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Dear Helen,

Brain Injury Australia (BIA) is grateful for the opportunity to respond to the draft National Disability Advocacy Framework ("the Framework"). What follows is the result of extensive consultation with BIA's State and Territory Member Organisations. BIA notes that few of them had received copies of the Framework until it had been circulated by BIA. This is disappointing given that all are involved in either systemic or individual advocacy (or both) and some are funded directly by the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) for such purposes. It is also disappointing given the review of the National Disability Advocacy Program - with which BIA and its Member Organisations have been directly engaged - has been some years in the running.

BIA and its Member Organisations congratulate Commonwealth, State and Territory Governments on their commitment to improving the delivery of advocacy services and look forward to working together to enhance the outcomes for people with an acquired brain injury (ABI).

BIA's overall impressions of the Framework are as follows. Firstly, BIA and its Member Organisations acknowledge the centrality given to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the National Disability Strategy (NDS) in determining "the principles and priorities" of the Framework. While BIA and its Member Organisations welcome the Framework's commitment to the human rights of people with a disability, reflective of the UNCRPD, commitment needs to include the *social inclusion* of people with a disability – reflecting the specific psycho-social disabilities as a result of ABI. BIA and its Member Organisation believe that people with an ABI comprise some of the most socially isolated, if not ostracised, Australians. A commitment in the Framework to the social inclusion of people with a disability, to their integration into the community, is required. Such a commitment would still represent only half of the Framework's "Objective" to "protect and ensure" Australians with a disability experience "their full and equal enjoyment of human rights and enables them to participate as valued members of the community and to pursue their life goals." The other half, missing from the Framework, is a commitment to changing the attitudes of "the community" towards people with a disability, to raising community awareness about disability generally.

Secondly, BIA and its Member Organisations know that its advocacy always comes from a base of solid evidence about the lived experience of Australians with an ABI. It also believes that both the outputs and outcomes from such advocacy are positive, and measurable. The Framework suggests throughout the development of an additional document that will hopefully detail the "data directions", "outcome based reporting" and a "National Quality Assurance system for disability services" that FaHCSIA has in mind for the disability advocacy sector. BIA trusts that such a document, in draft form, will be made widely available for the sector's response and FaHCSIA's review and re-drafting.

BIA offers the following responses in regards to specific sections of the Framework:

1. "Introduction"...3:

"...The Disability Policy Research Working Group (DPRWG) agreed to 'develop a nationally consistent framework for advocacy that covers individual and *system wide* [italics added] advocacy, common definitions and desired outcomes and data issues'."

Was "systemic" intended here? To avoid confusion and for the sake of consistency in terminology, BIA recommends that the descriptor "systemic" be used throughout the Framework.

BIA recommends that "systemic" be used throughout the Framework.

2. "Definitions":

- BIA and its Member Organisations felt strongly that a **definition of disability** itself - derived from either the UNCRPD or the Disability Discrimination Act 1992 - should be included.
- They also felt, as per the above, that the definition of "advocacy services" provided under the Framework should add a **commitment to social inclusion** to the "safeguarding" and "advancing" of the "human rights, wellbeing and interests" of people with a disability.
- The "Definitions" should also include acknowledgement that advocacy on behalf of individuals with a disability will often involve **advocacy for their carers, their families and their communities, as well as self-advocacy**.
- BIA and its Member Organisations applaud the Framework's repeated "focus on geographic and demographic factors" in the provision of disability advocacy services. The "Definitions" should include statements of commitment to the cultural security of both people with a disability from culturally and linguistically diverse (CALD) communities and Aboriginal and Torres Strait Islander communities in the delivery of disability advocacy services.

3. "Definitions" 6...(c):

"...Systemic advocacy seeks to introduce and influence *longer term changes* [italics added] to ensure the rights of people with disability are attained and upheld to positively affect the quality of their lives."

BIA recommends replacing "longer term changes to ensure" with "systemic changes to ensure that at a population level..."

Rationale:

- In noting the distinction the Framework seeks to draw between individual and systemic advocacy, BIA disputes whether time frames are relevant; whether, in advocating on behalf of populations or their subgroups, systemic "changes" are, by any definition, "longer term". As far as BIA is aware, there is no reason why systemic "changes" cannot be effected as readily as those of individual advocacy. Moreover, BIA is concerned that the inclusion of any time frame in the Framework's definition of any advocacy will simply serve to let governments "off the hook" at effecting change to meet the needs of Australians with a disability.
- BIA is likewise concerned by the reference, in "Objectives"...7., to Australians with a disability accessing "independent disability advocacy that promotes, protects and ensures their full and equal enjoyment of human rights" etc. as being "the *long-term goal* that

governments should strive for in the provision of disability advocacy". Commonwealth, State and Territory Governments have been on notice about the range and extent of the unmet need for individual and systemic advocacy for many years. That the Framework's section devoted to the its sole "*objective*", above - something precise, narrow, tangible and concrete – then refers to that "*objective*", instead, as a "*goal*" – broad, general, intangible, abstract - only serves to heighten BIA's concerns that this section invites governments to further delay.

