

There's no more certain death to an audience's attention than bogging them, YOU, down in my problems. But one of the first things I do NOWADAYS is scan the room for familiar faces. The ex-journalist deep down inside where I live frets mightily over always having something NEW to say. My apologies, in advance, to those who'll have HEARD IT ALL BEFORE, who'll roll your eyes IN YOUR IMAGINATION at my same old schtick. Wherever you are, I hope you'll forgive it, ME as...old tunes, beautifully played, at least.

I could re-tell the story of MY return to work after a severe traumatic brain injury, 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 wrestling with nurses to get access to...a 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 – days when, due to rattled frontal lobes, I would LITERALLY say or do 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. And, look, in the interests of full disclosure, I DIDN'T pick the title for my presentation either: "How DES can GO DEEPER into the community to work with people with acquired brain injury". Rick did. But I...get it. The DETAILS of DES contracts have always made my head spin. But the sense I get is that "going deeper" - rather than, say,...skimming the cream - might become more commercially? attractive – with, for example, Risk-adjusted Outcomes Payments. Indeed, that clients with a brain injury – who I sense have been seen as "high cost, low return" - that clients with a brain injury might get their fair share of favour in the new contract.

So, I wouldn't be earning my keep if I didn't seize this opportunity to put in a pitch, with you, FOR those clients whose numbers in the DES have sat miserably, for as long as I can remember, barely north of 1 per cent.

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Soon after I started in this job, like any other...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 THEN most recent – 2012 - iteration, they came back with 730,000 - crucially, Australians whose brain injury MEANT 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. I reckon it's still likely an UNDER-estimate 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. 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...”.

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Australia is...blessed with the some of the best, and longest, longitudinal surveys of the outcomes from severe TRAUMATIC brain injury (of which there are between 2 and 3 THOUSAND each year. And what follows - perhaps in less dramatic fashion - applies to the TWENTY THOUSAND “young strokes” per annum – strokes in people aged less than 65). The findings in severe TRAUMATIC brain injury BROADLY include the following. As many as 9 in 10 returns to the care of their family; their costs of care were over \$100,000 per year; half report having lost friends, becoming more socially isolated since their injury; only 40 per cent of

people are employed 5 years post-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 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 the DES. AND, as I understand it, while the TOTAL number of participants in DES has INCREASED 7 per cent since 2011, those with a brain injury have FALLEN by 10 per cent. (And as of 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. 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.)

I may be hanging way too much on just one – the ABS' - estimate, but how I see Brain Injury Australia's core REPRESENTATIONAL challenge remains unchanged since day one - 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.

(To give you an inkling of how lapsing into literally EM-BEDDED patterns of care results in disengagement from the world of work – of the 400 consumers who responded to a 2014 Brain Injury Australia employment survey, HALF were not working or looking for work. Half of THEM stated that they would LIKE to work. BUT less than half of THOSE knew of any agency or service that could help them find work - just some of the 240,000 people with disability that the Department of Social Services estimates are eligible for the DES but don't use it.)

I don't want, THERE SIMPLY ISN'T THE TIME, to get all Marxist-Leninist with you...but there's another truth about Brain Injury Australia's "known unknown" constituents that can bear re-stating; brain injury - like other disabilities - tracks social-locational disadvantage. Those people at the greatest risk of 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. To bring it home - to MY home, but I think it's safe to say that brain injury is similarly spread across each of Australia's metropolitan centres) HALF of the Sydney metropolitan area's young, risk-taking, severe traumatic brain injuries - the motor vehicle accidents, the assaults and so on - HALF occur between the, what, longitudes of Parramatta and Penrith. Residential postcode information for the 450 participants in New South Wales'

Lifetime Care and Support Scheme – the majority sustaining a severe traumatic brain injury from motor vehicle accidents – found fewer than 1 in every 5 came from areas with a mean taxable income in the top four deciles; that is, \$55,000 per annum and above. For those of you who might have imagined that stroke is the great social equaliser, a 2011 analysis of over 3,000 patients from Perth, Melbourne, and Auckland, New Zealand found those from disadvantaged areas were 70 per cent more likely to experience stroke than those from more affluent neighbourhoods. This is likely due to the higher prevalence of risk factors such as hypertension, diabetes and smoking in more deprived areas. (And for those of you seeking comfort in the median age for stroke – 75 years – 1 in every 4 now occurs in a person aged less than 65 years. And their numbers are increasing.)

