



Please find enclosed the submission of OurVoice Australia Inc. to the Review of the National Disability Advocacy Framework.

We thank the Review Committee for the opportunity to contribute our submission to this very important matter. We hope that this inquiry will lead to a greater understanding of the unrepresented issues currently remaining outside of the advocacy framework and too often considered an afterthought by those who have led systemic advocacy in this nation for decades.

Our desire is that this review leads to a greater understanding that one voice cannot possibly represent everyone unless there is a desire that advocacy continues to be homogenised and built upon a flimsy framework based on the issues of age, sex and cross-cultural issues - in our opinion a hollow log than cannot possibly respond to the complexities of disability itself across the continuum.

We also hope that something different will emerge from this review and that something different will be funded carer-family advocacy at regional and national level. This is something that has never been done before; the timely and hitherto missing voice of people with severe/profound intellectual and complex disabilities through the agency of their carer-families.

We extend the Review Committee our every best wish in their task and look forward to the results of the review.

Yours faithfully

A handwritten signature in black ink, appearing to read "Marylou Carter".

Marylou Carter  
Board Member

A handwritten signature in black ink, appearing to read "Maree Buckwalter".

Maree Buckwalter  
Board Member

A handwritten signature in blue ink, appearing to read "Nell Brown".

Nell Brown  
Board Member

Submission to the Review of the National Disability Advocacy Framework

The National Disability Advocacy Framework is built upon the UNCRDP - in our opinion, an extremely flawed document as set out below.

*Our Voice Australia questions the scope of the UN Convention on the Rights of Persons with Disability on the basis of its discrimination against children and people with severe and profound intellectual and complex disabilities.*

*With respect to children with disabilities specifically, that Article 23 of the UN Convention on the Rights of the Child was not migrated into the UNCRPD is significant. Because Article 23 refers to children with disabilities and how their discrete needs must be met by the State parties.*

*It is for this reason that OurVoice Australia believes the UNCRPD was designed by and for adults with physical disability who do not have intellectual or cognitive disabilities and they were simply forgotten - just as they are forgotten in the battle-lines that have developed across the board in the fight by some, for advocacy 'supremacy'. There are various articles within the Conventions that exclusively refer to physical disability and the rights of persons to have specific assistance with respect to their needs. However, the Convention is deafeningly silent on the discrete and specific needs of people with severe and profound intellectual and cognitive disability.*

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

For the majority of people with disability the framework is satisfactory, however does not sufficiently recognise the diversity of disability. Most disability is either physical or sensory impairment in nature. Most people with physical and/or sensory impairment are capable to some degree of self-advocacy. Our Voice is a newly formed parent-led systemic advocacy group run by and for families of people who have complex needs. Our target group is rarely able to self-advocate. We believe that we have a vital role to play in the funded advocacy mix, although funding has never been availed for this target group. The people who are our target group are people who have moderate and severe intellectual disability alongside other complex needs.

In the current systemic advocacy environment, notwithstanding the claims made by various advocacy groups there is in reality, no advocacy for this group at all. Those claims are merely lip service because of the homogenisation of disability that portrays all people, their needs, aspirations wants and desires to be the same. Advocacy needs a range of skills and experiences as well as lateral thinkers to ensure that all of the key decisions take into account the disability diverse perspectives of the key stakeholders.

This homogenisation of disability has caused our target group to be completely overlooked and excluded by governments and policy-makers within the advocacy mix because of the very nature of their disability. They have no voice and it is very easy to ignore their discrete needs - currently done by merely bolting them onto the framework as an after-thought. OurVoice Australia believes families are the vital link that is missing from the advocacy framework. Being the fundamental group unit of society, it is the family that looks to the best interests of ALL its members, whether with or without disability. The overwhelming majority of families do not overlook or ignore the needs of their family members with disability, they know those needs personally and intimately and make every effort to have those needs met.

The family is the recognised mainstay of the disability support system and provides 93% of all care for people with complex needs. Yet, the family continues to be given lip service, while excluded from

being at the table in every area of policy-making which directly affects their lives, and more importantly, the lives of their family members with moderate/severe intellectual and complex/multiple disabilities.

The group we are talking about will require the most government resources over their lifetime and yet no-one speaks for them.

It is time for government to either disclose the reasons for silencing families or to finally step up to the plate and fund a voice for disability carer-family advocacy.

The phrase 'one-size-does-not-fit-all' is bandied about *ad nauseam* while at the same time portraying disability as a unified experience. The reality is that a person with a severe intellectual disability has precious little in common with a highly articulate, highly educated, eminently employable person with a physical or sensory disability. Each faces a different set of barriers and the only thing they have in common is the word 'disability'. Carer-families begin the advocacy journey with their family members with disability from the moment of diagnosis and are therefore an invaluable point of reference for systemic advocacy.

Particularly when individual and systemic advocacy is built from the individual experiences of disability and a well-grounded hands on understanding of complex needs, something extremely lacking in the Australian advocacy environment..

