



OUR VOICE Australia Inc is a self-funded organisation providing a voice for people with moderate to severe intellectual disability and complex needs- their families and carers – because this group of people is not formally represented by any of the existing advocacy services - funded or otherwise.

Our Mission, Vision and Objectives is attached as Appendix 1

This submission builds on our previous submission to the Advocacy Review. For continuity of interpretation and information, we ask that our earlier submission be treated as an integral part of this one.

Our self-funded existence is the result of continual refusals by Governments – both Federal and State, to formally recognise this vulnerable group of people with a disability, their families and carers. On the cusp of national the roll-out of the National Disability Insurance Scheme (NDIS) this gap at the policy and decision-making table cannot be allowed to continue. These constituents form the core of the NDIS – yet they are locked out of the whole conversation.

The background advocacy data – provided by the Department – states the existing funded National Disability Advocacy Program (NDAP) has 101 formally recognised providers. Of these 16 are for Intellectual Disability. The NDAP provides \$16.4m to 58 separate advocacy organisations delivering 6 different models of advocacy.

- Self- advocacy
- Family advocacy
- Individual advocacy
- Legal advocacy

- Citizen advocacy
- Systemic advocacy

The current funding and placement of these agencies excludes people with moderate to severe intellectual disability and complex needs because the delivery of advocacy services is to the person with the disability. That may be considered as the correct focus, but the NDIS is built on *choice and control* and where a person with an intellectual disability cannot self-advocate nor articulate, there is a growing exclusion of the right of family members to act as advocates.

This is not new. Advocacy services since the 90's have been based on ideology and increasingly, the Government determination not to resource the families to provide family advocacy in a national arena, has meant that the landscape has been dominated by those whose needs can be addressed by facilitation, by mobility equipment, by living close to existing facilities – and an incorrect assumption that everyone with a disability can “work with the right support”, that community inclusion excludes any form, no matter how personalised or small, of congregate care, even though the NDIS is working towards a model to deliver such accommodation for those with complex care needs, that families are “negative” and that all people with a disability should be encouraged to experience the “dignity of risk” without real evidence of the value add of such risk to the lives of this cohort, nor the ultimate cost in human terms or financial terms. Whilst the focus is now on “able-ism” not disABILITY – the reality is that the current national disability advocacy program does not deliver on the stated goal to;

1. Facilitate the key concept that “It’s important to be able to put your view” (DSS Advocacy Video) and
2. Promote, protect and ensure equal and full enjoyment of all human rights enabling full community participation

In fact the formal NDAP Report after national consultations- in 1998 stated that “**despite the Government emphasis on the important role of families, there was no significant representation of the views of families of members with disabilities at the national level**” (pages 33-34). The subsequent Recommendation was that a National Voice be established to represent the interests of families with members with disability.

It was never delivered and incorporating it as one service complementing 5 others within the National Disability Advocacy Program, has not worked. The Government refusal to accept and implement the recommendation built on the strength of unfunded family groups like Australian Parent Advocacy, National Family Carers Voice, the Carers Alliance, the Carer’s Coalition and now the birth of **OurVoice Australia**- for the group of people who we represent. Those views, by way of family carers, are assessed as being met by a “one size fits all” approach to all services

– advocacy included. Unless this changes, and changes quickly, these vulnerable people are forever- destined to remain in the “too-hard basket” as an add on to the needs of others.

Our earlier submission, the public record, the National Family Carers Voice, the ABC “Hidden Army” , the “Walk a Mile in my Shoes campaign” – and the current supported employment debate on the role of ADE’s - are all on the public record. Also it is an irrefutable fact that ideology reigns supreme in the hands of those funded under the NDAP to support people with moderate to severe intellectual disability – their families and carers – to ensure that they are “*able to put their view*”.

It is not our intention to reiterate the facts previously provided in our earlier submission - but it is that background which encompasses our formal response to the questions you have raised within your Discussion Paper.