4. "Objectives" 7:

"...People with disability have access to independent disability advocacy that promotes, protects and ensures their full and equal enjoyment of human rights and enables them to participate as valued members of the community and to pursue their life goals."

BIA recommends inserting the word "All" at the start of the Framework's statement of "Objectives".

BIA also recommends replacing "independent" with "appropriate" in the Framework's statement of "Objectives".

Rationale:

BIA's Member Organisations prefer the following wording for the Framework's "objective": "All people with disability have access to *appropriate* disability advocacy that promotes, protects and ensures their full and equal enjoyment of human rights and enables them to participate as valued members of the community and to pursue their life goals." The insertion of "all" is in recognition of the chronic unmet need for advocacy services for people with a disability. It also serves to strengthen the statement by making it more outcomes-focused. The argument for the replacement of "independent" with "appropriate" reflects what follows (see below re. "Reform And Policy Directions"...12. (b))

5. "Outcomes" 8.:

"Advocacy provided under this Framework will contribute to the following outcomes...":

- BIA and its Member Organisations felt strongly that this lead statement should include reference to advocacy that is "responsive, effective and measurable".
- BIA and its Member Organisations also felt that reference should be included here to building the capacity of people with a disability to advocate for themselves and to their empowerment, alongside recognition of, and respect for, cultural diversity and cultural security.

6. "Principles"...9. (g):

"Disability advocacy will foster strategic alliances across the sector and governments to develop capacity to identify and respond to the needs of people with disability."

BIA and its Member Organisations believe this represents an opportunity to describe an optimum relationship between individual and systemic advocacy services - where the experiences of the former are regularly communicated to the latter, and those of the latter are grounded in the former, and that the two advocacies exchange data wherever possible.

BIA and its Member Organisations recommend the Framework contain a description of the optimum working relationship between individual and systemic advocacy services, including a commitment to exchange data wherever possible.

7. "Outputs"…:

BIA and its Member Organisations felt that "outputs" should include reference to:

- the empowerment of people with a disability to advocate on their own behalf;
- the social inclusion of people with a disability;
- the prevention of acquired disabilities such as ABI and;
- the fostering of partnerships between individual and systemic advocacy services.

Rationale: in order to better tie the outputs to the Framework's principles, outcomes, and goals.

8. "Outputs" 10. (a):

BIA believes that an "output...tailored to meet the *individual* needs of people with disability *including a focus on geographic and demographic factors* [italics added]" potentially conflates and confuses individual with systemic advocacy. The "individual needs of people with a disability" may not necessarily coincide with, nor reflect, the needs of people with a disability on a regional or population basis.

Furthermore, while ideally complementary, the two advocacies often operate in isolation. BIA would welcome any government initiatives - with funding attached - to bolster the relationship between agencies involved in individual and systemic advocacy (see above, re. "Principles"...9. (g)).

BIA recommends the Framework contain separate outputs for individual and for systemic advocacy, and an additional output reflecting the need for robust relationships between these types of services.

9. "Reform and Policy Directions"…12. (b):

"Disability advocacy should be independent and autonomous from the broader service system that provides support to people with a disability and their family/carers."

The Framework's commitment to independent disability advocacy was welcomed by BIA and its Member Organisations. But they argued that it may not always be possible to have an advocacy organisation separate from one delivering services. (In fact, one legacy of the chronic under-funding of advocacy was the need to offer other services as a means of cross-subsidising advocacy.)

BIA and its Member Organisations recommend that where an advocacy organisation also provides other services, then strategies to provide for independent advocacy through governance, management and practice strategies can, and should, be demonstrated.

10. "Reform And Policy Directions"…12. (c) (iv):

"The funding and administration of disability advocacy should be transparent, informed by available evidence and consider the geographic and demographic factors that impact on the needs of people with disability to improve accountability and access for people with disability..."

BIA and its Member Organisations welcome the commitment in the Framework to establishment of an evidence base for disability advocacy, as well as to greater access to advocacy services for people with a disability experiencing "geographic and demographic" disadvantage. The Framework, like the "Issues Paper" produced as part of the Productivity Commission's current inquiry into long-term disability care and support, suffers from the same faulty presupposition - that people with a disability comprise a coherent population who: firstly, know their disability; secondly, know their needs arising from it; and thirdly, can readily express those needs for the purposes of receiving advocacy support or other disability services. This is fundamentally misguided, and there are individual and social contexts specific to ABI that are relevant here.