In her excellent paper *For Better or Worse - How have people with intellectual disability fared in a whole of disability service framework* published in Interaction Magazine Volume 23 Issue 3 2010 (See addendum No 1) Deidre Croft makes the following observation:

*There is a need to reclaim and define a distinct intellectual disability profile in which the unique characteristics and needs of people with intellectual disability can be clearly articulated and promoted.*

- *Intellectual disability specific data: data required to enable monitoring, informed advocacy and evidence-informed action to address the unique needs of people with intellectual disability.*
- *A dedicated advocacy focus: recognising that many people with intellectual disability cannot speak for themselves or speak well themselves, there is a need to strengthen and adequately resource a strong intellectual disability specific advocacy voice which can represent the needs of people with intellectual disability and their family carers based on the best available data and evidence.*

In her paper Deidre Croft makes this concluding personal comment:

*As a journalist/wordsmith by professional training, I am interested in how we use language and the meaning we attribute to the language we use. On which basis, I experience a certain inconsistency in the use of the word "dis-ability" as a generic label to describe people who are limited in their physical or intellectual capabilities, compared to the more precise definitions we apply to people with superior physical and intellectual "abilities". It seems ludicrous to assume we would group elite sportspeople with high flying academics into a singular category as if superior ability in either domain created a unifying experience. Yet we have no problem grouping people who have a physical or intellectual disability on the assumption that the experience of disability must also create a common cause. To my mind, it's lazy language and conceptually flawed. Some years ago, a highly intelligent colleague with severe vision impairment reported to me that the only thing she had in common with a person with intellectual disability was "humanity".*

*Surely, it is the same quality that unites us all.*

The irony will not be lost in this review that the 'carers' peak is thought to be resourced under similar parameters as disability advocacy - with the dominant thought being that caring is a homogeneous

experience - as though caring for someone in the final years of life, is the same as caring for someone for all-of-their-life. Caring is no more a unifying experience with its many facets than is disability a unifying factor for all people with disabilities.

The 'Carers' peak is not, as many believe, an advocacy group. It is a provider of services and referrals for carers. The fact that this peak allocated in a 6-month period from July 2014 - Dec 2014 just \$104,000 of its multi-million dollar government-funded income stream for policy development and advocacy for the entire population of 2.7 million unpaid family carers, indicates the paucity of resources dedicated to advocacy and the lack of effective advocacy for family carers of people with moderate/severe intellectual and complex/multiple disabilities. (See Addendum 2)

*The bulk of Carers Australia's rather large budget is dedicated to service provision. As indicated above, less than 1% of its budget is allocated to advocacy. Therefore for the government and its agencies to say, promote and accept that Carers Australia is the peak advocacy organisation for carer-families of people with moderate/severe/profound intellectual and complex/multiple disabilities is simply unacceptable.*

*The only group of carers for whom there is absolutely no discrete funded advocacy anywhere are carer-families of people with moderate/severe/profound intellectual and complex/multiple disabilities. These carers are being short-changed and given short shrift to the detriment of their family members. OurVoice Australia believes this situation gives rise to two circumstances:*

1. a deliberate and direct conflict of interest, perpetuated against a most marginalised group of citizens; and
2. a discriminatory practice designed to ensure that carer-families have no voice and no say in the services they or their family member needs. It is, and will remain the families that government depends upon to provide the majority of disability support services - even under an NDIS.

*So, having put to rest the incorrect belief of many, that the Carer Peak is actually funded to provide advocacy, the reality remains, as our opening strongly suggests, that there is no advocacy for people with moderate/severe intellectual and complex disability, nor is there any advocacy for the families that support this cohort, often for all-of-their-life.*

*This lack of systemic advocacy is not only a breach of trust, but it also amounts to nothing short of disability discrimination. No voice for the very people who in reality have no voice, who have the greatest needs and who will continue to have no voice without the advocacy of the family.*

By and large it is the family that is the original and primary advocate for the person with moderate/severe intellectual and complex disabilities. The family's overarching purpose is to provide security, but also to advocate for, and to look out for and protect the rights of their young and adult children with moderate/severe intellectual and complex disabilities who more often than not, literally cannot speak for themselves.

Even the Discussion Paper's definition of what disability advocacy is - does not recognise the significant barriers that people with moderate/severe intellectual and complex disabilities face in the advocacy environment. It is the families who have intimate and life-long evidence and knowledge of the preferences and needs of their family members and it is these same families who should be resourced as a funded peak to individually and systemically advocate for their young and adult children with moderate/severe intellectual and complex disabilities.

For generations now the voice of this cohort of people with disabilities has not been heard because there is no strong and well-resourced voice to represent their discrete needs nor the needs of their carer-families based on the best informed and best available data and evidence.

Deidre Croft has clearly shown that people with moderate/severe intellectual and complex disabilities are significantly worse off in real terms since the homogenisation of disability.

The situation for people in this cohort of people with disabilities will improve markedly with the provision of funded carer-family advocacy at systemic level because it is a system that is set against individuals who have no power and no possibility of changing the system on their own account.

This is the missing link in disability systemic advocacy and it is the reason why the situation for this cohort of people with disabilities has deteriorated significantly; in as much as they are perceived as a problem or an add-on rather than a specific target group with discrete needs and the need to have their voices heard and met through the agency of the family.

The family is the nuts and bolts of any framework. Without the family at the heart of the Disability Advocacy Framework it will continue to be a flimsy inadequate structure - particularly as the NDIS recognises that without the family the Scheme will fail utterly.

1. 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?

We believe the principles are not appropriate for guiding the delivery of systemic advocacy. Nowhere within the guidelines is the principle of matching systemic advocacy to the discrete needs of target groups - particularly moderate/severe intellectual and complex disability. Again the homogenisation of advocacy is seen in the amorphous and discriminatory guidelines of this review - have your say when the people with disabilities for whom we make this submission - simply cannot have their say because of the very nature of their disability.