Before answering the set questions we preface our response with the necessity for the correct identification of the target group, their individual needs and their necessary supports relevant to their needs.

We predicate our response based on our identification of care and support needs by “carer” type as our target group often have no voice of their own without the support of their family.

- *Life-time carer* (i.e. the group for whom we advocate is an example)
- *Time- of- life carer* (Aged care – usually limited in time span) Now, however we have a cohort of ageing people with disability – for whom no provision has ever been made, because they normally never lived this long. Some now outlive their parents and the responsibility is increasingly falling to siblings. This has also never been recognised as an emerging issue)
- *Term-of-life carer* (Acquired brain injury or through trauma, degenerative conditions or illness)
- *Young carer* (children caring for parents when they should be free to live an ordinary childhood)

As part of this “carer” identification the different types of disability also dictate the types of advocacy and supports required.

Our response is limited to the first group – people with moderate to severe intellectual disability and other complex needs. Their care requirements are “*life-time*”. With the best will in the world, some of these people will never be able to self-advocate or to even make the decision to contact an advocate. They are the core group of the NDIS because of the level of their disability, but they are currently locked out of funded advocacy by the very nature of their disability.

Response to review questions:

1. How do people with disability, their families and carers benefit when agencies are funded to provide one or two models of support?

Every person has individual needs which will always differ – so no model can be everything to everybody. The variety of expertise required would make it difficult to deliver everything from one agency. Coming from such a low base there will be a shortage of expertise to handle multiple models – even if that would be more beneficial in an NDIS environment. This question raises the issue of service delivery and advocacy – within the same model. In many cases there would be benefits, but in others there would not.

2. What are the drawbacks?

The principal drawback is conflict of interests if the suggested two models of support were advocacy and personal support within a service delivery model. i.e. accommodation and or employment. When self- advocacy is not possible the service provider is often the only external link for some people. They know the person well, and they have their trust and confidence however, in some cases it is the service provider which precipitates the need for advocacy at first instance. There are fewer drawbacks for the delivery of different types of advocacy within the same model of advocacy.

3. How do we value and support the various models of advocacy while ensuring equitable access to individualised, fit-for-purpose advocacy, regardless of location.

The problem with this question is the qualification of “regardless of location” and the complexity of the target group.

The “location” problem could be solved by using existing mechanisms – and not creating “more of the same”.

It is difficult to value and support an advocacy service if you don’t have access to one, or as is happening more regularly, the one to which you could have access will not support the needs as identified by primary carers and/or service provider because of the organisational philosophy underpinning the values and requirements for access to that service. Access is addressed in the following question.

2.1- How do we improve access for.....?

The issue of access after the issue of the ‘universal need model’ is our key problem.

There is insufficient identification of the target group by disability type, location, and other constraints as identified in the 4 sections of that question. Additionally the advocacy goal and allocation of funding should be qualified by adding the words to enabling full community participation – “relevant to individual needs”. That means not someone else’s ideology, not what suits a staff roster, but rather if the person has complex needs, impaired decision-making especially, with reduced physical, psychosocial or sensory capacity, then it’s important to have someone who actually knows that person well. More often than not this is the family. Sometimes it could be the service provider, but access to the current system of available services is being restricted by ideology for the group of people for whom we advocate.

2.2 What are the strategies or models that have worked? What are the strategies that do not work?

It is obvious that the current family advocacy model is not working for those with moderate to severe intellectual disability and complex needs. Those with mild to moderate intellectual disability, those able to self-advocate, those with physical – and not intellectual impairment and the other listed models of advocacy appear to be effective. Our submission can cover only the deficits in the advocacy program as we have identified them for the past 30 years.

