

In this short time, I just wanted to pick out a few points from Brain Injury Australia's submission to the Inquiry and then offer something of a (semi-informed) political reality check.

Brain Injury Australia always tries to retain a keen sense of needing to serve a constituency. Married to that, in my mind - without wanting to get precious about it - is that the Australian taxpayer pays my wage. Neither do I want to sound like the head of the local chapter of the Tea Party Movement - but to paraphrase the rallying cry of the American Revolution; there should be "no taxation without representation". The following statement probably applies to all disability advocacy organisations based on a membership model, but I suspect the question of how representative disability advocacy organisations is a little more, well, acute with brain injury: Brain Injury Australia's constituency is broader than its Member Organisations, broader again than the members of its Member Organisations, broader certainly than the people who know we even exist. In its submission Brain Injury Australia acknowledged the commitment written into the Inquiry's Issues Paper to extend the support of any proposed scheme to those who, well, languish on the outskirts of service provision. But our submission also pointed out the faulty presupposition that seems to predetermine the Inquiry's [entire] thinking: that people with a disability somehow comprise a coherent population who know both their disability and their needs arising from it and can not only express those needs, but pursue them for the purposes of receiving disability services and support (including advocacy).

This is not meant as special pleading, let alone some undifferentiated whinge about brain injury being every other disability's poor cousin. But brain injury is often referred to as the "invisible" disability. This operates in a variety of ways, the most oppressive of which is at the level of the individual, the person: the majority of people with a brain injury – around 3 in 4 - make a good physical recovery and show no outward signs of disability. Some of the most common effects of injury - poor short-term memory, fatigue or irritability - are regularly misinterpreted as simply flaws in the person. They're mistaken as drunk, unintelligent, uncooperative, unmotivated or alternatively aggressive and unpredictable. And they are seen as a function of just who the person really is. But a similar kind of invisibility operates at the level of population. I am in the midst of completing a policy paper for the Australian Government on people with a brain injury and the criminal justice system and find it both astonishing - and frustrating - that the most recent Australian Bureau of Statistics Survey of Ageing, Disability and Carers - even with the injection of an extra \$6.5 million from the nation's Community and Disability Services Ministers to boost its sampling – didn't include Australia's 30,000 prisoners, the majority of whom have one (or more) brain injuries, intellectual or psychosocial disability. Neither did it capture remote parts of Australia, where Aboriginal and Torres Strait Islanders are concentrated. Their rates of brain injury are around 3 times that of the rest of the population. The Survey - which, incidentally, found that prevalence of disability in Australia had fallen 1.5 per cent since the 2003 survey - the Survey, its findings, its

data is, will remain one of the fundamental drivers of disability policy and research for years to come.

Brain Injury Australia welcomes the commitment to systemic advocacy contained in the National Disability Strategy. And for as long as Brain Injury Australia is included in that commitment, we will continue with what we think of as the real guts of our work; building awareness of a disability that lags around 20 to 30 years behind that of others, especially within those "invisible" populations, where their brain injury might be undiagnosed, or unknown. Certainly, to bring them into any new scheme of "disability care and support". Some of the most powerful - and most sobering - words I've read on this kind of "work" comes from Michael Ignatieff's 1984 book "The Needs of Strangers": "there are people who have had to survive on so little for so long in our society that their needs have withered away to barest necessity. Is it wrong to raise their expectations, to give them a sense of the things they have gone without? Is it wrong to argue that the strangers at my door should not be content with the scraps at the barrow? Any politics which wants to improve the conditions of their lives has to speak for needs which they themselves may not be able to articulate. That is why politics is such a dangerous business: to mobilise a majority for change you must raise expectations and create needs which leap beyond the confines of existing reality. To create needs is to create discontent, and to invite disillusionment. It is to play with lives and hopes. The only safeguard in this dangerous game is the democratic requirement of informed consent. One has no right to speak for needs which those one represents cannot intelligibly recognise as their own."

If Brain Injury Australia is successful in this work with "invisible" populations, will governments fear the floodgates opening? Will they begin to draw in the fences around eligibility and assessment for any new scheme (for what the Productivity Commission reckons is the 360,000 Australians with "severe" to "profound" disability)? I haven't had the time to read the 800 pages of the Commission's two volume draft report (who has?) and I know that the architecture of any proposed disability insurance scheme is "work-in-progress" but I did get a chance to keyword search the draft report for references to alcohol and other substance-abuse related disability, including brain injury. And while I got the sense that the geography of any proposed scheme might extend to the heroin overdose with hypoxic brain injury, and to the early teenage petrol sniffer, it was nowhere near as clear to me whether the abuser of a cask of tawny port every night for the last 20 years would be...eligible (and their numbers can only really be guesstimated). And I also know the last time a disability insurance scheme was floated - during the Whitlam years - it was sunk in part by the disability sector's infighting about who'd be in or out.

My real point in introducing you to these "invisible" populations isn't to risk the certain death of a disability insurance scheme a second time around, but rather to suggest that if governments are seriously serious about social inclusion there are some

political realities that, I believe, the sector needs to face. There's a whole other presentation I'd love to give on the idiosyncracies of how Australians perceive risk - and how they do or don't insure against it - whether it's of flooding, climate change or disability. And whether the new scheme is funded by some manner of legislated "National Disability Insurance Premium Fund", or by some GST-style arrangement with State and Territory governments or a levy on marginal tax rates - if the politics of the *reception* of a \$1.8 billion Queensland flood levy and an unpriced carbon price, carbon tax, "great big new tax" are anything to go by, getting a 12 and a half billion (that's an *additional* \$6.3 billion on top of the current disability spend) getting a 12 and a half billion national disability insurance scheme legislated so that it's funding is quarantined from the whims of changing governments - is going to be a political enterprise on a scale of difficulty on a par with raising the Titanic with tweezers.

This is not intended as rain on anyone's parade...but if it isn't already, the disability sector should brace itself for the next round - not sure how many rounds they've been, perhaps this is the...12th? - of welfare-to-work reforms. And even though it's 18 months out from the next election "you don't need a weatherman to know which way the wind blows"; with not-so-heavily coded political speech about the "benefits and dignity of work", the welfare "kindness that kills", the need for governments to be "firm to be fair". And whether it's an ever-tightening labour market or someone's election promise to return the budget to surplus by 2012-2013, politicians are already picking what they think of as electoral winners - the \$13 billion Disability Support Pension (the Commonwealth's fifth biggest spend) and the 230,000 long-term unemployed are already on the hit list. And whether it's the politics of the dog whistle or downward envy, I can almost hear the whispers adjudicating the "deserving" from "undeserving" disabled, beginning perhaps with drug users and substance abusers.