We need look no further than the newly funded 'National Cross Disability Alliance' to see the level of acceptance by government of the homogenisation of 'disability' and alongside that the homogenisation of 'Disability Advocacy'. This Alliance has been forged not to advocate for targeted and discrete disability needs, across the entire community, at a time when the entire support base is changing and people are entering a market based system, but rather on targeted societal interest groups whose members happen to have a common link - the label 'disability'.

The diversity of this alliance appears to have very little correlation to the unique issues that arise from the impacts of disability and how we as a society address and respond to them at this time in history.

While there is always a place for cross-cultural issues, the importance of childhood issues and issues of gender within the advocacy framework, there are also other forums in which these issues can be ventilated and considered as the dominant ideology or movement for change - not as the National Peak to address the overarching issues at hand as we progressively build upon the NDIS.

Why have we given this 'Alliance' the 'lead' systemic voice at this particular historical point when there is such a pressing need for a whole-of-nation response built upon the back of both unmet need and historical ill-considered all-of-community development?

This is also where the work needs to be done because it is vital and necessary to build upon the opportunity that will arise for so many when the NDIS is fully implemented - if and only if the foundations of society are addressed. It will not and cannot be addressed by government alone, it will take a nation building exercise - bringing in private sector development to achieve the overarching aims of NDIS.

The entire premise of the catch-call 'nothing about us, without us' is simply wrong. There are many voices that need to be heard, including the voice of people with disabilities. It will take more than the advocacy of people with disabilities themselves to reshape our communities to be disability welcoming.

There are so many issues within both the broader community and the disability support system that drive crisis. Issues such as employment opportunity, community engagement, safe-to-need housing, education, health, transport, the built environment, neglect and abuse and other critical matters that will come to the fore as the NDIS expands. How do we challenge and change the mindset of many service providers in a way that forms a partnership? These are not issues of age, race or gender but issues of building a whole-of-community response not only to unmet need, but for opening the door of opportunity.

If the problem of community capacity and community engagement is not addressed the NDIS will become the formal funding response that compensates people who have a disability who do not have a life of meaningful engagement and participation in their local communities. This will be expensive and ultimately unsustainable and will not build upon the promise of the good that could come from a well funded NDIS.

With the current advocacy agenda of the lead group in this 'alliance' virulently emphasising it's 'only about us' without tackling in a uniformed and considered way the systemic societal/community barriers that need to be concurrently addressed alongside person-centered, individual and community-focused support services, we have and will continue to have, a problem.

It is time to move advocacy away from being a 'club' to becoming a negotiator, not only of disability specific issues, but also for community development across a broad spectrum of interest in order to develop our communities to be more disability welcoming and friendly. Community education and awareness of disability must be framed in such way that disability is mainstreamed. Disability must become recognised by the community as not as a matter of difference but as matter of diversity; that disability is simply part of our community's human diversity. Ensuring acceptance and inclusion of people with disability must be a community-wide project. The insularity and narrow focus of disability advocacy has, and continues to inhibited the innovation and dynamism which the broader community can always contribute to any situation.

This is the essential national conversation that has remained absent from current stakeholder consultation and policy formulation.

(a) If the primary principle of the Australian Disability Advocacy Framework rests on the UN Convention on the Rights of Persons with Disability (UNCRPD) then indeed it will fall short as it is a flawed principle because that convention specifically excludes any mention of the family, even though the entire NDIS framework is built upon the support of the family. Furthermore, the UN Convention on the Rights of the Child should be intrinsic to the Disability Advocacy Framework, particularly Article 23; and that framework sees the family as the fundamental group unit of society.

(b) As a guiding principle we agree that disability advocacy should promote the interests and well-being of people with disabilities. This is an admirable principle but as set out in Addendum No 3 herewith, it has been the experience of some that a publicly-funded disability advocacy organisation have and do, collude with government agencies and a disability service providers against the best interests of the person with a disability and seek to interfere with the natural flow of love and affection between the person with disability and the family to the detriment of the person with disability. This is not an isolated incidence, but the attached Addendum provides an insightful look at the bald face of some individual advocacy when it is mishandled; it can both damage and devastate.

The annexures to Addendum 3 could not be provided as they are lodged with the NSW Parliamentary Library, the Review can access these documents and if not we are happy to provide them on an 'in confidence' basis. Irrefutable proof (sourced under FOI laws) was provided to a NSW Upper House Inquiry by a parent of a person with disability. We have access to the addendum's but felt it inappropriate to include with this submission.

We urge the Review to obtain those annexures because they clearly show the intent to fracture the family based on the hearsay of the service provider, even though the 'advocacy client' was the both the person with disability and the family.

If an advocacy group is led by people who appear to be prejudiced against the family unit, then how can advocacy be balanced? Some individual advocacy groups understand that these interrelationships are vital, but often they are not the ones with the biggest say in the formulation of policy.

However, what constitutes *full and valued inclusion*? Again amorphous words unhinged from practical reality. Inclusion is the paramount goal of every person, although it rests upon the individual's ability, likes, dislikes, wishes, feelings and goals.

We agree that all people should be supported for "*inclusion as contributing and participating members of the community*" Every person has value and through diversity of its people, a society is strengthened.