3.1 What mechanisms could be used to ensure information on systemic issues gets to the right people and organisations?

Firstly you need to understand why the current information systems are failing

- (i) Services that adopt a “one size fits all” ideology will always fail
- (ii) Australia is a large country. Queensland is 7 times larger than Victoria and Western Australia is 11 times larger than Victoria – but most of the “focus” groups – that designate service types – and the information – are centred in Sydney, Melbourne or Canberra. Check your advocacy locations – they all work on electronic information systems with an incorrect assumption that everyone with a disability, their family and/or carers has computers, understand them and can use them. Well the reality is that they don’t. Many are ageing. Lack of transport is a problem. The increasing cost of postage poses another barrier for effective and efficient distribution of information to the target group.
- (iii) The target group is people with a disability, their family and carers. Assess your target group and understand the different level of care, support and advocacy needs that underpin the type of carer, thus the type of care needed and the type of advocacy needed.
- (iv) This is the classic analysis of “who” “what”, “when”, “where” “why” and “how”. In a disability advocacy program they all have one common factor. They’d be on your Centrelink and Medicare registers. The privacy requirements have been over-

implemented – again rights have been super-imposed over everything else – and families are locked out yet again – as are many organisations because service delivery and advocacy have two separate functions which must be seen to be separate. The separation of powers in another dimension!

So having established what information needs to get to whom and where that is, then the “mechanism,” is possibly the common data base you already have – plus the organisations providing the services – information which you would also have.

Look further afield and you will find that every person in every part of our nation lives in an area, any area, which is serviced by another level of Government and that is the local Council. All areas do not have Medicare, Centrelink or DSS offices, but they have a council building that houses their Local Government. Increasingly Local Government has to deliver on community development as part of its charter and every area. Everywhere has people with a disability. Some of these residents can self-advocate but many cannot. The community has a sense of commitment to these people which the NDIS should recognise and build upon. We need to stop re-inventing the wheel. Assess what our communities have and use it.

Where necessary build individual advocacy into local government as part of the rollout of the NDIS. With appropriate funding it simply adds another dimension to community life – especially valuable in the more regional, rural and remote areas of our nation. Many Councils now have Social Action Plans, Disability Action Plans and a whole range of community programs for health, community and inclusion. Moreover they have the resources and buildings, which are under-utilised and, more often than not, a community development program/ centre or officer. The introduction of the NDIS is an ideal time to build disability advocacy in as another layer of community involvement. It should form part of the National Disability Strategy 2010–2020.

3.2 How can we help disability advocacy organisations work with a wide range of other organisations with similar aims, such as;

- **Disabled people’s organisations (DPO’s)**
- **The Australian Human Rights Commission**
- **Ombudsman organisations**
- **Aged care advocacy organisations**
- **State Disability advocacy organisations**
- **Peak Bodies?**

The issue of “similar aims” needs to be aligned to the type of “carer” identification previously instanced.

Australian communities function more holistically than the decision-makers realise. The problem with advocacy as it has previously been provided, is that some organisations can and do refuse advocacy support that is required for ideological reasons. No – we don't support ADE's, No – we won't advocate for you if you want a group home, or cluster housing or whatever.

But the sense of "community" is still strong in Australia and resonates well in the areas with geographical restrictions. Those communities are adept at filling the gaps, they are accustomed to improvisation and have a strong sense of local ownership. That's why families started the services for children with intellectual disability, the community never catered for them, so families started their own workshop, day activity, respite service and whatever else the families felt their children needed. The community then took over with service clubs, working bees and council assistance.

This remains one of the strengths of Australian communities, but Governments are slowly eroding it. The NDIS which aims to break down the barriers between State and Commonwealth and delivers individual supports is an excellent way of re-kindling this community spirit and the resources that it provides.

The review is framed in such a way as to indicate more funding is needed when in fact funded advocacy has failed for decades to represent our target group. As the service system is finally being built to properly accommodate service and support needs by the NDIS. The NDIS should mean less need for individual advocacy for those able to self-advocate, rather than more.

