

SPEECH BY NICK RUSHWORTH, EXECUTIVE OFFICER BRAIN INJURY
AUSTRALIA TO THE LAUNCH OF BRAIN INJURY AWARENESS WEEK
– 12 AUGUST 2013, SIMONDS STADIUM, GEELONG

Thanks, Kylie. In spite of appearances from what follows, I've given this awareness week business some genuine thought. The (grizzled) journalist deep down inside where I live knows that every week is an awareness week for some worthy cause, every day is an awareness DAY for some obscure disease, some unsung affliction. And that these days and weeks are like ocean waves that rise, break, wash over publics only to re-form. Every year.

One of Brain Injury Australia's perhaps lesser responsibilities is to set the "theme" for each year's Brain Injury Awareness Week. Since I've been in the role, the "themes" have been built around policy papers I've written for the Australian Government on: the leading cause of death and disability in children who have been abused; inflicted traumatic brain injury (sometimes called "shaken baby syndrome"); the leading cause of traumatic brain - or head - injury across all age groups and causes – falls, due to the ageing of Australia's population; people with a brain injury in the criminal justice system - as many as 60% of Australia's 30,000 adult prisoners have a brain injury; and last year it was concussion in sport.

Because there are more worthy causes than weeks in the year the awareness-raising business is a competitive one. And the natural temptation, one I've given in to - annually - is to...catastrophize brain injury: to talk up its numbers; to weigh it in "burden"; and as more burden-some than other disabilities. I've seen this kind of sport referred to as a "misery olympics" – a business that often competes in burden, and for the public attention that makes for awareness. And because my background is in journalism, bad news is nothing less than stock in trade. Old habits die hard.

But this year, for a change, is same same but different. Different, because it's a celebration of the "launch" of DisabilityCare Australia. DisabilityCare Australia is, genuinely, a once-in-a-lifetime opportunity - for which the Australian Government oughtta be congratulated and one that Brain Injury Australia and its State and Territory Member organisations plan to sieze, and/but optimise, for the over 600,000 Australians living with an acquired brain injury.

If you've worked in this sector a day in your life, you'd be well used to advocates from so-called "Disabled Person's Organisation" special pleading for the unique needs of their constituents, perhaps also for their unmet needs, unmet needs that are somehow greater than for people living with other types of disability. This year's

Awareness Week will be same same because I'll be no different. There's a whole other speech buried underneath this one - and dying to get out - on the centrality of, the indispensable, use of the imagination in person-centred disability services provision. I reckon if I've learnt anything from my time in this job, it's that anyone involved in the "human services" business – my business and, my guess is, many of your businesses - has to at least try and transplant themselves, in imagination, into something of the life circumstances of their client, their customer - as both a first principle and a starting point.

And so, I don't think that I'm going out on an (unsafe) limb by saying that I am coming - I have come - to the conclusion that the lived experience of acquired disability is distinct and different from that of congenital- developmental, disability. For many of Brain Injury Australia's...constituents, their brain injury is a prime of lifedisability, occurring right at that point of entry into adult life, and of maximal expression of independence from the constraints of a too-long childhood - in leaving home, adventuring in the world of work, embarking on further study. Instead, their injury becomes the watershed event of their life. Often just a 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. And coming to terms with the reality that the watershed cannot be completely bridged is often a lifelong struggle. I met with a young woman last week who held the sharpest self-consciousness about her new, her odd - she called it her "lazy" - eye, and - as is often the way with brain injury - about her meandering, serpentine speech. What, it appeared to me, she wanted most fervently was to not stick out from the crowd, to fit in, to be continuous with the...landscape of people.

At the same time - it might give you some idea of the disparateness and diversity of this disability - brain injury is often referred to as the "invisible" disability. The majority of people – the rough rule of thumb suggests three in every four – [the majority of people] make a good physical recovery but will sustain often debilitating and permanent cognitive disability, including difficulties with their memory and concentration, resulting in a reduced ability to learn, to plan and to solve problems - many of the exact same abilities necessary to exercise the kind of control and choice over their individualised funding that's at the heart of DisabilityCare Australia. People with a brain injury are regularly thought unintelligent, unmotivated, uncooperative – doubly disabling, RE-disabling for the person affected: not only are their "invisible" disabilities not recognised as resulting from brain injury, they are seen only as a function of who they really are, and have always been.

Brain injury is also the hidden disability: it's a home truth that bears re-stating: brain injury, like other disabilities, tracks social-locational disadvantage. People at the greatest risk of a 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. For those of you who know Sydney at all well, half of its greater metropolitan area's severe traumatic brain injuries associated with risk-taking behaviour in the teens and twenties - the motor vehicle accidents, the assaults, the drunken falls and so on - half of those occur between, what, the longitudes of Parramatta and Penrith. I'm no bleeding heart but many 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.

The 650,000 Australians the Australian Bureau of Statistics guess-imates have a brain injury are also radically under-represented in the disability services system. Brain Injury Australia fears for its hidden, unknown number living at, or beyond, the margins; Indigenous Australians, the homeless, the incarcerated, those living in their pyjamas being cared for by...Mum, whose brain injury might be unknown, unrecognised or undiagnosed.

Also, it took me too long in this job before realising I belonged to the lucky club of brain injury's...acceptable faces. Its "members" need: to have made a...superior recovery; to be able - to some degree - pick up their pre-injury life where they left it; to live in the more...genteel parts of metropolitan Australia; their injuries to be compensable; and they were...fault-less. I only (even more) recently realised that I don't know anyone, perhaps may not have met anyone from that lost tribe, where their brain injury was also their...fault. And there are over 20,000 hospitalisations for traumatic brain injury every year in this country, between 2 and 3 thousand of those moderate to severe injuries associated with some manner of profound, and permanent, disability. Even 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. I haven't been able to imagine a more insurmountable obstacle to engagement with, participation in, a wider world.

Which is why Brain Injury Australia wants to...restrain this week's celebration. Make no mistake. Many people with a brain injury will be able to navigate the brave new world of DisabilityCare Australia as easily as the old services system. But some will not; Brain Injury Australia imagines those with fewer...resources, and/ or more hurdles. Brain Injury Australia has a... truck-load of unfinished - and neglected - awareness-raising and advocacy business to try and invite, bring those into that wider world. They may need some help accessing DisabilityCare Australia. And I just doubt whether everynoe with a brain injury is going to be able to readily transform themselves from relatively passive customers of disability services into active retailers of the funding in their personal, goal-based plan, without an...enabling infrastructure. Which is precisely why Brain Injury Australia is helping its Member

organisations - including here in Victoria - [is helping its Member organisations] prepare to deliver "Plan Management Provider" and "Support Coordination" services under DisabilityCare Australia - to help people with an brain injury develop and manage their own individualised plan, identify and then choose from those services and supports best qualified to meet their needs. Brain Injury Australia is building that enabling infrastructure.

If you want to find more about what we do, I have brought with me brochures, policy papers and information about our annual fundraiser, Sidetember. Over there. Or please, just come and talk to me at some stage today.

Thank you for listening. And thank you for coming today.