(c) We agree that disability advocacy should seek to influence positive systemic changes in legislation, policy and service practice and should work toward promoting inclusive communities and awareness of disability issues.

Positive influence in the disability sector that brings about positive systemic changes can only be achieved by the fostering of positive goodwill between all people in the disability paradigm. That is, between people with disabilities themselves, carer-families, funded disability advocates, disability service providers, Ministers of government with portfolio responsibility for disability and social services in all jurisdictions. This includes departmental staff as well as the broader Australian population.

There needs to be a fundamental paradigm shift where a collaborative approach is adopted bringing the community into the disability dynamic. Hitherto disability advocacy has been too internally focused. Disability advocacy must have a broad community application, and should not have a narrow agenda fused to a narrow set of targets. It is not simply about legislation and policy it is about whole-of-community. The aim for disability advocacy should be also for community education and awareness to foster acceptance that disability is simply part of our human diversity. Accordingly, disability advocacy should include members of that diverse community who can partner with the disability sector to achieve those very laudable ends.

Board members of publicly funded disability advocacy organisations must be in the forefront of promoting positive influence in all public domains. In this regard Board members and staff members of publicly funded disability advocacy organisations must be very careful and circumspect in comments made in the public arena to ensure that a positive aspect is portrayed of all people with disabilities and those who support them and are associated with them.

It is therefore very disappointing for OurVoice Australia to report that we have been contacted by parents of young people with severe disability who have produced overwhelming documentary evidence that some Board members in publicly funded disability advocacy organisations do not hold positive views in relation to disability. They use counter productive language in personal descriptors, but what is most alarming, is the nature of comments in relation to parents of children and young people with disability and unsupported accusations which have been hurtful, harmful and certainly unhelpful in promoting positive influence and attitude in relation to disability in the community.

(d) Disability advocacy promotes leadership and capacity building - for an undefined group of people with a disability. This needs to be further defined - those who have the skills to effectively articulate and communicate their own specific needs and goals, but how can our target group fall under this guideline without the resources being provided for disability carer-family systemic advocacy?

(e) Disability advocacy *should* ensure that the views represented meet the individual preferences, goals and needs of people with a disability.

However, for a small group of people who cannot effectively communicate, how is advocacy possible for them unless the family provides the information, knowledge and personal advocacy to ensure any formal advocate has the correct information personal to the individual. When the family are excluded or derided by the very people 'advocating' 'for' the most marginalised, how can these views be represented except by 'osmosis'(sic) '*I know what is best for you even though our lives will never intersect, even though I do not know anything about you and your natural abilities, your hopes, dreams, desires or most basic needs - but I can be your voice because you will/must want what I either want or want for you - based on my own personal living framework - why? - because we share a common link - the homogenised concept of disability*'. Ridiculous? - yes.

(f) Disability advocacy strengthens the capacity of people with disability to speak for themselves by actively supporting and encouraging self-advocacy - once again; Many people with moderate/severe intellectual and complex disabilities cannot and will not ever be able to speak for themselves, nor self-advocate because of their disability. As a small a group within a large cohort of very eloquent people, it is very difficult, due to the complexity of their support needs, to find the common link that binds this group to the aspirations of those with the funded voice.

Self-advocacy is not possible for this group. A person with mild or borderline intellectual disability, because of their own intellectual disability cannot fully understand the complexities of needs of people with severe/profound intellectual and complex/multiple disabilities nor because of their disability can they adequately represent the complex needs of our target group, in particularly in relation to the myriad areas of policy which affect their lives.

And yet disability advocates say people with mild intellectual disability - including those sitting on their Boards, can and do represent all people with intellectual disability, which flies in the face of the claim that one-size-fits-all does not fit all, nor can it respond to a plethora of need across the very broad spectrum of intellectual disability.

This tokenism does serious disservice to people with moderate to profound intellectual and complex/multiple disabilities who must have fulsome and well balanced representation - not a tokenistic feel-good sop.

(g) Disability advocacy may recognise and respect the diversity of people with disabilities; but not all people with disabilities are given equal recognition and respect because of the nature of their disability.

(h) Disability advocacy should ensure that the rights of people with disabilities to privacy, dignity and confidentiality are recognised and upheld; This is an admirable principle but we refer to Addendum No 4 where the advocacy group PwDA sought to gain access to people with severe/profound intellectual disability without seeking consent from either guardians or the service provider. Not only did PwDA seek to breach the privacy of individuals with severe disabilities, but PwDA then publicly traduced the reputation of the service provider in the media and online; when the service provider (NSW government) and its staff had sought to protect the privacy of the individuals with disabilities.

That a leading disability advocacy organisation that has been in the sector for decades, knows so little about the issues surrounding confidentiality, organisational procedures, the duty of care of both formal and informal guardians and their place in this space, is beyond our comprehension.

We have attached this addendum to show that in other arenas they might be adequate advocates who know about, and can advocate for the needs of their target group, which seemingly are only people with physical and sensory disability or those capable of self advocacy, but their target group or



knowledge, based on these quite detailed conversations, does not extend to people with moderate/severe complex intellectual disability with communication disability.

