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I take this opportunity to thank the Department of Social Services for the opportunity to provide comment on the review of the National Disability Advocacy Framework.

I write to you as a parent, carer, guardian, and family-advocate over almost 30 years of experience in the disability field. Our family has three adult children, two of whom have multiple unrelated disabilities. My husband, Irwin, worked until recently as an Executive level officer with the Commonwealth government. For my own part, apart from my parenting role, I have been a voluntary Secretary for an unfunded disability support organisation (Williams Syndrome Family Support Group of WA) and during my paid employment have worked in the Western Australian Public sector in both the Department of Health and the Disability Services Commission. I continue to take an active interest in disability-related issues.

The National Disability Advocacy Framework has relevance to both my children with disabilities; however my focus in this submission is towards advocacy for our daughter with severe autism, intellectual/decision-making disability and developmental delay. This is for the simple reason that our daughter, Sarah, is unable to communicate her wants or needs because she neither talks, reads, writes nor uses augmented communication. Accordingly, we find ourselves as being the conduit for making her requirements known through observation, body language and decades of personal experience. We have plenary administration orders for managing Sarah's accounts and, in keeping with new advice, are in the process of applying for general formal guardianship orders. This is because, amongst other things, we have found that informal guardianship is not worth the paper it is written on.

Our experience is that parent-carer-advocates and family-guardian-advocates for people with severe intellectual disability, particularly for those over the age of 25 years, have been shut out within the greater disability sector by both active and passive disregard for their concerns and undermined in their attempts to engage in constructive discussions by certain sectors of the Australian disability sector. The commentary of specific Board members of People With Disability Australia Inc. (PWDA) are of particular concern.

I have observed and taken part in online discussions in which family-carer-guardian-advocates have been denied a 'voice' in discussions on matters which directly and indirectly affect the life and well-being of their family member with a disability, because of their parent/family caring roles. And this happens even when guardianship and administrative orders are in place because the family member with a disability is unable to communicate for themselves. It is a complete contradiction to current guardianship laws across Australia.

The situation has reached a point in which my husband and I, on behalf of our daughter, have been forced to place a formal disability discrimination complaint with the Australian Human Rights Commission (AHRC) regarding PWDA as the membership and advocacy requirements (sections 6.1 and 20) as stated in their current Constitution<sup>1</sup> are, in our

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<sup>1</sup> People with Disability Australia Inc., "Amendment of Constitution - People with Disability Australia Inc.", <http://www.pwd.org.au/documents/orgdocs/constitution.doc> . Accessed: 31 Jul 2015.

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opinion, discriminatory towards persons with a disability who cannot write or communicate for themselves.

In the case of Women With Disability Australia (WWDA) the organisation's current Constitution<sup>2</sup> also states that membership requirements also required a written application (section 3.1.a). However, as noted in Section 4, membership rights are not transferrable which effectively denies membership to any woman with a disability who is unable to write for herself and denies that person the communication alternative of an advocate. Once again, given their own Constitution makes a mockery of the statement "Women With Disabilities Australia (WWDA) is the peak organisation for women with all types of disabilities in Australia"<sup>3</sup>.

For people with severe intellectual/decision-making disability like my daughter, this effectively denies her representation and us as her parent-advocates, are unable to represent her interests accordingly. In my opinion, this is disability discrimination on both a direct and indirect level against both the person with person with a disability as well as us as her family-carer-guardian-advocates. Given that Sarah and many others with similar level of disability are probably the single biggest recipient cohort of the NDIS, this is a ridiculous state of affairs.

I find it astounding that at least two of the new National Cross Disability Alliance funded peaks have membership rules which affectively deny people with severe intellectual/disability decision making disabilities access to their services. Even more, that Department of Social Services have been happy to fund these organisations without checking that they were capable of engaging with such a broad-ranging representational base as what they purported to do in their initial funding tenders.

In a number of these public conversations through social media, it has been urged that family-advocates find an agency to represent 'their' (the parent's interests) such as Carer's Australia. This is despite being referred to Guardianship documentation and the legal notion that in such cases as our daughter, we **have** been speaking for her. The simple notion of family-advocates as defined by the United Nations Convention of the Rights of Person's with a Disability section x seems beyond their grasp. That is that:

"...the family is the natural and fundamental group unit of society and is entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities..."<sup>4</sup>

I would draw your attention to commentary provided by the Endeavour Foundation's submission on ideological confrontations between current advocacy organisations and

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<sup>2</sup> Women With Disability Australia, "Women With Disability Australia Constitution", Available: <http://wwda.org.au/about/const/>, Accessed: 31 July 2015.

<sup>3</sup> Women With Disability Australia, "Women With Disability Australia About Us", Available: <http://wwda.org.au/about/>, Accessed: 31 July 2015.

<sup>4</sup> United Nations, "Convention on the Rights of Persons with Disabilities", Preamble section x. Available: <http://www.un.org/disabilities/convention/conventionfull.shtml>, Accessed: 30 July 2015.

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lived-experience representation by parent-advocates for people with significant sensory, intellectual, developmental and decision-making disabilities. Our own experiences are further supported by the Endeavour Foundations statements on these matters, as well a number of other personal submissions to the NDAF review.

Further to the commentary regarding representation of the family-carer by Carers Australia, my personal experience across the past 20+ years as a family-advocate is that Carers Australia is an advocacy organisation and service provider more concerned with aged-care related disability rather than disability-related care which starts in childhood or youth. And that the correlation between the funding that they receive for providing HACC services can be seen as a strong connection to their advocacy methodology and its actions. To my mind, there is also a question on the potential for conflict of interest when you consider Carers Australia's status as an independent advocacy group and their actions a service provider within the same executive body.

