

There's no more certain death to an audience's attention than bogging them, YOU, down in my problems. But, egad, I've been in this...job role nigh on 10 years. And while as good as it is to be able to almost TASTE the leave that comes with my...long service, I still feel - good Australian expression? - I still feel like I stick out like dogs' balls on a program like today's. And being a stranger in a list of speakers doesn't mean I'm NEW to many, to ANY of you. One of the first things I do NOWADAYS is scan the room for familiar faces. The ex-journalist deep down inside where I live always reaches for that NEW something to say. My apologies, in advance, to those rolling your eyes IN YOUR IMAGINATION at my same old schtick. I hope you'll forgive it as, what, old tunes beautifully played.

I could re-tell the story of MY return to work [after my TBI], but it'd be relevant to today ONLY BY WAY OF CONTRAST. I was, I REMAIN - I think - an outlier, out-of-the box. Because I was on my way to work, according to my family, I spent most of my time in hospital perseverating on getting access to my...desk. I generally strained at the leash. I LIKE to think that I...chaired my own discharge meeting from rehabilitation. I'm sure I was high maintenance. And from the vantage point of this here and now, those days seem such a loopy fog, it can't have been all that PLAIN sailing. My guess is, NO, I can RECALL - for instance - frontal days of literally saying or doing the first thing that came into my head.

More than 20 years on, it's also my ANCIENT history. And from a systems perspective, it may as well be the mezozoic age for return-to-work, with nests of Commonwealth Rehabilitation Service offices supporting staff SPECIALISING IN BRAIN INJURY, like...pterodactyls, swooping and scooping their clients back into work

I'm not going to talk about any of that. Instead, I offer my mongrel mix of anecdote, intuition plus some things that I read, I hope critically, somewhere some time.

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Soon after I started in this job, like any...politician I wanted to find out how many...constituents I had. I asked the Australian Bureau of Statistics for their best estimate based on their triennial Survey of Disability, Ageing and Carers, disaggregated for brain injury. From its most recent – 2012 - iteration, they came back with 730,000 - crucially, Australians whose brain injury MEANS daily "activity limitations" and "participation restrictions". That number often surprises people. As high. I'm not a statistician, so can't debate the finer points of the Bureau's multi-stage sampling technique but I reckon it's still likely an UNDER-estimate, though, when you consider 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. (In both these cases, small numbers of potential participants in the NDIS relative to other DISABILITY types but RELATIVELY high cost per plan.) 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..."

Australia is...blessed with the some of the best, and longest, longitudinal surveys of the outcomes from severe TRAUMATIC brain injury (ROBYN TATE's Brain Injury Outcomes Study, for example). Their findings, BROADLY, include the following. As many as 9 in 10 people sustaining a severe TBI returned to the care of their family; their costs of care were over \$100,000 per year; half reported they have lost friends, had become socially isolated since their injury; only 40 per cent of people were employed 5 years post-injury; they ran 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 had dissolved within 6 years of injury; and 1 in 5 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).

I may be hanging way too much on just one estimate, but the way I see my core representational-political challenge remains unchanged since the ABS sent me the results of their survey - to somehow 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 "known unknown" constituents comprise men AND women, sometimes in their 40s or 50s, living in their pyjamas being cared for, more often than not, by...mum. (And what gets me out of bed in the morning is making the often highly rarefied work - "work", dare I say, such as...this here today - the often 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, as compassionate, and as...welcoming, as possible.)

Among the range of answers to that puzzle – and, sorry, it’s as bleedingly obvious as it can bear re-stating – is hammering the differences between the lived experience of ACQUIRED versus DEVELOPMENTAL disability. For many of the 2,000 or so people who sustain a severe TBI each year, for some of the 20,000 or so "young strokes", 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. For many people living with a severe TBI, they describe it as THE watershed event of their life; where a...moment divides their life in two. And it seems to me no less obvious that one of the first responses to a person radically challenged by the adaptation to such a disability should be to help them reach for any and all continuities with their...past. To try and tap any wellsprings of pre-injury work, diversions, interests, to harness and steer pastimes and passions – as a means of...breaching that watershed. I'm still surprised by how uninterested many professionals who work with people with a brain injury, how uninterested they seem to be in...excavating what person the person in front of them was...BEFORE. A corollary of which - and believe me, there's nothing more RE-disabling - a corollary of which is being thought nothing BEFORE, thus nothing ELSE than the sum total of your...impairments.