They are not only flailing, but worse, appear to believe that 'their rights' as advocates 'to see for themselves' as articulated by a lawyer advocate from PwDA, supersedes the rights of this very vulnerable group to their privacy and confidentiality. Even their 'lawyer advocate', as indicated in Addendum 4 (a) & (b) has little understanding of the legalities surrounding privacy, protocol and procedure. To then throw their ill-founded opinions out into the public arena appears to have been little more than crass attention-seeking and a chest-beating exercise of 'institution-bashing'; in the full knowledge that Stockton Residences are well into the devolution process into community settings as part of the Stronger Together 2 growth policy.

Furthermore, if you read the conversation, the claims made variously by an office-bearer and Board members in the public domain on Facebook were actually false claims, as pointed out in this conversation by John Ryan, former MLC and former Shadow Minister for Disability Services and now Executive Director of Contemporary Residential Options in NSW ADHC, and who is, directly responsible for the Stockton devolution process. John Ryan pointed out that process and procedure were simply not followed. For all intents and purposes this was nothing but an exercise to 'get the government' in a very public attempt to once more highlight their own organisation's agenda in the public space. Also from this discussion, the lawyer advocate simply believed that she had a right to know and that, to her, superseded the right to privacy of others.

It would appear that some disability advocacy organisations are totally insensitive to the ingrained and well-founded fears of families who saw the devastation wrecked on vulnerable people by the poorly implement Richmond Report recommendations of the 1980s. Rather than a 'we-know-best' attitude which runs roughshod over the sensitivities of families with respect to the uncertainties of change, advocacy has a very important part to play in sensitively, carefully and patiently walking the families step-by-step through the resounding benefits that devolution can bring. Advocacy should allay fears and build trust for families to know that there are now better and more personally beneficial places to reside in the community which will meet the specific needs of family members with severe disabilities. Advocacy can reach out to families through personal forums or through social media forums such as Facebook where discussions can be had and fears allayed by shared experiences.

Instead, some disability advocacy organisations publicly lampoon these worried and fearful families (see Addendum 5a and 5b Save our Sunny Hills) and in doing so undermine their purpose and the trust of these families. Well targeted advocacy can contribute a lot of good for this group, by supporting them through and past their fears and forward to embracing a different future, but not when these families become the butt of cruel and hurtful public lampooning by the very people who are publicly funded to be a 'national voice'.

The families of OurVoice Australia and many others who have contacted us, have never before, and hope never again to see such public displays ridiculing vulnerable groups; people with disabilities or their families in the public space as we have constantly seen over the past 12 - 18 months. We are dismayed at the level of damage this kind of behaviour is doing. Furthermore we are concerned that the damage is irreparable while this particular peak advocacy body retains the ear of government.

Furthermore this advocacy peak, in their published report 'National Disability Insurance Scheme Citizens' Jury Scorecard, made false claims regarding denial of access to the residents of Stockton as if the service provider had something to hide. When in fact the service provider was protecting its clients from an invasion of their privacy because those seeking access *had not followed process and had failed to seek permission in the correct manner*. Furthermore, even though they were made aware that their organisation was in the wrong, no apology was forthcoming either privately or publicly. This goes to the core of this organisation's incapacity to effectively advocate for our target group, because of a fundamental prejudice; from their prejudicial behaviour through to the total lack

of understanding and appreciation of what 'functional capacity' and 'consent' actually means. This is a great shame as the 'Scorecard project' itself was a great idea, albeit too early into the NDIS rollout - and with the exception of these two pages, a heartwarming document.

Please see Citizens' Jury Scorecard pages page 17 and 18 in Addendum 6 (a) & media in (b)

- (i) Disability advocacy should foster effective strategic alliances to develop capacity to identify and respond to the needs of people with disabilities. Again we agree this is an admirable principle however, to quote John Roarty, the original disability advocate and one of the founders of the disability rights movement in Australia, who said of his colleagues: "...we spend too much time trying to score over each other instead of uniting for the benefit of all".

## OBJECTIVES

(a) Any Framework should give voice to the discrete needs of all people with disabilities irrespective of the type and/or severity/complexity of disability. At the moment people with moderate/severe intellectual and complex disabilities are rarely conversant with the niceties of international treaties and often are not aware in any way of their inherent human rights. However, their carer-families are most assuredly aware of those rights and when those rights are infringed, particularly those families who are of the generation which was caught up in the human rights movement that swept to the shores of Australia during their formative years.

There is a pervasive mindset in the disability sector particularly with respect to disability advocacy, haunted by the ghosts of the development of institutions and practices of the past with respect to people with disabilities. By all accounts that may be for good *personal* reasons and we can understand those fears and abhorrence of any possibility of a return to those dark days. However, this mindset has spread like a cancer and has stunted the capacity for innovation and improvement, stifling the dynamism of the disability sector. This has been particularly true with respect to people with moderate/severe intellectual and complex disabilities where government agencies and others attempting to improve their lot have been condemned out of hand for considering a raft of innovative ideas for supporting the discrete and defined needs of people with moderate/severe intellectual and complex disabilities.

Furthermore, the fear of a return to the institutionalisation of this particular target group is unfounded. There is no evidence that government in any jurisdiction intends to return to that model of service provision. The National Disability Insurance Scheme should set aside that fear as the Scheme is implemented nationally and inclusive options are presented.

These people are people of the past and not of the future. Knowledge and understanding of the history of the disability rights movements is absolutely key to ensuring that the practices change, but living with the attitudes of the past and bringing that to the forefront of the interpretation of the now and of the future, has no place in this space in which the NDIS plays a dominant role.

