

Thank you for the opportunity to put my view forward with regard to what in my view is the broken National Disability Advocacy Program.

There is no area of public social policy where all people are viewed as having the same life needs, wants and desires as the majority cohort and as having the same abilities to make complex decisions, able to give voice and personal representation to those choices, except in one area of social policy and that is in the area of disability policy.

Can all citizens exercise individual autonomy, no matter how severely intellectually disabled they are? If they can why do we have the term 'person responsible' or Guardianship Laws or in case of incapacity, Powers of Attorney?

How have we come to this place in time where disability has become a homogenised concept and family excluded from the national conversation, meaning that along with family members, people with moderate, severe or profound intellectual disability and other complex needs are also by default excluded?

My submission is a global assessment of the state of play of the Australian Advocacy Movement and the failure of advocacy to work with and acknowledge the lived experience of the family within the disability landscape. The result of this has been the discrimination of the rights of people with moderate/severe/profound intellectual disability with other complex needs, to have their unique needs represented by those who understand the individuals needs, who understand how to support their decision making in areas where they can have greater autonomy. The NDIS Act allows the NDIA to recognise a participant as having an agent/nominee. It recognises the role that family, carers and other people important to the person have in assisting them to make decisions about services and supports, but also on a participant's behalf.

The family are the champions of the people they support. They look to their interests now as they ever have done. For many of us, advocacy has been a learning curve, adding much value but also it fails many people and can cause friction through the tunnel vision of simply one view regurgitated nationally that will brook no challenge.

I have included as a major part of my submission a cut and paste of an explanation of the history of the NDIS prepared by the then legal counsel at FACS NSW, written in 2013. It is the background to the National Disability Insurance Scheme. It shows that if it wasn't for the advocacy of family carers, the NDIS would likely not exist. **Blue** is FACS research, **black** are my comments where I add further information based on my own knowledge and experience of these times.

Background to National Disability Insurance Scheme

Dan Taylor's feature in the Sydney Morning Herald of 1 July 2013 refers to the origin of the National Disability Insurance Scheme in Bruce Bonyhady's 'light bulb moment' in 2006.

"2006 was the year following the National Carers Coalition (2005) delivery of their paper on population based benchmarks for Disability Services and the Commonwealth taking responsibility

for all people with disability to the Australian Parliament. It was also the year following the actuarial study by John Walsh from PriceWaterhouse Coopers (PwC) for a proposal of what was to become the NSW Lifetime Care & Support Scheme for NSW accident victims”.

While people and their ideas were vital in turning aspirations into action it is arguably realistic to see the NDIS as being made possible by a number of parallel ideas and developments that came together in the mid 2000s. These included:

- The evolution of compensation for accident schemes,
- growing protests from unpaid carers of people with disabilities,
- the emergence of the disability rights movement,
- new communication technologies that gave people with disabilities a stronger voice, and.
- a new approach to public sector management and service delivery

Accident schemes

During the 20th Century traditional legal remedies were seen to be inadequate to compensate people for accidents caused by motor vehicles and industrial accidents. The response was state intervention in the form of motor accident and workers compensation schemes based on a compulsory insurance model. In Australia, state administered schemes were seen to be vulnerable to cost blow-outs and inequities for those injured in ways not covered by the schemes.

In 1967, a NZ Royal Commission chaired by Sir Owen Woodhouse, recommended a national no-fault accident scheme for all injuries regardless of the circumstances under which they arose. While the Accident Compensation Scheme was adopted in New Zealand, a 1974 report by Woodhouse commissioned by the Whitlam Government resulted in a bill which would have extended benefits to all people with permanent incapacity. It was considered by the Senate Standing Committee on Constitutional and Legal Affairs which recommended that the Bill be withdrawn. A further bill limited to accident compensation was tabled in 1975 but lapsed with the dismissal.

State governments continued to administer separate motor accident and workers compensation insurance schemes later followed by criminal injury compensation. Compensation for accidents caused in the home or in public places was dependent on tort legal claims where there was a relevant insurer. People who were born with a disability or acquired it otherwise than through an accident were left to the health system to support.

In 2005 John Walsh an actuary with Price Waterhouse developed proposals for long term care for people involved in catastrophic motor vehicle accidents which were implemented under the Motor Accidents (Lifetime Care and Support) Act 2006 NSW. Walsh's proposals for costing and structuring long term disability support, were shared with those pursuing reform of disability services more generally and popularised acceptance of an insurance based model for people with disability. (Bonyhady 2010).