I'm no bleeding heart (10 years, 10 months, 10 weeks in journalism will drain that out of you) 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.

Among the range of answers to the aforementioned puzzle – high prevalence, high unmet need confounded by low income and other support uptake – is the radical difference between the lived experience of ACQUIRED versus DEVELOPMENTAL disability. For MANY of the 3,000 or so Australians who sustain a severe traumatic brain injury 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. And then, that MOMENT'S inattention on a highway, that casual brush-up against someone in a nightclub that escalates into full-blown interpersonal violence becomes THE watershed event of their life - DIVIDES IT IN TWO. 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.

(And I think it's NEITHER ...incorrect, nor CONTROVERSIAL to say that, while two-thirds of people living with severe traumatic brain injury have their SHORT-TERM memory impacted, their recollection of their life BEFORE injury and disability remains clear, AND VIVID. Whereas for people living with a DEVELOPMENTAL disability, it is – ordinarily - ...the only life they've ever known.)

And when I..."train" people in brain injury – particularly those about to wade into the muddy waters of the psychosocial adaptation to brain injury - what I invariably ask of them is to reach for any and all CONTINUITIES with their client's PAST. To try and tap any wellsprings of work, diversions, interests, PRE-INJURY pastimes and passions – as a means of...breaching that watershed. (And which is why - in further adventures of the bleeding obvious – the literature on return-to-work for people with a

brain injury regularly demonstrates higher rates of return to PRE-INJURY employment over starting from scratch in a new job. This is also due, in part, to capitalising on the momentum generated from accelerated recovery in the first couple of years post-injury.)

Last week in Sydney, I had the privilege of hosting a breakfast for 150 staff and clients of Pricewaterhouse Coopers – part of a multi-year public education campaign dedicated to women, family violence and traumatic brain injury. (ONE woman dies in Australia each week as a result of domestic and family violence. THREE women are hospitalised each week with a traumatic brain injury the result of family violence.) The breakfast featured two women WHO'VE PRIVILEGED ME by sharing their experience of violence and recovery; one was attacked by her stepfather with a claw hammer, the other shot point blank in the back of the head by her boyfriend. The word “inspirational” has been used so often, and so promiscuously, in describing the FEELING, the EFFECT that the non-disabled WANT from the stories of people with disability, as to be degraded currency. What is, INSTEAD, REMARKABLE about the post-CATASTROPHIC injury lives of these two women is that BOTH were not only able to forge a path to their past but pick up their pre-injury lives where they left them, and in spite of significant physical and cognitive disability – as a yoga instructor and arts therapist, respectively.

(I wanted to pause you there, to skip – quickly - down the byway of injury compensation, and the lottery of external cause. It's one of those screamingly obvious life lessons you can only TRULY learn 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. I continue, to THIS DAY, to dine out on my story. Because it was a motor vehicle accident, my injury compensation gifted me a toehold into the Sydney property market. The maximum compensation available to THESE TWO WOMEN – under the NSW Government’s Victims Support Scheme – is \$30,000 for economic loss and something called a “recognition payment” of...\$1,500. And both women - who wouldn’t mind me saying this about them here - still struggle with how THEY might have brought the assaults – AND the disabilities they now live with - upon themselves.)

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My apologies if this is like teaching you how to suck eggs, but I’m trusting you can see that, in working with these two women – in whatever therapeutic or community re-integrative fashion – requires getting to know ...FOUR women, in the hope of RE-joining two radically disconnected, pre- and post-injury lives. Each.

Believe me, you'd be surprised - as surprised as I was during my return-to-work rehabilitation - by how uninterested many professionals, DES providers included, 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. There's, believe me, nothing more RE-disabling than being thought nothing else than the sum total of your...impairments.

(I wanted to pause you again there, to skip – quickly - down the...highway of the NDIS. One of Brain Injury Australia's concerns about the headlong rush to jam 460,000 participants into the Scheme by 2019-20 is 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. Perhaps, then, it's 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.

But another result, I reckon, of the sacrifice of medium-to-long-term goal setting on the altar of first planning is that participants and their families accentuate the negative – reckoning 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. There's a thousand things to say. Among them, it's no surprise, perhaps, that the Scheme's last quarterly report to COAG noted QUOTE "increasing package costs over and above the impacts of inflation and ageing" as well as QUOTE "lower than expected participants exiting the Scheme."