ABI is often referred to as the "invisible" or "hidden" disability. This operates in at least, four ways. Firstly, at the foundations of an evidence base for delivery of disability services – in estimates of prevalence and incidence, many Australians with an ABI are simply unknown to governments. For example, one of the fundamental documents in estimating the prevalence of disability in Australia, the Australian Bureau of Statistics' 2003 "Survey of Disability, Ageing and Carers" ("the Survey"), significantly underestimates the real number of people living with an ABI. The survey's sample comprised "14,000 private dwellings and 300 non-private dwelling units", covering "people in both urban and rural areas in all states and territories, *except for those living in remote and sparsely settled parts of Australia.* [italics added]" Estimates of the prevalence of ABI in Aboriginal and Torres Strait Islander communities generally - and in the Northern Territory specifically, where Aboriginal and Torres Strait Islanders comprise 30% of the population - indicate rates up to three times that for non- Aboriginal and Torres Strait Islander communities. Furthermore, the Survey had no capture of the criminal justice system or homeless Australians, where estimates of the prevalence of ABI range between 40%-80% and 10%-30%, respectively.ⁱ The Survey estimated that 432,700 Australians (2.2% of the population) had an ABI with "activity limitations" or "participation restrictions" due to their disability. Because of the deficiencies in the Survey's sampling, BIA is confident in its estimate that over 500,000 Australians have an ABI. While verifiable *incidence* rates (the number of new cases in a given year) for ABI are difficult to come by, over 22,000 Australians were hospitalised with traumatic brain injury (TBI – the result of external force applied to the head from motor vehicle accidents, falls, assaults etc.) during 2004-2005 and, in 2010, Australians will experience around 60,000 new or recurrent strokes (where blood supply to the brain is stopped by a clot or bleeding).ⁱⁱ

Secondly, due to the severity, multiplicity and complexity of disability experienced by people with an ABI, or the circumstances in which their brain injury was acquired (chronic alcohol or other drug abuse, for example), many individuals "hidden" from such government surveys may not know they have a disability.

Thirdly, due to the circumstances in which their brain injury was acquired, or as a function of the resulting disability, many people with an ABI may choose not to disclose their disability. The Survey recognised this: "A number of people may not have reported certain conditions because of: the sensitive nature of the condition...[and] a lack of awareness of the presence of the condition on the part of the person reporting..." Also, "The need for help may have been underestimated, as some people may not have admitted needing help because of such things as a desire to remain independent..."

Fourthly, the majority of people with an ABI make a good physical recovery. Often the injured person shows no outward signs of disability. Common effects of injury such as poor short-term memory, fatigue, or irritability can be easily misinterpreted as simply flaws in the person. Such a lack of public understanding of ABI is doubly disabling for the person affected: not only are these “invisible” disabilities not recognised as resulting from an ABI, they are seen as a function of who the person really is. If the Framework is serious about "improving" "access" of people with an ABI from backgrounds of "geographic and demographic" disadvantage to advocacy services, it needs to - as indicated above - include a commitment to community-level disability education and awareness-raising. This will enable both those unaware of their ABI to recognise their disability as well as those who are reluctant to disclose their ABI to seek advocacy support.

BIA and its Member Organisations look forward to the further re-drafting of the Framework. If any further information, or explanation, is required please do not hesitate to contact me.

Sincerely,



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ⁱ “2003 Young People in Custody Health Survey Key Findings Report”, Psychological and Specialist Services Unit, NSW Department of Juvenile Justice, Haymarket, 2003, Belcher J and Al-Yaman F, “Prisoner health in Australia: contemporary information collection and a way forward”, Canberra, AIHW, 2007, Butler T, Kariminia A, Bond J, Trevathan L. Injury surveillance in the New South Wales prison system, Australian Journal of Health Promotion 2004;15:146–149 and Hatzitaskos, P. (1995) “Crime Times”, Vol. 1, No.1-2, p.5., Byrne, B. (1997) SRS Socialization Facilitation Project (Caulfield General Medical Centre, Melbourne) and Community (Residential Services) Visitors’ Board, Annual Report of Community Visitors, 1996, Health Services Act 1988 (Office of the Public Advocate, Melbourne) cited in HACC Program Development & Access SRS/Rooming House Project, Final Report December, 1998, McGregor, Robb (2000) “Comparative data between clients with alcohol related brain injuries and other clients, Ozanam Community Support Services Outreach Program.

ⁱⁱ Helps Y, Henley G & Harrison JE. 2008. Hospital separations due to traumatic brain injury, Australia 2004–05. Injury research and statistics series number 45, Adelaide, 2008 and National Stroke Foundation.