4.1 What steps or organisational structure should be put in place to ensure conflicts of interests do not arise, or are minimised.

Conflicts of interest already exist.

Our members representing workers, their families and carers now fund their own costs for representation of the workers and their families at the industrial Conciliation Process on the ADE-supported employment issue. The actions have been initiated by two funded advocacy agencies, so it is impossible for those funded advocacy agencies to fund the opposing view to which they, as the initiating agency are ideologically opposed. The Federal Government has directed our Member to Carers Australia a carer service provider – not an advocacy organisation - for the necessary financial resources to provide continued representation of these workers and their family carers in the industrial process. This has been to no avail as they are not a disability advocacy organisation that supports a family carer voice. One funded voice remains at the table and once again the pragmatic view of the family is largely ignored and its legitimacy challenged for want of proper and equitable systemic funding.

It is a pity these same funded agencies will not concentrate their considerable energy, talents and funds on getting people with disabilities who can work into the workforce rather than trying to ensure those who are working with the necessary, sometimes intensive supports - albeit in congregate settings such as ADE's, are protected from unemployment.

People with a Disability – especially those with moderate to severe intellectual disability and complex needs - are among those most in need of advocacy – especially disability family advocacy.



* Relevant others can become significant others depending upon individual circumstances, particularly when there is no family representative or an alternate, acceptable advocate

Identification of a conflict of interest must be;

- Weighed up with the individual needs of the person with the disability
- The nature of the conflict
- The availability of a quality alternative service to remove or minimise the perceived conflict of interest
- Any possible detriment to the PWID that results from the removal of a service to meet the conflict of interest criteria – whatever they are determined to be.

The reality is that advocacy is not geographically available in many places and, if physical contact is too far removed the efficacy of advocacy is lost. Some services are already delivering two models of support - within the same service because to remove a service could be of greater detriment to the people with intellectual disability (PWID).

4.2 How do we avoid gaps between supports provided by the NDIS and advocacy funded by the NDAP?

The reality is that the PWID – and their family – will need assistance with NDIS planning. The gap is already there, it's how and by whom that gap is filled which must be addressed. Disability Family Advocacy is the most obvious solution for those with family support. Family actually know and live with, or have lived with, and understand the specific needs of the PWID so they have, generally, become adept at accessing or procuring the necessary supports – or providing them themselves.

4.3 What policies and strategies do we need to protect the rights of people with disability?

We need policies that are sufficiently nuanced to recognise that some people with intellectual disability, especially our target group, have limited capacity to understand the concept of “rights of people with disability”. A prevailing attitude that the PWID – not the family - is the client – has led to situations where necessary information on matters of behaviour and health have not been released to family because it breaches the rights to privacy of the PWID. Again it is critical that care needs are identified and what might be a breach of rights for one person with a disability might be essential information in the hands of a family carer of a PWID.

A growing ideological mantra that “special services” shouldn't exist, that people with a disability ‘are not vulnerable’, that choice and control should be exercised by all people with a disability – denies the reality of the *lifetime* lack of informed decision-making capacity of our family member. Exercising a “right” that could create detriment to the PWID - like the “dignity or risk” is misplaced ideology and should not be countenanced within the NDAP.

5.1 What forms of legal review and representation do people with disability need most ?

Because of the impaired decision making capacity of their person with an intellectual disability, families are continually encountering problems with obtaining Guardianship of their family members. Reaching the legal age of 18 means nothing to someone whose intellectual capacity is never going to be fully developed to a point where they can make legal decisions. But, increasingly there is legal reluctance to provide Guardianship Approval to families as this removes “the right of choice and control” from the PWID; even though some do not have the capacity to read, understand, nor sign a contract, do not have legal capacity, which makes any contract invalid and illegal without a significant other as co-signatory. It makes absolutely no sense and only affects those with legal decision-making incapacity. It is not a ‘mainstream’ disability issue.