Disability rights

The story of disability rights over the past 50 years can be seen as a move to replace a deficit, handicap or medical model of disability with a social model that positively values the capacity of

people with disability and shifts the responsibility to the broader society to remove barriers to their full enjoyment of rights and opportunities.

Conventional accounts of the emergence of disability rights have tended to emphasise institutional responses and ignore or downplay the role of grass-roots activists. Tom Shakespeare has argued that the basic idea for the social model was first developed in the UK in the 1970s by disability activists in the Union of the Physically Impaired Against Segregation in opposition to the way services were currently being delivered, and further developed in the 1980s by sympathetic academics before being accepted by the mainstream. His article goes on to explore some of the tensions arising from the successful acceptance of the model (Shakespeare 2002).

On the international level, disability began to be framed from a human rights perspective starting in the late 1960s. In 1971 UN the General Assembly adopted a resolution entitled "Declaration on the Rights of Mentally Retarded Persons". In 1975 the UN adopted the "Declaration on the Rights of Disabled Persons". The Declaration asserts that persons with disabilities have the same civil and political rights as other human beings and that they are entitled to measures designed to enable them to become as self-reliant as possible. In 1982 the UN adopted the World Plan of Action Concerning Disabled Persons. Further work by the UN Committee on Economic, Social and Cultural Rights explored the implications of a rights based approach. With the UN's adoption of the Convention on the Rights of Persons with Disabilities in 2006 and Australia's accession to the Convention in 2008, Governments were challenged to provide supports in a way that maximised the autonomy and participation of all people with disability. The Convention also operated with a broad social definition of disability that challenged the existing selective provision of supports by Government.

Australia's initial response to international rights agreements was in the area of anti-discrimination law, with a separate Commonwealth Disability Discrimination Act enacted in 1982. The NSW Anti-Discrimination Act 1977 did not initially cover disability discrimination. Discrimination on the ground of physical impairment was added in 1981 and on the grounds of intellectual impairment in 1982. An amendment in 1994 recast the definition of disability to include mental illness. The existing disability discrimination provisions have been criticised on the basis that they still reflect a medical or deficit model of disability, but arguably this has been overcome to some degree through disability case law that recognises the Convention and by the standard making powers of the Minister under the Commonwealth Act that have a greater focus on removing barriers.

Family Carers movement

The progressive closure of large institutions providing accommodation for people with profound physical and intellectual disabilities and mental illness following on from the 1983 Richmond Report, can be seen as a positive step for disability rights. However it placed a greater burden on families left to care for children and other relatives as very little was provided to replace these antiquated models.

In March 2005 ABC TV broadcast a Four Corners documentary, The Hidden Army that made a powerful case for recognising the burden placed on unpaid family and volunteer carers for people with disabilities and older people. Many of us will personally recall the powerful case for action provided by the personal stories covered by the program.

"This program was a partnership between the ABC and what was to become the National Carers Coalition. This program grew from the release to Four Corners of National Family Carers Interim Report by family carers.

The National Carers Coalition was formed because in Australia lifelong primary carers had no voice that would pursue a rights based framework for family carers and the people they supported - often the most marginalised of the disability and carer cohorts."

On 13 September 2005, in response to the interest generated by Four Corners the National Carers Coalition organised a National Day of Action: walk a mile in my shoes and followed it with a November 2005 submission to the Council of Australian Governments.

The submission highlighted unequal support for people with disability under existing Commonwealth /State arrangements, urged the Federal Government to assume responsibility for all Australians with disabilities, regardless of their age or disability, and demanded:

- *The abolition of 'age discrimination' in supported accommodation choices and access for people with disabilities.*
- *A fair deal in support services to all families providing an unpaid care service to the national economic good.*
- *The immediate provision of 'age appropriate' high care facilities to eliminate the practice of placing young adults into aged care facilities.*
- *an end to Age Discrimination in the delivery of carer support options for those families caring for people with dependent disabilities aged less than 65 years*
- *An end to the exploitation of unpaid family caregivers as free supported accommodation providers.*
- *Increased levels of respite and in-home support services to be offered to all full-time primary Carers regardless of the age of the care recipient, including in-home and facility-based respite choices equal to that of aged care services.*

"The paper was based on population benchmarks for disability services, with three tiers, low, medium and high support packages. It was, in 2005 estimated to cost \$10 billion annually.

