From: Mary Lou Carter & family

To: The Review Committee
National Disability Advocacy Framework 31 July, 2015

Time does not permit to fulsomely address all the elements of the discussion paper released with respect to the review of the National Disability Advocacy Framework (NDAF). However, as the parent of a young person with severe intellectual disability I feel compelled to submit something of our experience of requesting formal advocacy and what I have learned about advocacy over the last 24 years.

With respect to formal advocacy our experience has been that formal taxpayer funded advocacy has left me and my family bitterly and utterly disappointed. I realise this is a somewhat jaundiced view. I know many families and people with disabilities who have been very well supported by formal advocacy and for that I am very happy. In fact, after 24 years I am now part of a group of families who has engaged a formal advocate and am comfortable as part of that group seeing that the best interests of my son are being pursued.

When our child was very young and we didn’t realise our little boy had disabilities, we had no formal diagnosis until he was almost six years old.

Our family entered the world of disability with this comment from a highly respected paediatric neurologist: “your kid’s retarded”. One hopes that 24 years later families are delivered such news with a little less cruelty and a little more cushioning sensitivity. What was even worse was the total lack of any hope or guidance. I remember my husband at the reception desk that day, waiting to pay the bill, staff were chatting and laughing oblivious to the tears sliding down my husband’s face and his utter devastation as he silently paid the bill and we left. Outside with our little boy in his stroller, we held each other and he said: “We have each and we’ll get through this”.

In the ensuing years I can only say we felt and were totally totally alone; we just did not know what to do or where to turn. We just knew we had to survive from day to day. As for formal advocacy, we never knew of its existence even though we had an allocated case worker from either YACS or was it FACS or DAHC, we were never advised of what a caseworker does or of other services that might be available to us.

We finally reached out for help to a taxpayer funded advocacy organization when our son was 12 years old. To say the least the experience left us feeling disrespected, scorned, insulted, degraded, bullied; in fact we felt violated by the experience. Little wonder our family is highly suspicious of engaging with formal advocacy. The organisation pushed an ideological line and was not in the slightest bit understanding or supportive, nor were we given any guidance whatsoever of any alternative.

Since that experience I have made a detailed study of the history of disability in Australia; particularly from the lived experience of being the parents of a child who has severe intellectual and complex disabilities, for which I must say there is virtually no research whatsoever in Australia. I have come to the realisation that essentially little has changed for families of people with moderate/severe and profound intellectual and complex/multiple disabilities (our target group), notwithstanding the dawn of a new century. The knowledge, experience and expertise of families is still disrespected and devalued by those whom I have dubbed the we-know-best-brigade.

This is still the case and has been borne out by the fact that despite their families being the primary supporters of people born with (or acquiring) moderate/severe and profound intellectual and complex/multiple disabilities, their carer-families are the only cohort in Australia for whom there is no funded carer-family advocacy and support. None whatsoever.

For the government and its bureaucracies to claim that Carers Australia, a service provider to carers, is also their advocate is simply unacceptable. It is axiomatic that the service provider cannot be the advocate for the service user because of conflict of interest; however, it seems it is axiomatic for every group except for carer-families of our target group. The funded advocacy which is missing is the advocacy that recognises the inextricable connection between carer-families and our target group. That inextricability is recognized by the *Disability Discrimination Act*, 1992 and providing funding for carer-family advocacy and our target group would be new, dynamic and holistic approach that will enhance and strengthen the advocacy framework.

Furthermore robust advocacy for our target group will ensure that they will no longer be the overlooked, ignore or forgotten in the development of policy which affects their lives, often in a detrimental way because their discrete needs are not considered. In fact the continued refusal to fund a discrete advocacy voice for our target group through the agency of their carer-families directly and indirectly discriminates against them. This has born out by research undertaken by Deidre Croft in her published paper: *For Better or Worse* which is attached.

This research provides evidence that the opportunities and options and available services for our target group have been significantly diminished in real terms in the last 30 years since the passing of the iconic *Intellectually Disabled Persons (Services)* Act, 1986. That legislation has since been repealed which shows precisely that governments and bureaucracies and disability advocacy organisations do not recognise or acknowledge the discrete needs of people with intellectual disability.

By and large families of our target group eschew formal advocacy. They do so, I believe, for the same reasons as our family has done; because of the lack of support, understanding and recognition that carer-families seek options which will assist their family members to have the best outcomes possible and to be included in the community to the greatest extent possible.

