

**Submission**

**Review of the National Disability Advocacy Framework**

**July 2015**

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**Who we are**

NSW Council for Intellectual Disability (NSWCID) has been a peak body representing the rights and interest of people with intellectual disability for nearly 60 years.

NSW CID is funded by the NSW Government as a systemic advocacy and information service.

People with intellectual disability lead NSW CID.

Since 2004, the majority of the board must be people with intellectual disability and the chairperson has been a person with intellectual disability.

Other board members include family members and advocates.

NSW CID has a strong track record in creating positive change in the lives of people with intellectual disability.



**About the NSW CID Submission**

Overall our impression is that the National Disability Advocacy Framework is contemporary, needing only minor revisions. Our submission will address both the key questions and other significant issues that are of relevance to the provision of advocacy with and for people with intellectual disability.

The submission includes quotes and comments about advocacy from people with intellectual disability. This highlights the key safeguarding role that advocacy plays in people’s lives. This especially important for people with intellectual disability who are over 60% of National Disability Insurance Scheme participants and are very vulnerable to abuse and neglect.

Also attached is a NSW CID Credo, highlighting where we believe we are demonstrating good practice in key areas:

* People with intellectual disability as leaders
* Supporting people to develop their skills in choice and control
* Systemic advocacy

Good practice in systemic advocacy also includes campaigns:

* Based on key priorities for people with intellectual disability not just on current agendas of governments
* Using strategies that work:
* Being evidence based – both the experience of people with intellectual disability and their families and research evidence
* Working with allies and building coalitions including other advocacy groups, researchers, professional groups, service providers and eminent individuals (both within the disability field and across the broader community)
* Setting a goal but also focusing on achievable incremental progress
* Being assertive, constructive, practical and persistent
* Building positive relationships with, and taking account of the interests of, decision makers

NSW CID would welcome any opportunity for further discussion of our submission.

Aine Healy Jim Simpson  
Executive Director Advocacy Senior Advocate

**What do people with intellectual disability say about advocacy?**

Through engaging with our Members and people with intellectual disability in the wider community much has been said about advocacy:

* Even if people have self advocacy skills, it still can be hard to learn a new process.
* Many people don’t know about advocacy services. Or they can’t get an advocate when they need one.
* Some people do not have family or friends to advocate for them.
* Sometimes family are not the best advocates for them.
* A paid advocate is sometimes needed.
* Speaking up makes me feel worried about the outcome.
* There should be no repercussions if people make a complaint.
* A good system for helping us speak up and make complaints will also help us to keep ourselves safe.

People often speak of the role of advocates and how this had been helpful when they had experienced difficult circumstances.

* Always there for you, get you out of trouble.
* When you’re up the creek!
* Advocates can weigh it up for you.
* Easy to make a complaint because (name of local advocacy organisation) can help me.
* Having people who can support me to sort out problems that are a bit too complicated for me or that I am having trouble trying to fix – like with Telstra, or Department of Housing.
* (Name of local advocacy service) - They do whatever you need to help you sort stuff out.
* They help me to say what I want to say. They also make sure that other people listen to me.

**Questions**

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

We are concerned that the definition of “disability advocacy” in the discussion paper does not clearly include systemic advocacy.

The framework needs to continue to explicitly state the role of systemic advocacy.

“In an era in which systemic issues often lie at the root of critical challenges, in which diverse perspectives are required for sustainable solutions, and in which cause-and-effect relationships are not immediately apparent, the capacity to raise penetrating questions that challenge current operating assumptions will be key to creating positive futures”. (Vogt et al 2003:2) This is a key function that systemic advocacy offers providing an independent or outside voice to analyse, critique, and provide alternatives to current practices, policies and systems.

Throughout 2015 NSW CID has conducted significant work on the quality and safeguarding of the National Disability Insurance Scheme, including facilitation of a national roundtable in March 2015 attended by people with intellectual disability and a wide range of other leaders in the disability field.

One of the central themes that emerged from this is that advocacy is an essential part of any consideration of quality and safeguarding, both at an individual and systemic level.

There was strong support for the need for community advocacy bodies, from participants including the NSW and Commonwealth Ombudsmen, the Victorian Disability Complaints Commission and Public Advocate and the President of the Australian Society on Intellectual Disability.

Capacity for choice and control will not just happen for people with intellectual disability. Capacity building is essential. Advocacy groups that focus on developing self advocacy skills in individuals and in group work play key roles in building natural supports. This includes in developing people’s understanding of their rights and how to make complaints.

Independent, community advocacy groups have essential roles to play in quality and safeguarding. These roles complement those of other quality and safeguarding mechanisms.

Central to the value of advocacy is that it is independent and community-based. When people with disability and their families have concerns about providers of disability support, mainstream services and statutory bodies, it is advocacy bodies that they tend to go to first and see as a trusted ally.

NSW CID has recommended that the NDIS Quality & Safeguarding strategy needs to include particular focuses on people living isolated lives on society’s fringe, and on the role of advocacy in developing people’s abilities in self-protection, choice and control.