There needs to be a renewal in how disability advocacy is delivered and how disability advocacy can be more effective and efficient.

One need only examine the well-established disability advocacy organisations to see that many of the executives of those organisations and many of the Board members have been in those positions for many years if not decades.

Moreover, the immediacy of modern communication and the involvement of carer-families who are well-educated, well-researched and devoted to ensuring the best interests of their family members with disabilities are well served, will ensure that regressive policies will not be tolerated. There have been enormous gains made for people with disabilities since the early 1970s when people with disabilities risked all to speak out about their being '*captives of care*' and of the "... *dominating*,

*paternalistic, overprotective attitude of the authorities...."*. Through their early efforts and the relentless agitation of families, incremental change was implemented and the nascent disability advocacy movement began to make inroads into the community.

The internet has empowered everyone with knowledge and confidence, and has been an unprecedented impact on unifying families and many of the more 'liberated' people with disabilities, who respect families for their care and efforts to improving their lives. Once these groups were isolated and excluded by the very nature of their care responsibilities for one and the nature of the disability itself. Not so today.

(b) Advocacy itself is not a means to economic and social participation. It is the inherent nature of the individual's ability which will determine their capacity to achieve economic participation and social inclusion. The NDIS outcome-domains support categories that support economic and social participation are the skill-building items where the participant improves their lives with targeted daily activities. This skill-building will be across the disability spectrum of need. This means that advocacy must not remain as it currently is - ideologically driven, it must person-centered and person-driven. It is the discrete needs and inherent abilities of the individual that must be paramount in the advocacy paradigm.

However, advocacy also has an important part to play in this and in the development of inclusive communities at every level, but it does not have sole responsibility here and people with disability themselves are not and should not be the only voice needed. A lived experience of disability for a person with severe intellectual and complex disability is of course lived by the person but it is also lived by the person's family. On the journey of disability it is the family which is the vehicle in which the journey is made.

With respect to economic participation advocacy must adhere to the UN Conventions on Civil and Political Rights which broadly support the right to work, to the free choice of employment; to just and favourable conditions of work, and to protection against unemployment. Advocacy must not jeopardise the employment of any person with disability based on an ideologically-driven agenda. You must build *BEFORE* you tear down, something seemingly lost to some.

Social inclusion means that the person with disabilities should be free to choose their society and their circle of friends, not be coerced into an ideological view of what constitutes a contrived or pre-determined choice by very able people as to what is acceptable social inclusion and what is not.

(c) It will indeed be an admirable outcome for the advocacy framework *if people with disabilities are able to enjoy choice, well-being, and are provided with the supports to pursue their life goals.*

(d) It will indeed be an admirable outcome for the advocacy framework if people with disabilities are able to make decisions that affect their lives or, where necessary, are supported to make those decisions. However, advocacy must have due regard and respect for the inherent ability of the individual with disability. In other words, there are people whose intellectual disability is such that they have no capacity to comprehend matters that impact, adversely or otherwise, on the quality of their lives. It is for this reason that carer-families must be part of the advocacy paradigm. It is their input, which can enhance the quality of the lives of people with moderate/severe intellectual and complex disabilities, through love, support and knowledge.

(e) We view this item "people with disability receive independent advocacy support that is free from conflict of interest" as problematic. Whether by intent or not, it would appear that it directly targets the input of families. *We are concerned that independent advocacy is not always free of ideological imperatives and is therefore no more independent than that of the family - with one difference - it is the family that know the person well and it is the family left to pick up the pieces if the ideological imperatives fail as they have, do and will continue to do, for some*

target groups. This can also give rise to a conflict of interest when it directly impacts on the best interests of the people with moderate/severe intellectual and complex disabilities, not because of need, but rather ideology.

(f) It will indeed be an admirable outcome for the advocacy framework for the needs of people with disability experiencing multiple disadvantage to be met.

(g) We have no idea how this outcome is to be achieved by the advocacy framework for people with moderate/severe intellectual and complex disabilities. Unless of course there is due consideration given to funded, well-resourced carer-family advocacy that mirrors the advocacy provided to people with physical disability who have the capacity to self-determine and self-advocate.

2. Are the outputs of the Framework still relevant or should different outputs be included?

The outputs of the Advocacy Framework is relevant for people with physical disability and those who have the capacity to self-determine and self-advocate.

However, a large part of the Framework needs to be reviewed in order to be inclusive of the discrete advocacy needs of people with moderate/severe intellectual and complex disabilities and the families that support them.

(a) Individual advocacy within the Advocacy Framework can be discriminatory and is not tailored to meet the individual needs of people with moderate/severe intellectual and complex disabilities, and this includes those experiencing multiple disadvantage. Please see addendum 7 which is an email from a parent who requested the assistance from a disability advocacy organisation for individual advocacy for her adult child to secure supported accommodation in his community.

(b) There is no such thing as disability advocacy that is informed by a broad based publicly promoted evidence base, they appear to pick and choose their evidence at will. Nor is it provided in an accountable and transparent manner. A case in point: is there any data collected and made public by each disability advocacy organisation as to how many individuals with moderate/severe intellectual and complex disabilities have received individual advocacy from their service? Is there annual data collected and made public by each disability advocacy organisation as to how many, if any, turnaways there have been, and the reasons for the turnaways? Is there any data collected and made public by each organisation indicating the satisfaction rates of those who use the services of their disability advocates for individual advocacy, or any data collected and made public by each funded advocacy group on the effectiveness of their individual advocacy and the outcomes? Is there any requirement by the funding agency for such data to be collected and made public to assist with informed knowledge for a would be user weighing up where to turn?

