

# From the President



The work has only begun - if you can think of Christmas time as being like standing on a bridge between the year that's been and the one coming. Because the year that's been was the last in a series spent getting the Association "right". And because I'm convinced that the next few entail some real challenges.

I've banged on in previous columns about what the numbers (of people with an Acquired Brain Injury) suggest about how representative our advocacy efforts are. My apologies for doing so again (consider it a Christmas gift to myself). The numbers are important not the least reason for which is that it's no longer the case that governments will respond to personal beefs, on their own. It used to be enough for one aggrieved constituent to bend the ear of a politician at a Sunday barbeque for it to become policy Monday morning.

The authority on the "prevalence" (the number of instances of a specific health condition present in a population at a certain time) of ABI is still the Australian Bureau of Statistics' "Survey of Disability, Ageing and Carers". In 2003, it estimated that 432,700 Australians were living with an ABI. The number of people surveyed was small; from 14,000 households and 300 units of "cared-accommodation". And it didn't capture "those living in remote and sparsely settled parts of Australia" (which, given the numbers of Indigenous Australians living with an ABI - around three times that for non-Indigenous Australia - would have resulted in significant underestimation) prisoners or the homeless (where, though the figures are a little rubbery,

people with an ABI are radically over-represented - comprising between 40% and 80% of the former and between 10% to 30% of the latter). Also, its estimates were based on people with an ABI "self-reporting". Would it be safe to say that the actual number of Australians with an ABI easily exceeds 500,000?

Regardless, the Survey showed that 1 in every 4 people with an ABI reported four or more disabilities, compared with 1 in 18 of *all* people with a disability. And 1 in 3 people with an ABI reported 5 or more health conditions, compared with 1 in 8 of all people with disability. This is all what's known: ABI is around 10 times as common as spinal injury and produces, on average, 3 times the level of disability. However large the numbers of Australians with an ABI actually are, they are generally highly, multiply and complexly disabled people. Yet relatively few of them use government-funded services: less than 12,000 accessed Commonwealth State/Territory Disability Agreement (CSTDA)-funded services in 2004-05. And even fewer of them belong to their State-based ABI advocacy organisations, like the Brain Injury Association of New South Wales.

It bears repeating that people with an ABI are *generally* drawn from the same populations as those at the greatest risk of *any* injury - from backgrounds of social disadvantage: where family breakdown, parental alcohol and other drug abuse and mental illness are common; sometimes involving child neglect or abuse, and relatively low levels of education and workforce participation. My reading of most of the "outcomes" studies on ABI is that the disability simply increases people's sense of exclusion. It's been my impression that the *membership* (and the membership "model" of involvement in systemic advocacy on behalf of people with an ABI is a whole other question) of ABI advocacy organisations barely reflects these worlds and that "consumer" advocates greatly tend to be people like...me: white, middle-class-or-more, who made better-than-good recoveries, whose injuries were compensable, who live in metropolitan Australia and

who live in real homes.

This is not the stuff of a bleeding heart. Rather basic representational politics. Since people who work in publicly-funded disability advocacy are disability *politicians* - for no lesser reason than they represent a constituency, whether it's bounded by a map of an electorate, a state border or the breadth and diversity of experiences of injury. Advocates are used to referring to ABI as the "invisible" disability (because its consequences, even when they can be "seen", are so often not associated with disability generally let alone ABI specifically). I fear that many people with an ABI are rendered doubly invisible by virtue of their social exclusion, whether it be behind poverty lines or prison walls. If the slogan of the American Revolution holds true - "no taxation without representation" - then ABI's politicians have got a lot of work to do to become intact with all their constituents.

Though I believe that the Australian Government's commitment to its "social inclusion" agenda is genuine and genuinely "whole-of-government", genuine inclusion is expensive and the more excluded the people are whom you're trying to reach, the more expensive inclusion becomes. The Australian Government has worked hard and dreamt big in reform in its first year. Its new National Disability Agreement (the renamed CSTDA) promises an extra \$408 million in funding for disability services alongside the \$1.9 billion already committed for 24,000 supported accommodation, respite and in-home care places. Work continues on its planned national disability "insurance" scheme which will include catastrophic injury - in all its forms, regardless of cause - in the initial stage. The second challenge for the ABI advocacy sector will be to modify its heightened expectations of a once surplus-laden Government in the light of the "global financial crisis". As pundits are used to saying, that's a "game-changer".

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