These demands were an impetus for additional funding by both State and Commonwealth governments but did little to fix a broken system that was driven by crisis rather than need. Families were the only voice at this time looking at the funding models while funded advocacy was looking at service/social models".

Both activist streams have benefitted from the growth of the Internet which has provided new ways for people to communicate their demands.

Rights activists have often been loud in their criticism of government and service providers for paying lip service to the social model while not applying it in practice. For a time this was seen to sour relations between organisations representing people with disability and those representing service providers and carers. However the emerging proposals for a NDIS provided a platform around which all groups were prepared to unite.

Convergence

Bruce Bonyhady (now the chair of NDIS) made a submission to the incoming Labor Government's April 2008 2020 Summit. Bruce's paper was delivered to the Summit.

"This was done via Katrina Clark, a parent carer who was a founding member of the Carers Alliance and inaugural member of the National Carers Coalition. Katrina had been invited to attend the Summit which was by invitation only, while Bruce had not. So Katrina, in her wonderful, determined way, presented Bruce's paper to the 2020 Summit which saw much interest generated for the idea. The rest is history".

This led to the Summit's report endorsing the creation of a NDIS as one of its 'big ideas'.

From this and all of these past actions, the National Disability Insurance Scheme was developed.

Administrators, carers and advocates built a sense of common action around proposed reforms to disability services. This resulted in the formation in 2009 of the National Disability and Carer Alliance drawing together the Australian Federation of Disability Organisations, Carers Australia and National Disability Services (Manne 2011).

'The only group that remained marginalised, without a funded voice, or any voice at all in this newly formed 'Alliance' were the family carers of people with moderate/severe/profound intellectual and complex needs, whose member not only put Bruce's paper forward, but whose advocacy first put together an idea for one level of government to fund disability services using population benchmarks, which is what we have today with the NDIS - albeit far more complex scheme with the merging of social model of person centred supports with the funding model based on actuarial modelling".

On 17 February 2010 the Assistant Treasurer, Nick Sherry referred a proposal for a national disability long-term care and support scheme to the Productivity Commission. On 31 July 2011, the Productivity Commission

Solicitor Law and Justice
Department of Family and Community Services | Ageing, Disability and Home Care

Today

These family carers are those expected provide all-of-life care and are the voice for those who are truly marginalised, those without a voice, given short shrift by funded advocacy.

So while ever this remains unequal, while the family voice is not heard, there will continue to be a disparity and unease that those voices are locked out of the very system that grew from their unpaid, unfunded advocacy. It was the family carers whose determination that justice for all must be front and centre of government policy that has led us to where we are.

We warmly applaud the NDIA for forming the Intellectual Disability Reference Group to inform the NDIA comprised of people with borderline/mild intellectual disability, but there must be disclaimer that this reference group cannot possibly comprehend the issues of people with far more complex and challenging needs. They can only really speak (and they do articulate exceptionally well) for people with similar needs to their own and the experiences that they have lived.

The reference as being 'the' voice that advises the NDIA on issues of intellectual disability must be seen as very limited and should not be countenanced as a broad based view of intellectual disability and the needs of more complex cohorts. There is a world of difference between the levels of capacity of people within the group labelled 'intellectual disability' - just as there is a world of difference between the needs of a person with mild physical disability and someone who lives as a ventilated quadriplegic.

Do people with mild **physical** disability inform the scheme on the needs of individuals with high level, complex physical care needs? They might be able to do intellectualise it, but not from the lived experience and true understanding of the complexity of needs and the day-to-day struggles.

People with an intellectual disability will be a large cohort of NDIS users and yet there had been no formal engagement with the very families who have the lived experience of supporting and planning for people with moderate/severe/profound intellectual disability and other complex needs to have a good life. This is the major group for whom funding packages will be a premium, not a group who are unsure if their capacity is such that they will get minimal, if any funded support - as discussed in the video link from the Intellectual Disability Reference Group.

One would think that far more recognition and attention should be paid to this group with intense need by informing the scheme and understanding the complexity of needs of this group through the agency of their family.

Printed with permission of a family member who attended the Zero Tolerance seminar;

"I went to the Zero Tolerance seminar in Melbourne recently where NDA and VALID presented. VALID gave a good presentation on how people with disabilities could "speak out" if they experienced abuse. When I asked about people such as my son who is non-verbal and profoundly intellectually disabled I was told NDS would cover it. Of course they didn't. And then the classic .. NDS guy, said that we should stop using the word "vulnerable" with people with disabilities. People with disabilities are not vulnerable because of their disability - try telling Kurt Fearnley he is vulnerable. Well at this point, I am gobsmacked. This is the agency responsible for safeguarding people like my son and your loved ones. I am so angry it's hard to type".