Families do not want generic services which is what the mainstream offers. They want specialist services and supports that recognise and meet the discrete needs of their family members with moderate/severe/and profound intellectual and complex/multiple disabilities. They know that the mainstream does not have the time or the elasticity or the flexibility required for the consistency, patience, imagination and innovation that will meet the discrete needs of their family members, through specialist programs.

Overwhelmingly the families of our target group are very much part of the lives of their family members and expend all their energies on ensuring the best outcomes for them.

The very fact that a National Disability Insurance Scheme (NDIS) has been implemented is a direct result of families at a grassroots level agitating for change. This agitation was conducted by carer-families already enervated by the very nature of what they do every day and at great personal and financial cost to themselves. The campaign for an NDIS was undertaken by carer-families without funding, without resources and through the animated determination to change a broken system.

Until late 2012 -2013 no funded advocacy organisation can claim to have ever advocated for such a Scheme as the NDIS which is a population-based, benchmark-funded disability service delivery scheme. It was a Scheme proposed back in the 1960s by a parent of a child with severe disabilities, brought to the Whitlam government and was on the way to implementation had the Whitlam government not lost office in 1975. (The parent-led Carers Alliance political party went to the 2007, 2010 and 2013 federal elections with such a Scheme as a key plank of its platform).

Over the ensuing forty years funded advocacy did not call for such a Scheme. The movement to have such a scheme implemented was parent-led, a re-imagined idea that emerged from the Rudd government 2020 Summit, proposed by a parent and ardently campaigned for by carer-families and finally driven by a community campaign by the inspired Every Australian Counts which was funded by disability service providers. The NDIS was not a result of formal funded advocacy though there have been claims to the contrary. Funded advocates only came on board very late in the piece and only when its inevitability was manifest.

It is for this reason that I strongly recommend the institution of funded carer-family advocacy and support at regional and national level. Carer-families have already demonstrated that such advocacy will be efficient, effective and efficacious for people with severe and permanent disabilities. I guarantee that our communities will be the better for it.

The most egregious deficiency for the people of our target group is the discrimination against them in every jurisdiction. They are discriminated against every day while ever they are denied the following:

1. the guardianship, of which tens of thousands of our target group are deemed to be in need through the agency of their parents/families; and
2. the legal agency on an ongoing (not episodic) basis to make decisions through the agency of their parents/families/guardians.

The disability community is at this very moment engaged in debate as to whether there should be substituted decision-making or supported decision-making for people with decision-making incapacity. It has been proposed by the Committee that oversees the UN Convention on the Rights of Persons with Disabilities, that there should only be supported decision-making creating the fiction that our target group, who have permanent decision-making incapacity, can be supported to the extent that they can do what they cannot do, because of their disability.

It appears there are those in the disability sector that deny the extent and degree of disability of one group of people with disabilities in order to create the fiction that their disability is a confection and can be supported into non-existence. I find this kind of thinking nonsensical and offensive as applied to our target group; it denies their inherent dignity and value. Such blanket notions can only be countered with strong and effective advocacy from the carer-families who know, honour, value and accept their family member with disabilities; who do not rely on fiction but fact to promote and advocate for the best outcomes for their family members with disability.

**The NDAF and the NDIS**

The NDIS is a scheme for people with permanent disability, it was never intended nor designed to be the catch-all for all impairments; for which there are other mechanisms within the social services systems to cater for those service and support needs. To campaign for every impairment to be serviced by the NDIS will make it unaffordable and unsustainable. I trust funded advocacy will not go down that path.

I believe that funded advocacy must be a choice available for eligible participants of the NDIS and that advocacy must be a component of their NDIS funding. This proposal should recognize and included the NDAF as it intersects with the NDIS so that NDIS participants and their families can choose the advocate who will best advocate for the individual service and support needs of the NDIS participant.

I thank the review committee for the opportunity to make this short submission. I look forward to some history-making from this review: the funding of carer-family advocacy. Whereby through the agency and advocacy of carer-families our family members with moderate/severe/and profound intellectual and complex/multiple disabilities will finally be directly included in the making of policy which will fundamentally affect their lives and the lives of their families.

It’s time.

 Yours faithfully , Mary Lou Carter