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

It is welcomed that the NDIS will fund decision supports, safeguards supports and capacity building for participants.  Advocacy organisations are the natural provider of at least the first two of these.  In addition they need to be provided free of any conflict of interest.

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

NSW CID suggests that an additional outcome is needed, which relates to a focus on changes occurring in legislation and service systems.

With regards, to the outcome of people with disability being actively involved in all aspects of the development, delivery and evaluation of disability and broader government policies, programs and services that impact them, NSW CID has much experience in facilitating this. Sufficient resourcing and expertise is needed to achieve this, including provisions for accessible communication, participation support and training for people. NSW CID also works with other organisations and government to improve their accessibility, a process which can take much time. Provisions for this need to be made, otherwise it simply does not become possible.

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

The following output should be amended to include professional bodies and researchers. It is critical that collaboration with these groups occur.

*Disability advocacy that is planned and delivered in a coordinated manner and supports communication between disability advocacy support, disability services, mainstream services and governments.*

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

The National Disability Strategy, of which the NDIS is just one part, has the potential to rectify the numerous systemic and societal barriers that prevent the inclusion of people with disability in Australia. Systemic advocacy has a key role to play in this and is already experienced in working across numerous jurisdictions and complex environments. However, it is difficult to have impact on this with extremely limited resourcing or appropriate avenues to provide input. The result of this is policy and practice that is not enabling. If the NDS is to lead change across Australia, systemic advocacy needs to be supported to have a strong role in this.

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

**Resourcing**

The disparity of advocacy organisations around the country makes it difficult for people to access advocacy when they need it or for systemic advocates to be able to comprehensively address the numerous issues that present as barriers to the full inclusion of people with intellectual disability in community. It is currently inequitable. Additionally not all advocacy organisations or representatives groups have accessible participatory structures for people with intellectual disability.

Bigby, in recent research concludes that “in Australia, only a handful of independent self advocacy groups exist” (2015:2). For people with intellectual disability these groups can provide a valuable source of peer support, capacity building and access to information. Many people have expressed they would appreciate the opportunity to take part in such groups.

NSW CID has certainly experienced a demand for our expertise in recent years and input to an increasing range of state and federal policy developments. NSW CID has been unable to respond to all of these – in NSW there is currently very limited systemic advocacy occurring on many issues such as education, employment and transport on behalf of people with intellectual disability.

Significant increases in the resourcing of advocacy organisations will need to occur if the outcomes of the NDAF, NDIS and the National Disability Strategy are to be realised. An investment in advocacy would allow for a more proactive than reactive approach to advocacy which potentially has the benefit of saving both personal stresses and community resources.

**People not accessing the NDIS**

There are many people who will not have access to the NDIS, nor be able to seek access to it without outreach and engagement. For people who are unable to access support it is imperative that there is still advocacy available as they attempt to navigate multiple service systems such as health, mental health, justice, housing and social security.

There is a continued role for systemic advocates to provide training, education and support to mainstream organisations to ensure that their practices are inclusive of people with intellectual disability. An example of this in NSW has been where NSW CID has worked with drug and alcohol agencies on best practice guidelines for working with people with intellectual disability.

**Measuring Impact**

“It is rare that key advocacy messages are immediately adopted and internalised. More common is that these messages are counter to established views and thus act as a kind of counter culture view until they are in time given greater credibility”. Kendrick (2008)

Effective systemic advocacy takes a persistent and longitudinal approach to achieve success. Advocates work across multiple systems and in a very political environment. Changing societal attitudes and norms, many of which are deeply embedded in relation to people with intellectual disability, is a challenging process. When change is not evident immediately it could be easy to view systemic advocacy as unsuccessful, rather than be aware of the context in which it is operating.

Seibert suggests that in Australia we need a stronger focus on emphasising advocacy’s positive impact. (2015). Advocacy often works with divisive and challenging issues that are not easy to solve – there are often not straightforward solutions. Additionally, the mobilisaition of people with intellectual disability is difficult due to people’s historical access to education, employment and resources. Communication and social isolation issues are also a factor here.

NSW CID has been working on health issues for over 20 years, with significant gains made. These are easy to review in retrospect, and assist with evaluation of our practices, but point to needing to have an adaptive, multi -faceted approach to advocacy in order to be successful. As such we recommend that the NDAF needs to give consideration to what reasonable outcomes are within a relative timeframe.

**References**

Bigby, (2015) *Self Advocacy and Inclusion: A summary of the study “what can be learned from speaking up over the years?*

Kendrick, M (2008) *Advocacy as Social Leadership,* The International Journal of Leadership in Public Services 66 Volume 4 Issue 3 October 2008

Seibert, K, 2015, *Wanted: Stronger Emphasis on the Positive Impact of Advocacy*, Pro Bono News

Eric E. Vogt, Juanita Brown, and David Isaacs, 2003, *The Art of Powerful Questions, Catalyzing Insight, Innovation, and Action*

**NSW CID publications available at** [**www.nswcid.org.au**](http://www.nswcid.org.au)

NDIS Quality and Safeguards Position statement

Participants or Just Policed – the NDIS and people in the criminal justice system