatest value

possible from the least amount of expenditure in order to maximize the total value derived from the dollars in your plan - imagine what utility maximisation would constitute for MANY of Brain Injury Australia's constituents in, what, a fully mature NDIS where its supermarket equivalents compete with each other on the basis of contracts as dense and impenetrable - and with as many acres of fine print - as those currently on offer for mobile telephony.

There's a ways to go.