Adding to these above questions, it must also be said that after a desktop search of NSW, the only area we found with any representation of people with moderate/severe intellectual and complex disabilities is in a few disability advocacy organisations which represent people with disabilities of indigenous heritage or people with disabilities from non-English speaking background where the carer-families are recognised, respected and included by allowing them to represent their family member with disability.

(c) Disability advocacy is not always delivered in planned and coordinated manner. It is agenda-driven and not responsive to the needs of all target groups. In particular people we have been discussing and the carer-families who support them, are almost totally excluded from almost all disability advocacy organisations not only by virtue of the nature of their disability, but also the organisational structures and/or the very Constitutions of the disability advocacy organisations.

By the nature of their disability, those people with moderate/severe intellectual and complex disabilities cannot join disability advocacy organisations on their own account because, by and large,

many cannot speak, many cannot use the telephone, except in a minimal personal way, most cannot access the on-line membership forms nor can they complete those forms. Furthermore, their carer-families are prevented from joining the organisation as their representative/personal advocate because the Constitution of the disability advocacy organisations expressly excludes them. Therefore, the people with moderate/severe intellectual and complex disabilities are directly and indirectly discriminated against as are their families.

(d) Disability advocacy that promotes community education and awareness of disability issues and rights would be a most admirable achievement. However, in that regard there is no doubt that much work needs to be done in order to achieve this. Community education and awareness building must be undertaken at every level from Universities to Chambers of Commerce and Local Government. The Universities produce the leaders of the community and awareness must be built at all levels of society.

Community education and awareness of disability issues and rights will not be achieved without a wider range of voices, including through the agency of their families.

It is ironic that there appears to be a chasm opened up in the last couple of decades between carer-families advocating untiringly for their family members with disabilities at every stage of their life and the funded disability advocacy organisations. Why this chasm exists is not clear and it is certainly not excavated by families who ardently wish for a united front in disability advocacy because in unity there is strength.

Associate Professor Dr Kristy Muir has undertaken research work in relation to supporting full participation and the rights of all family members where families include a young person with a disability and challenging behaviour. Dr Muir's work has been published in 2011 by Taylor & Frances in the scholarly journal *Disability & Society* Addendum 8 contains a copy of her article: *Complementing or conflicting human right Conventions? Realising an inclusive approach to families with a young person with disability and challenging behaviour.*

(e) Systemic advocacy will not support the agreed outcomes because it excludes people with moderate/severe intellectual and complex disabilities and their carer-families.

In fact, systemic advocacy in its current form is little more than a fulsome rug under which to hide the shortcomings of disability advocacy in general. Without the input of carer-families on behalf of people with moderate/severe intellectual and complex disabilities, legislation will always be deficient and insufficient for the purpose for which it is enacted. Policy and practice will be tokenistic and will remain "about us without us" because the people with moderate/severe intellectual and complex disabilities will remain unrepresented.

Notwithstanding the claims of disability advocacy organisations that they can represent the full gamut of disability, no one organisation can represent everyone. There must be a mix of voices and the missing voice hitherto has always been the voice of people with moderate/severe intellectual and complex disabilities through the agency of their carer-families.

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

The Framework does identify what is needed however the mechanism to meet the need for disability advocacy for some discrete target groups who are always outside the consideration of policy-makers and legislators is the missing link.

Continuing to exclude the advocacy of carer-families becomes active discrimination against people they support.

4. Do you have any other comments, thoughts or ideas about the Framework?

## OurVoice Australia Inc Submission to the Review of the National Disability Advocacy Framework

For more than a decade carer-families have been calling for funded disability carer-family advocacy that mirrors funded disability advocacy provided to people with disabilities who can self-direct and self-advocate.

There is or was one national peak for intellectual disability. However, the target group of this national peak has invariably been people who have borderline intellectual disability and those who live on the periphery of service provision, or people with mild intellectual disability who are able to articulate their needs.

We have been informed by a parent and former board member that they failed to get this organisation to advocate for the discrete needs of people with moderate/severe intellectual and complex disabilities as they are not 'flagship candidates' to prove the efficacy of their social inclusion agenda. *Once again these issues will not be resolved without the voice of disability-family -advocacy. Sadly, most leading peaks are agenda-driven rather than person-centered which may sound rather strange given their message, but the reality is that disability is a broad brush and what may be great advocacy for some, fails dismally for others...*

Just as we were about to send this submission we were sent the 'Why disabled people don't like Steptember' on the 'End September' campaign and the change petition campaign to end Steptember that is concurrently running on change.org with the campaign below.

What is the Steptember campaign that the advocates are so appalled at?