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Look, a kind of chronic grumpiness is THE occupational hazard of SYSTEMIC advocates like me. And I may not be looking in the right places or looking hard enough, but commitments to "capacity building", let alone "STRENGTHS-based" approaches to service delivery for people with a brain injury seem to me to be honoured as much in the breach as than the observance.

AND I DON'T WANT TO STEAL any of John Walsh's thunder but Brain Injury Australia's fundamental reservations about the National Disability Insurance Scheme - the "NDIS" - remain unchanged since the bill for its establishment was drafted. If the international AND local evidence from other self-directed/ individualised funding initiatives is anything to go by, uptake by people with a brain injury will be both low and late. As at the 30th June, only? just? 2,500 of the National Disability Insurance Scheme's 90,000 approved plans were for people with a brain injury - 3,500, once you include stroke. How that, what, penetration rate compares with other so-called "hard to reach populations" - people living with psychosocial disability, for example - is anyone's guess.

NEITHER - since I am about to begin facilitating a "community of practice" in brain injury for the National Disability Insurance Agency, to be piloted here in Sydney – NEITHER do I want to join the queue taking turns at the Scheme as punching bag, but the Agency is steadily backpedalling on

funding outreach efforts. Scheme philosophy remains, it seems, simply; BUILD IT, AND THEY WILL COME. Moreover, I doubt whether wrapping ANY disability initiative in human rights bromides like “choice and control”, is going to be good enough to sell participation in the Scheme from people with a brain injury, perhaps from people with ACQUIRED disability generally. Even if it does, 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 able to meet the "disability requirements" of 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. Without an enabling infrastructure to do so.

Agency staff - ordinarily from head office in Geelong - USED TO talk of a 30 per cent target of Scheme participants SELF-MANAGING their plan - paying invoices, hiring and firing staff etc. - USED TO talk of a 30 per cent target as something more than...aspirational. And while it's still early days for the Scheme, the self-management rate sits at about half that - across ALL participants (I suspect that rates of self-management for participants WITH A BRAIN INJURY will be among the Scheme's lowest). Again, Agency marketing of self-management seems to be built on nothing more than a foundation of INTRINSIC reward; self-management as an exercise IN SELF-FULFILMENT, an exercise OF "choice and control". For some? many? participants with a brain injury - engaged in what's often a long-term, a lifelong, struggle to adapt to their disability - I suspect that taking

on self-management will strike them as letting government off the service-provision hook. Moreover, apart from helping government fulfil its obligation under international conventions, what's the SOCIAL utility of self-management, where's the broader, participatory ...where's the beef? Brain Injury Australia's modest contribution to an enabling infrastructure is early stage discussions with Pricewaterhouse Coopers about developing a small, highly targeted pilot in self-management COACHING for Scheme participants with a brain injury, where the reward will be some manner of qualification, of certificate, that could act as a calling card for employment.

I hope this doesn't betray a LACK of "what, then?" thinking in the Agency, a thinking focussed on fulfilling the Scheme's promise of up to 218,000 people with disability, and the up to 104,000 carers, who'll be able to up their hours worked or join the workforce. And at, what, the atomic level of the participant, the Scheme holds out the prospect of the "ordinary life" envisaged by the NDIS Act - that "people with a disability [are enabled] to exercise choice and control in PURSUIT OF THEIR GOALS, and the planning and delivery of their supports". AND should I wonder, should I worry about - regardless of whether, in Scheme scalability terms, it's early days or five minutes to midnight - worry about HALF of the \$4.7 billion in total annualised costs of approved plans going to core supports for activities of daily living - the largest part of which would be attendant care?

I promised you ONLY a mongrel mix of anecdote, intuition plus some things that I read. And remember that, as an advocate - often of last resort - I work at the receiving end of a self-selecting sample of the MOST aggrieved of customers of the Scheme. Just last week, a parent rang me last week to complain about her daughter NOT complaining about an attendant carer NOT watching her daughter watch television but instead spend the entire time tinkling her own mobile phone. It was a regular arrangement, the mother said. Hence the call. Needless to say, I have neither witnessed the care nor eavesdropped on any calls between mother and daughter. Regardless, I've heard of such, well, glorified baby-sitting arrangements before that the truth of them takes on a, what, iterative quality. And as sterile and unproductive as it might SOUND, these arrangements MAY, they MAY suit ALL parties involved. Except the mother. And except, perhaps, taxpayers with both long-held concerns about the Scheme being a bucket brigade to treasury, and agitated by newspaper articles about lawnmowing and garden-maintenance companies registering with the Scheme. QUOTE "NSW lawn-mowing contractor Paul Bussey told *The Australian* newspaper that he was preparing for what could be an exponential increase in business thanks to the NDIS".

