

BREATHE!

Good morning, and thanks for coming to this workshop on “getting the best” from the National Disability Insurance Scheme for people with a brain injury. I’m Nick Rushworth, the Executive Officer of Brain Injury Australia.

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This Forum is being held on the traditional lands of the Gadigal people of the Eora Nation and I wish to acknowledge them as Traditional Owners. I would also like to pay my respects to their Elders, past and present.

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A few bits of housekeeping before we begin.

- Toilets are directly behind you. There is also a toilet with disability access out the door and to my left.
- Could I ask you to turn your mobile phones to silent? For those of you who need to be reachable, if I could ask you to try and leave the hall to take or make a call. Thank you.
- In the unlikely event of an emergency, the evacuation point is directly outside to the left in front of the tennis courts.
- For those of you with special dietary requirements, your food will be clearly identified on tables outside the main doors to the Hall.
- For those of you interested in seeing more of Royal Rehab - including its Brain Injury Unit - the Clinical Operations Manager FOR the Unit, Bryan San Martin, has kindly offered to be your guide during

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the lunch break. Before we break for MORNING TEA, I'll ask for a show of hands from those interested in taking the tour. Lunch begins at 12:30. To ensure those going are fed and watered, the tour will begin at 1:00 p.m. and take about 15 minutes.

- For the...digital among you, can I please encourage you to spread the word about today's workshop using the Twitter HASHTAG <NDISworkshopABI> and these HANDLES? Thanks.
- We've set aside an hour and a half of today's workshop for question and answer and discussion. It's been my experience that days like today only really...sing when the presenters take a back seat to free-wheeling discussion. So, I hope you've come armed with questions and *de-identified* client, *participant* stories that can be submitted to the wisdom in the room.
- They're the bane of learning and development activities like today - I know - but on each of your seats is an...EVALUATION FORM. Because the optimisation of the experience of the NDIS for participants with a brain injury WILL remain core business for Brain Injury Australia – and well beyond the Scheme's full implementation in 2020 – we want to make sure that we're getting events like today right, or could get them RIGHT-ER. So, I'd really appreciate both your bouquets and brickbats. Could you PLEASE complete and

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return the evaluation forms whether today, or hereafter – via the addresses at the foot of the form. Thanks.

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Before I introduce Libby Callaway, I wanted to steal a minute or two to – what – go back to taws on Brain Injury Australia's take on the Scheme.

Soon after I started in this job – which sounds like the beginning of a very shaggy dog story, it WON'T take long, I promise...and for those of you who've heard what follows all before, I trust you'll forgive it as old tunes, beautifully played... 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

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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...”.

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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. 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,

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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.

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, social marketing for Scheme seems best summed up in simply; BUILD IT, AND THEY WILL COME.

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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.

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That infrastructure still isn't in place, which is where the idea for this workshop came in. And AS GOOD AS TODAY WILL BE as an interrogation of the crucial points of fit, and friction, between the Scheme and the lived experience of brain injury, I'm tempted to say...talk is cheap. Many of you will remember this brutal 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 fully lands on June 30<sup>th</sup>, 2020...or before the wings start falling off.

Brain Injury Australia is facilitating a NATIONAL "community of practice" in brain injury for the National Disability Insurance Agency, being piloted in Sydney. 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. Its next meeting is the 4<sup>th</sup> December. Consider this an open invitation to each of you to engage directly with the Agency through the community, and through me as its facilitator. I couldn't be easier to find. There's my email. And Brain Injury Australia's 1800 number diverts to...my mobile.

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It's now my privilege to invite Libby Callaway to speak to you. Libby is a registered occupational therapist, having worked for the past 24 years in the field of neurological rehabilitation in both Australia and the United States. Libby has also consulted to the National Disability Insurance Agency during development of their Specialist Disability Accommodation Framework, and worked with Scheme participants on pre-planning and plan implementation. In addition to this clinical work, Libby is a senior lecturer and researcher in the Occupational Therapy department at Monash University, where she leads a national collaborative research program on housing, technology and support design for people with disability. Please welcome Libby...