*"Snowboarder Ben Tudhope doesn't let cerebral palsy stop him from achieving great things. At just 14, he represented Australia in the Paralympics—the youngest competitor of any country. Now Ben and Dr Andrew Rochford are challenging fellow Aussies to join 'Steptember' and get fit for a good cause.*

*Ben's cerebral palsy means that he is partially paralysed down the left side of his body. But that didn't stop him from finishing 10th in the world at the Winter Paralympic Games in Sochi last year.*

*Cerebral Palsy Alliance ambassador Dr Andrew Rochford recently interviewed Ben and asked him why he was passionate about 'Steptember'. Ben told him, 'I think we all spend too much time sitting still. Steptember is a great way to be more mindful of how much activity you're getting into your day.'*

*When you sign up to Steptember, you commit to taking 10,000 steps a day for 28 days straight. Unlike Ben's snowboarding career, there's no training required. And the best part is that every step you take helps raise much-needed money for kids and adults with cerebral palsy—many of whom face incredible physical challenges on a daily basis. It's fitness for a good cause".*

*This is viewed as so awful that umbrage has been taken at the message delivered by the fundraising campaign. In the opinion of the President of PwDA, Craig Wallace, "There's something peculiarly patronising about a fundraising event that we're specifically excluded from". OurVoice is told that PwDA speaks for all people with disability no matter the disability. We seriously question this as they have a distinct lack of understanding about differing disability and needs. Cerebral Palsy has a broad spectrum of both physical and intellectual abilities.*

*Did PwDA call Cerebral Palsy Alliance to try to put their perspective forward and in turn listen to CPA's perspective before they launched two campaigns to discredit this initiative?*

*Whether you agree with, like or dislike the campaign, it is irrelevant. There are ways of working with people to get your message across and this is not the way to do it. It is divisive, negative and hardly a*

positive response to a community initiative, particularly when you are the President of a National Advocacy Peak.

We believe that government funding for Systemic Advocacy should be to build positive public relationships. Please see attached Addendum 9

We must maintain a robust broad spectrum of funding options and this must be understood by all disability advocacy organisations, particularly those with high profiles. We find these incessant negative, attention seeking campaigns not only tiresome, but divisive. They do not bring the sector together, they are damaging and are, we believe, extremely counter-productive.

Another Facebook' conversation;

Service Provider: *"It is also important that the NDIA Board has knowledge and expertise of people with an intellectual disability. There seems to be an over abundance of knowledge and expertise of people with physical disability and in fact at most conferences we only ever see see people with a physical disability presenting and assuming they represent those with other disabilities. People with an intellectual disability make up the bulk of the population for whom the NDIS has been developed. Many of these people are unable to participate at this level due to their impaired communication and understanding but their needs and aspirations must be understood and accounted for by others.*

PwDA Board member; *"Absolutely, ——— The PWDA board has a range of people with diverse disabilities - including people with mental health conditions, a person with an intellectual disability, an Autistic, two Deaf people, a blind person, some physically disabled individuals (including two people who are carers/guardians for people with autism and people with ID) - and the board is far richer for our diverse experience. We have to also recognise that although having individuals with good business sense and experience is necessary for good governance, there is also a role for very good advice. Why is it okay to constantly have 'advisory' groups made up of pwd for boards with no actual power but not do the reverse with groups of advisors who are lawyers and accountants?"*

The PwDA Board member then went on to say *"If I had to 'reset' the board, I would choose people who I knew had vision and business acumen and also people who understood the people who the scheme is for, because they have lived experience"*.

From the conversation above - the PwDA responder displays literally no understanding nor comprehension of what the service provider meant. There is a pervasive belief that personal knowledge of their own needs and the needs of their majority membership - those with similar disabilities and similar self advocacy skills can be extrapolated to encompass the lived experience of *all* people with disabilities.

That statement itself, covers it all...

*This misrepresentation goes to the heart of everything we have said in this submission. It is the families who actually have the 'lived experience' of the people with intellectual disabilities to whom the service provider was referring, NOT the majority membership of PwDA or WwDA or any of their Board members who have mainly physical or sensory disability or any board that denies the inclusion of the voice of the family.*

*Recent funding allocations by the Department of Social Services have condoned and given tacit approval to a number of organisations whose Constitutions effectively deny membership to a large number of people with significant intellectual disabilities. For this reason OurVoice Australia Inc contends that documents submitted by a number of disability advocacy organisations to the National Cross Disability Alliance tender process were factually incorrect and should have been excluded.*

OurVoice - in conclusion;

*It is our view that Systemic Advocacy built upon fabrication, vitriol, negativity and 'outrage' rather than building goodwill, strong communities and hope for a better future, will not advance the cause of people with disability and will leave our nation much poorer for the experience.*

*It is our view that it is time to bring true representation as well as community into disability advocacy and that can be done by inclusive advocacy that also funds the family. The family is the building block from which our society is built.*



*Addendums to OurVoice Australia Inc submission*

The following 12 Addendum's have been attached with this submission, they are all accessible from the public space and therefore pose no confidentiality risks with publication.

Addendum No 1 - Deidre Croft 'For Better or Worse'

Addendum No 2 - Carers Funding

Addendum No 3 - Mason submission

Addendum No 4 (a) Stockton on Facebook

Addendum No 4 (b) Stockton on Facebook

Addendum No 5 (a) Save Our Sunny Hills



Addendum No 5 (b) The idea for 'Save our Sunny Hills'

Addendum No 6 (a) Citizens Jury Scorecard page 16 & 17

Addendum 6 (b) The Australian article Citizens Jury

Addendum No 7 - Email from a parent

Addendum No 8 - Dr Kristy Muir '*Complementing or conflicting human right Conventions?*'

Addendum No 9 End Steptember '*Why disabled people don't like Steptember*'