

BREATHE!

Soon after I started in this job (which sounds like the beginning of a very shaggy dog story, but IT won't take any longer than my allotted time, I promise)...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 (remembering that both the Productivity Commission, and the Disability Investment Group before it, RELIED on the Survey for scaling and costing the Scheme)...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.

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(With BOTH these groups, perhaps SMALL numbers of potential participants in the NDIS relative to other DISABILITY types but RELATIVELY high cost per plan...remembering that Scheme participants with a brain injury have the THIRD HIGHEST average annualised committed support dollars after spinal cord injury and cerebral palsy)...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 (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,

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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 Disability Employment Services.

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

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And if the evidence from BOTH international and local individualised funding initiatives is anything to go by, uptake of the NDIS 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. If the recent backpedalling on outreach efforts with so-called "hard to reach populations" is anything to go by, Scheme marketing seems best summed up in simply; BUILD IT, AND THEY WILL COME.

Brain Injury Australia's fundamental reservations about the Scheme remain unchanged since the bill for its establishment was drafted. That, while SOME people with a brain injury will be able to navigate the new quasi-market of the Scheme as easily as the disability services system of old, MANY WILL NOT. Specifically, Brain Injury Australia suspects that few people with a brain injury who 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. That infrastructure still isn't in place. Many of you will remember this brutal? candid? assessment from Australian Government's 2014

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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 here 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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*There's a whole other...sermon – buried under this one and dying to get out – on the SUPPLY SIDE of the Scheme. In order to give meaning to “choice and control” for my constituents – perhaps the most disparate, diverse and...dispersed of any disability type – is there always? generally? going to be MORE THAN ONE provider with genuine, disability-specific capability available...to the node? Given that, as this stage of the build, two-thirds are for intellectual disability or autism, and as much as 90 per cent of support dollars in the Scheme belong to the top 25 per cent of the providers.)

*participant-facing marketing, and other, materials – outcomes...