You may also have seen media reports over the weekend about complaints about the Scheme to the Commonwealth Ombudsman QUOTE "soaring" 700 per cent in the last year, to...429. Most of the complaints related to the Scheme's approach to planning. A change of government notwithstanding, the headlong rush to jam 460,000

participants into the Scheme by 2019-20 has meant the abandonment of the blue-sky-blank-sheet-of-paper planning promise of "trial site" days, in favour of a more a narrow, canalised, and curtailed conversation about a participant's future, restricted to immediate needs, and held – more often than not – over the phone. One thing that I suspect has happened once medium-to-long-term goal setting has been cut adrift from planning, and SHORT-TERM planning at that, is that participants and their families accentuate the negative - the bleaker the picture painted of disability, the greater the supports they'll receive. Because they're not sure what supports might be funded around the corner, let alone over the horizon of their current plan.

Given the constraints around planning, it's perhaps little surprise that in the Scheme's Outcomes Framework pilot, only thirteen per cent of respondents indicated that the Scheme had helped them with employment, THE LOWEST OF ANY DOMAIN. The Scheme literally cannot afford to be viewed by participants with a brain injury and their families, indeed it cannot be IMPLEMENTED, as another COMPENSATION scheme which, in the words of the original Productivity Commission report that helped give birth to the NDIS, compensation schemes QUOTE "may act like a tax on recovery" from injury. At four years' follow up with over a thousand serious trauma cases in Victoria from 2011-12, Alex Collie and colleagues working on Monash University's RESTORE project found rates of return-to-work for those with NON-compensable injuries more than double that of the compensable.

I'd promised not to bag the Scheme, punch the bag. And, as per the title of my presentation, there IS evidence that the Scheme is "minding the

gap” between health and disability-funded services. That, where Brain Injury Australia’s constituents often likened discharge from specialist brain injury rehabilitation to falling off the edge of a cliff, conversations at the “interface” of the Scheme with health-funded services – however tentative – ARE being had about return-to-work, finding work, further study, even where they are susceptible to the familiar temptations to shove ducks and shift costs. Perhaps some of the invaluable lessons from longitudinal survey work – about the HEALTH benefits of work, about STARTING conversations about employment, about study as early as possible – perhaps they are filtering through. For example, Jennie Ponsford and colleagues’ 20 year survey of 2,500 thousand TBI patients of Melbourne’s Epworth Hospital - of those employed at one year post-injury, more than THREE-QUARTERS were employed at FIVE years. And of those UNEMPLOYED at one year post-injury, only a QUARTER of them were employed at five years.

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I will end as I began - by BREAKING, AGAIN, my promise to NOT tell you my troubles. There simply isn’t the time left for me to inflict upon you my continuing professional-personal crisis of relevance BUT, with so many of you in the room involved in research or policy development and with consumer/ end-user CO-DESIGN being “the new black”, I’d be crazy not seize this opportunity to implore you to double and re-double your efforts at genuinely representative consumer representation and recruitment in your work.

At a recent meeting, I swear this guy glanced MEANINGFULLY...MY way during a discussion about QUOTE “serial consumers”. And while contemplating what a...KNACKERY for consumer representatives might look like, I realised that it has taken me way too long in this job to learn that I belonged to the exclusive club of brain injury's...acceptable faces. Its "MEMBERS" need: to have made a...superior recovery; to be able - give or take some - pick up their pre-injury life where they left it; WHERE BRAIN INJURY TRACKS SOCIAL-LOCATIONAL DISADVANTAGE, its members need to live in the more genteel parts of metropolitan Australia, and be free of the cultural or racial....overlay that's going to make ticking the box of consumer representation more...challenging.

I don't mean to be churlish about the opportunities granted to me but consumer representation in brain injury remains a very small merry-go-round of largely the same faces going up, down, and around the exception rather than the rule in recoveries.

Thank you.