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Many of you will remember this brutal? candid? assessment from Australian Government's 2014 capability review of the Scheme, likening

it to QUOTE "a plane that took off before it was fully built and is being completed while it is in the air". There's plenty? of time to get the build right before the Scheme...lands on June 30th, 2020...or before the wings start falling off.

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Brain Injury Australia's, what, most crucial contribution to that BUILD is its facilitation of a NATIONAL "community of practice" in brain injury for the National Disability Insurance Agency, being piloted in Sydney – regular meetings of Local Area Co-ordinators, planners with senior Agency staff, a clinical lead and allied health representation. One of the community's core purposes is to expose the Agency to EXTERNAL expertise and experience and, in so doing, optimise both needs ascertainment and plan fidelity for participants with a brain injury. This will be followed by a NATIONAL training package for the Agency that Brain Injury Australia will deliver, also to be piloted in Sydney. Consider this an open invitation to each of you to engage with the Scheme on any systemic faults or failings in relation to participants with a brain injury, via me as the facilitator of the community. I'm easy to find. There's my email address. Brain Injury Australia's 1-800 number diverts to...my mobile.

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The Australian Institute of Health and Welfare's analysis of the then Commonwealth State Territory Disability Agreement's 2006-2007 National Minimum Data Set found that people with a brain injury were the QUOTE "most likely to need help with activities related to learning and

working—more than three-quarters of service users with [a brain injury] needed assistance in these areas”. However, people with a brain injury were QUOTE “less likely than service users generally to access disability employment services.” Separate, earlier research by the Institute - dating back to 1998-99 - nothing suggests to me anything's changed...[that] much, found that people with a brain injury had the second lowest representation in the clientele of open employment services; the highest mean number of hours to “get job”; the third highest mean direct support hours per client after people with autism and intellectual disability and, when compared with 1996-97’s “outcomes”, the mean level of client support required had fallen for all disability groups except for people with a brain injury.

And because so many traumatic brain injuries result from motor vehicle or workplace accidents involving third party compensation, they’ve been relentlessly surveyed by insurers. The various meta-analyses have settled, are stuck – spookily – on a miserable 40 per cent return-to-work rate, whether it’s at 2 years post-injury, 5 years or beyond.

But there’s some promising, AND local news. For the last couple of years, I’ve been the consumer representative on a pilot of a Vocational Intervention Program, funded by Insurance and Care – iCare – in NSW and administered by NSW Health through its Agency for Clinical Innovation and Brain Injury Rehabilitation Program (I’m also the consumer representative on the Rehabilitation Program’s Directorate). The Vocational Intervention Program comprised two interventions – “Fast Track” - a graded return-to-work with pre-injury employers, and “New

Track” – trialling of new work via unpaid training placements of up to 12 weeks. The interventions were implemented in the northern and western suburbs of Sydney, the NSW North Coast and Western NSW. 83 people with a brain injury were referred to the Program, 32 to “Fast Track” and 51 to “New Track”. Of the 29 outcomes from “Fast Track”, 22 – or 76 PER CENT – were working; 6 full-time, 16 part-time. Of the 21 outcomes from “New Track”, 6 were working with their host employer, 2 were volunteering with their host employer, and another 3 were volunteering with an alternate organisation. The results have been so positive that iCare’s Foundation has decided not only to fund the Program for a further 3 years but expand it to 12 sites statewide. If there any DES providers in the room interested in offering their services to this expanded program, I would be more than happy to direct you to the right people. Please do not hesitate to contact me via the details on the slide.

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I feel decidedly uncomfortable talking about growth in a market of ACQUIRED disability, because it comes at the cost of...people’s dreams. But as recently as 30 years ago, MORTALITY from the two most common causes of brain injury – trauma and stroke – was 50 per cent. Due to improvements in vehicle safety design and acute care, for example, that rate has been halved in recent times. It means, though, that more people are surviving their brain injury, but with more severe DISABILITY. This - alongside the untapped work potential of Brain Injury Australia’s “known unknown” constituents...living in their pyjamas being cared for by mum - demands Brain Injury Australia get in the market for a preferred DES

provider, with genuine interest AND capability in meeting the return-to-work needs specific to the disability. If any of you, or any provider you know, is interested in becoming Brain Injury Australia's premiere partner in DES, please do not hesitate to contact me.

Thank you.