"In discussions afterwards the NDS guy said he didn't think a Royal Commission was needed - it would be better to give that money to orgs like VALID etc. to educate people with disabilities about how to protect themselves against abuse. To say I was flabbergasted is a complete understatement'.

So do funded advocates represent as a unified group all people with disability or just the larger cohort with borderline/mild intellectual disability, sensory disability or physical disability because the understanding of this being a reality leaves many families gasping in despair.

We have no issues that advocacy mostly is only really representative of a particular group, but it is time to recognise this reality because this reality is the experience of families who have sought support and found that support does not exist if you do not fit into advocates defined parameters or belief systems.

The people for whom we speak could no more go to an 'education session' for skill training on self protection and take away valid skill building on this subject than fly to the moon, although we recognise for the target group - milder forms of intellectual disability - that much of their work and programs are excellent, but to attempt to maintain that these programs or training systems are valid across the entire spectrum of intellectual is nonsensical.

Furthermore National Disability Services is the peak for the service provider, not a voice for the voiceless and for funded groups whose scope is intellectual disability to shift the request for a response to the needs of this group over to the service provision peak shows the disparity of reality versus truth of those funded as a voice for the entire cohort.

This 'anecdotal' evidence is the deeply held understanding of most families who have tried to gain advocacy which is 'on paper' funded to be their funded body and to respond to the more complex and more difficult, less simplified needs of their family member.

So where do families go when they need either the human rights or care needs of their family members with moderate/severe/profound intellectual disability with other complex needs protected or for that matter to even become part of the national conversation?

Sometimes our families and the people for whom they care actually need protection from the funded advocates on a mission of normalisation that will end up excluding them because of ideology. These ideals while wonderful, are, like many ideals, often not practicable because of the intense support requirements and massive amounts of input which gets harder as families age or for those who may actually need to work themselves, in order to survive. Much of the normalisation activities on building a totally inclusive life (if the person you support had high support needs), is dependent on intense additional family day-to-day and one-on-one support and cannot be built with just funded staff input because of the intense support needs of our group.

I think most of us would agree that all people who advocate for people with disability have a *common* ideology in that we all want to break down barriers. We all want the best possible life that can be achieved for all people, where they take their place in society and are assisted to overcome barriers to the extent that they are able.

It is how we achieve this that might be different. This writer would not say that her daughter has the same ability to self advocate as others with different disabilities - but this is 'assumed' by advocacy.

It is assumed that her needs, choices and wants are the same as people with far less complex needs. The writers experience is that her daughters choices are far more simplified, need to be framed carefully from a limited palette so as not to confuse. Yes, supported decision making can

work and should be used whenever possible but not for overly complex decisions nor those decisions that focus on wellbeing because it is a concept that she for one, does not understand.

Disability advocacy has many voices providing a lot of positive things but where it falls short I believe, is the understanding the complexity of issues for people who actually have moderate/severe/profound intellectual disability and other complex needs and the over simplification of tacking this on to their advocacy for very different needs. So what I think is needed is a national voice for this group as separate from people with the functional capacity to need far less intrusive supports and who can, ultimately, speak for themselves. We need another voice, a voice targeting the needs of this unacknowledged and highly vulnerable (yes vulnerable), marginalised group.

It is clear that a more effective, consistent and reliable model of needs based advocacy is vital, sitting alongside the current advocacy streams. It is also clear that Systemic Disability Family Advocacy needs to be funded on an equal basis to Systemic Advocacy for those who already have two voices, both their own, as well as the voice of systemic advocacy.

Anything less is a continued violation of the rights of those with moderate/severe/profound intellectual disability and other complex needs, who remain the forgotten people within the current mix that informs both government and its agencies.

In closing, we must ask, exactly what is the desired outcome of advocacy?

Advocacy in all its forms seeks to ensure that people, particularly those who are most vulnerable in society, are able to:[

- Have their voice heard on issues that are important to them.
- Defend and safeguard their rights.
- Have their views and wishes genuinely considered when decisions are being made about their lives.

Thank you for accepting my submission.

With regards

A handwritten signature in black ink, appearing to read "Bill Brown". The signature is fluid and cursive, with a long horizontal stroke at the end.