I believe that it is time for a government funded systemic advocacy group which recognises the importance to family supports to people with severe intellectual/decision-making/developmental delay etc. One that is willing to talk and work with people with disability towards a common goal of supporting people with disability to achieve their needs, wants and lifestyle choices according to their particular, individual wishes. And that this should be done without encouraging further disparity within the sector. The formation of an organisation which will represent family-carer-guardian-advocates as valued supporters for those people with disabilities who are literally unable to communicate for themselves.

I find it disconcerting that there is no currently group that specifically addresses this issue. It is worth noting that the applications for the tender for the Cross Disability Alliance suggest that National Ethnic Disability Alliance tender is the outstanding document with at least 22 references to supporting carers and families as well as the individual with a disability. Unfortunately though, our family and many others with English as our primary language, fall outside the scope of their member base. And yet for many with English as our primary language, we share the same premise that family is usually the primary method of support for people with complex disabilities and form the essential link towards greater cultural and community supports.

In the case of people with significant intellectual disability, the family is still the mainstay contact point for providing accommodation, unpaid supports, administration and coordination of services and social networks for their family members. State and Commonwealth funded disability programs, Centrelink, health services and the guardianship and administration systems are still currently hinged on the family-guardian-advocate's unpaid labour and resource provision. Until such time as our family members with disability are fully supported to live as accepted, independent, integrated and respected persons within the Australian community and separate from the family home it is the family-carer-advocates which underpin the whole system. Parent-carer-guardian-advocates should be provided with funding for a representative body and consulted when issues that affect our family members and our own lives are concerned.

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**1) Do you believe the current Framework encompasses your vision of advocacy in the NDIS environment? If not, what changes are required?**

The principal of supporting people with disability to communicate self-advocacy is important. For those able to articulate their requirements in whatever format is suitable for them should be provided with the supports they need to address those needs. I believe that capacity building for those people with disabilities is also desirable.

However, there are a large proportion of people with severe intellectual/decision-making/developmental delay who can only make their needs known via their family advocates. The need for individual and systemic advocacy for people with significant complex disabilities and their families **must** be addressed. There needs to be acknowledgement of the role of family-advocate in providing a voice for their family member and individual and systemic advocacy and capacity building services to advance and support family-advocates to be an appropriate support for their family member with complex disability and publicly acknowledged as a voice for their family members.

Advocacy and capacity building services should be independent of the NDIS and made free for people with disabilities and family-advocates representing family members with disability. The formation of a government funded advocacy service which will promote services for family-advocacy to support the unique needs of complex disabilities over the age of 25 years would go a long way towards this currently unrepresented section of the disability community.

**2) Are the principles of the Framework appropriate for guiding the delivery of advocacy for people with disability in a changing disability environment, including in the context of the NDIS? If not, what changes are required?**

The NDIS is providing a platform of individual and cultural change within the disability sector for people with disabilities. Recent personal experience notes that legal responses with regards to people with significant complex disabilities including intellectual disability is moving towards an integrated approach. Guardianship and administrative changes are already adjusting. We have recently been informed that general formal guardianship is now the preferred arrangement for those expected to be supported by the NDIS in the future rather than informal guardianship that was considered the preferred approach when we initially applied in 2012.

Increasingly, the move seems to be away from family-advocate-guardianship. However, before that can occur there needs to be education and supports for families who have a family member with significant complex issues to be provided with introduction to the appropriate advocacies and supported to access legal systems during various transitions which occur through significant life stages.

At the moment, many family-advocates 'drift' into taking on an informal administrative role with banks and Centrelink payments without recourse to Administrative or guardianship orders even though the family member with a disability is over the age of 18 years physically but not developmentally. It is not until something unforeseen happens that there is sudden

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and urgent need to obtain the appropriate orders and this adds to the stresses that the crisis has already delivered.

The alignment of the various guardianship and administrative arrangements from a state/territory -by-state/territory basis to a unified system would also assist in protecting the interests of people with severe intellectual disability. It would provide safe-guards against possible misuse of funds or exploitation of those more vulnerable people with significant developmental disabilities.

Another transition point of concern is when the family member chooses or needs to move out of the family home. For example, where the family-member transitions to a new home of their own, when family-advocates are unable to care for their family member in their family home due to their own health or disability, or when the family-carer-guardian-advocate dies. There needs to be preparation and the development of trust and legal support well in advance of any anticipated transition period so that the family-carer has the necessary supports and advice to find and trust an alternative 'decision-maker', guardian and/or administrator to assist their family member with complex needs to be supported when they are no longer available to consult. Capacity building and community supports through advocacy systems familiar with such complex matters needs to be addressed, especially as Australia has an ageing population and, as the PwDWA submission alludes to, the level of informal supports as currently provided by family-carers, will no longer be available.

**3) Are the outcomes of the Framework still relevant or should different ones be included? If so, what should be included?**

I support the Outcomes of the Framework given that there is greater recognition on the complex issues that are associated with persons with significant complex disability including severe intellectual/developmental delay/decision-making disability when they are unable to communicate for themselves. Recognition of family-advocates as those best placed to communicate the wishes and needs of their family member with a disability. That family-carers are consulted involved in all aspects of the development, delivery and evaluation of disability and broader government policies, programs and services that impact on their family member.

**4) Are the outputs of the Framework still relevant or should different outputs be included?**

The Outputs appear possible, however only time and experience will tell if the system delivers in the way it is currently depicted.

**5) Does the Framework identify what is needed in the current and future disability environment? If not, what changes are required?**

No comment at this time.