Guardianship is a form of legal review and our families are continually being challenged, so a mechanism to assist families through this process at low/no cost is critically needed.

5.2 What barriers prevent people with disability from accessing justice?

The lack of intellectual capacity, the increasing reluctance to award guardianship to good caring families and the lack of low/no cost legal advocacy, indicates that in many cases where intellectual disability is concerned there is a distinct lack of dignity in the push for ‘dignity of risk’ above individual, personal considerations of ability to control that risk, understanding of risk and the outcome for the individual.

Engaging in risk may have consequences on the physical, emotional or legal wellbeing of that individual caused by engaging in risky activities without the ability/capacity to consider the likely outcome regarding cause and effect.

We are not talking here of minor risk considerations but where ‘the dignity of risk’ as a focus by advocacy for this group can lead to very distressing, life situations which can have significant ramifications on one’s capacity to live a good life, one not overrun by necessary additional responses to crisis often resulting in the need of more intrusive supports, both legal and social.

5.3 What models of legal advocacy are most effective

Some of our families experience a lack of legal advocacy services which has involved domestic violence in some cases. The Federal Government needs to fund a legal advocacy service that emanates from the Court or within a legal advocacy service working as an adjunct to the Court as being a separate issue to ‘disability advocacy’. The issues are far more complex than simply disability issues. Such an agency must have suitably qualified personnel competent to take into account the level of impairment for determining access for such a service, to ensure it is not

overwhelmed by those who should and could be accessing mainstream legal service systems due to ability to self advocate.

We hope that our submission will assist with a different kind of strategic thinking surrounding advocacy. We need targeted, person centred advocacy that responds to need rather than simply ideals. We need individual advocacy accessible in the communities where people actually live.

In closing

Encapsulating our submission are the words of Professor Christopher Oliver BSc, MPhil, PhD, CPsychol, Professor of Neurodevelopmental Disorders from the University of Birmingham, UK . Professor Oliver is the Director of the Cerebra Centre for Neurodevelopmental Disorders at that internationally distinguished education and research Institute. His main research interests are behavioural, cognitive and emotional disorders in people with severe intellectual disability, genetic syndromes and autism spectrum disorders. He was the Keynote Speaker at the recent ASID (Australian Society for Intellectual Disability) Conference in Melbourne.

When an Australian parent asked Professor Oliver his view on advocacy for people with intellectual disability in Australia; Professor Oliver's comment which follows is unambiguous and reinforces the tenor of our submission:

"The advocacy movement is dominated by people with mild disability and I am not sure it reflects the needs of everyone through the range of disability". Professor Chris Oliver

There cannot be a standardised way of thinking about disability because some people are far more disadvantaged and disabled by their disability than others. This impacts upon the support requirements needed which will be highly variable. It impacts on the choices people make which are highly variable. It impacts on the individuals capacity to live a meaningful life in the community without the right resources and support. It impacts on upon decision making, ability to communicate and individual legal agency.

It is vital that those without a voice are provided with a national voice through the agency of those who know them best - the family.

Disability Family Advocacy is not simply 'another stream' that needs funding. It is the missing link in disability advocacy, particularly in systemic advocacy where decisions are made by government

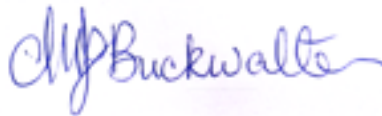
and its agencies based on flawed reasoning. More recently, the new 'go to' word for those who will brook no dissent nor accept valid criticism are cries of 'ableism', designed to shut down any conversation that does not suit their personal, social and/or political agenda.

While ever Disability Family Advocacy remains unfunded, NDAP is not and cannot be recognised as a National Disability Advocacy Program. It is a club that discriminates by disability type and capacity; all tied up neatly and securely as unacknowledged but quite deliberate disability discrimination, social pretence, social snobbery and social prejudice.

With regards



Marylou Carter



Maree Buckwalter



Nell Brown