**Barry Willer** is Professor of Psychiatry at the State University of New York at Buffalo. He has worked in the field of traumatic brain injury for over 30 years, written three books and 150 peer-reviewed journal articles and book chapters. He is the principle author of the Community Integration Questionnaire and the “Whatever it Takes” model. He was the first director of the Rehabilitation Research and Training Center on Community Integration and was a leader in the development of the Traumatic Brain Injury Model Systems database. He was the 2012 recipient of the Research Award from the North American Brain Injury Society. Please welcome Barry...

- 1. Some in the room may not be familiar with the ‘Whatever It Takes’ model. Can you tell us a little about where it come from and its key principles?**
- 2. When developing goals with people with brain injury, what should be the key focus?**
- 3. You have worked in brain injury rehabilitation during times of major system reform in the USA like we are now seeing in Australia. What are some of the challenges you have seen in that process?**
- 4. What are some of the opportunities?**
- 5. You’ve been a regular visitor to Australia during the evolution of the National Disability Insurance Scheme. From what you’ve seen and heard, what are your impressions of the Scheme?**
- 6. And what broad advice would you have for people working with Scheme participants with a brain injury – perhaps for those who are not only new to the Scheme, but who may have never worked with participants with a brain injury before?**

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**7. Whilst we all grapple with the changing disability policy environment, and uncertainty and inconsistency that comes with it, what are your key messages to the group here today?**

**Natasha Lannin** is Associate Professor in Occupational Therapy at Alfred Health in Melbourne and La Trobe University, and is Honorary Research Fellow at the John Walsh Institute for Rehabilitation Research, the George Institute for Global Health and the Florey Institute of Neuroscience and Mental Health. Natasha conducts clinical trials investigating the effectiveness of rehabilitation interventions as well as translation research into improving the long-term outcomes for those living with a traumatic brain injury or stroke. She has a keen interest in goal-setting and improving support for people with brain injury and their carers transitioning from hospital to the community. Please welcome Natasha...

**Sue Sloan** is a registered occupational therapist and clinical neuropsychologist. Sue works in private practice providing community-based rehabilitation for people with acquired brain injury. Sue is also Honorary Neuropsychologist in the Austin Health's Brain Disorders Program providing rehabilitation to people with brain injury and complex mental health co-morbidities. Sue has co-authored three books in the field, published in peer-reviewed journals and frequently presents on aspects of community-based brain injury rehabilitation. Please welcome Sue...

4:25?

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.

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Most disability support in Australia was previously based on a system where services were funded to a fixed dollar value per person. The National Disability Insurance Scheme offers a new, more flexible system, where funding is determined by an assessment of an individual's needs, support choices and actual circumstances to achieve outcomes.

Insurance principles in detail

The following four key principles have been developed by the Sustainability Committee

of the Board for the Agency, in conjunction with the Scheme Actuary:

- actuarial evidence
- a lifetime approach
- investment in research and innovation
- capacity building.

The Agency has adopted these insurance principles for the Scheme and makes decisions about supports, based on:

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- Actuarial evidence, to gain an understanding of the actual experience of the individual and evidence of their requirements.
- A lifetime approach, planning for supports that might be required throughout a person's life, creating a cost effective view of resources required in all stages of life.
- Investment in research and innovation throughout the Scheme, to continually improve and access new opportunities for plans.
- Building the capacity for independence (or social capital) of the disability sector and the community, allowing greater independence through learning.

A critical feature of the insurance approach adopted by the Scheme is early intervention and early investment in support and planning. This can enable an ordinary life for participants, while potentially decreasing support costs required later in life. Over the long term, this approach has potential to increase workforce participation by people with disability and their families and carers—both factors that contribute to a healthy national economy.

This early investment in support and planning means that in some instances, if early intervention assists significantly, participants may no longer need to access funds from the Scheme.

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The Scheme will create inclusive communities that benefit everyone, including those people with disability who are not eligible for the Scheme.

\* As the NDIS rolls out, demand for disability services is growing rapidly. An estimated 60,000 more full time workers will be required by 2019. The disability workforce is expected to more than double as the NDIS is introduced, from around 73,000 full-time equivalent workers in 2013 before the NDIS trials began, to around 162,000 full-time equivalent workers when the scheme is fully implemented in 2019-20.