

Civil Society NDIS Statement to the Council of Australian Governments (COAG) and the National Disability Insurance Agency (NDIA)

CALL FOR STRONGER ENGAGEMENT WITH PEOPLE WITH DISABILITY IN THE NATIONAL DISABILITY INSURANCE SCHEME (NDIS)¹

We are a diverse partnership of representative organisations of people with disability, disability advocacy organisations and disability peak bodies that have come together to call for stronger engagement with people with disability and our organisations in all aspects of the implementation of the National Disability Insurance Scheme (NDIS).

Collectively, our organisations are made up of, represent, work with and / or support hundreds of thousands of people with disability, including current and future NDIS participants. We have substantial, direct knowledge and understanding of the positive and negative impacts experienced by people with disability in relation to the NDIS, as well as expertise in identifying solutions and solving problems for implementation challenges, complexities and emerging NDIS issues.

There is now widespread and growing concern across Australia about an array of NDIS issues that demonstrates that we have reached a critical and risky moment where the NDIS appears to be shifting from its vision, intent and objectives. This concern is increasingly being expressed publicly by people with disability, stakeholder organisations, the media and other commentators.

In many cases, limitations and failures in NDIS design and implementation, such as 'First Plan' processes, reimbursement for self-managing participants, inaccessible administrative processes, barriers to communicating with NDIS decision makers and the failures of the NDIS online portal have resulted in significant additional costs to manage and address. These situations and the associated significant costs to fix design and implementation problems may well have been avoided if people with disability and our organisations were integral to the NDIS from the outset. Our involvement is underpinned by the vision, intent and objectives of the NDIS, but importantly, our involvement also makes good economic sense.

The NDIS is a significant reform measure for all Australians, and it is to be expected that there will be significant challenges in governance and implementation, particularly as the NDIS transitions to full roll out across Australia. However, these challenges must not be allowed to weaken or compromise the vision, intent and objectives of the NDIS as outlined in the *NDIS Act 2013*², and which broadly aim to support independence, social and economic participation, choice and control in the pursuit of life goals and the realisation of human rights. It is not the vision, intent and objectives of the NDIS that is problematic or in need of modification, but the processes, methods and means of pursuing NDIS implementation.

¹ This is the full version of the Civil Society NDIS Statement.

² National Disability Insurance Scheme Act 2013 Part 2: Objects and Principles.

Although we actively participate in NDIS engagement mechanisms with the National Disability Insurance Agency (NDIA) and the Government, we are concerned that these mechanisms operate in an unconnected and disparate manner, are not genuinely inclusive of people with disability, are often disconnected from the ‘grassroots’ reality of NDIS participants, are often unresponsive to the issues we raise, and at the local level, often have no authority or practical scope to act on concerns. This means that our expertise is not being utilised effectively or systemically to identify, address and respond to the significant challenges and concerns that are increasingly affecting NDIS implementation and that have significant, adverse cost implications.

Our organisations are 100% committed to the success of the NDIS. We continue to greatly appreciate bipartisan support and the strong multi-jurisdictional commitment demonstrated by the Council of Australian Governments (COAG) to a successful NDIS. We also greatly appreciate that the Board and staff of the National Disability Insurance Agency (NDIA) are committed and working hard to progress the full roll out of the NDIS.

In calling for stronger engagement with people with disability and our organisations, we outline critical actions to ensure a successful NDIS, one that identifies challenges early, that works with available expertise to design, review and refine issues appropriately and that ensures continuous quality improvement and cost effectiveness by ensuring that NDIS participants are integral to delivery, design and ongoing evaluation.

Co-design is a founding and integral concept of the NDIS, and the following measures are outlined within this context – people with disability need to be integral to every stage of the design, implementation and evaluation of the NDIS.

NATIONAL DISABILITY INSURANCE AGENCY

We appreciate that staff at all levels and the board of the National Disability Insurance Agency (NDIA) engage with people with disability in various ways, including through forums, working and reference groups, dedicated CEO Forums and individual stakeholder meetings. We also welcome evaluation and review of the NDIS through the NDIS Citizen’s Jury which directly engaged with people with disability and the Australian community.

We acknowledge the significant challenges faced by the NDIA in implementing the full roll out of the NDIS, including ensuring that people with disability are integral and central to this. However, we are increasingly concerned that the issues and concerns of people with disability are not being addressed, responded to or integral to the development of NDIS policies, strategies and practice despite engagement mechanisms.

3 NDIS Citizens’ Jury Scorecard, <http://www.pwd.org.au/issues/ndis-citizens-jury-scorecard-project.html>

The NDIA cannot become another Commonwealth agency that is part of 'big' bureaucracy and removed from the people it is meant to serve and engage. It has to listen to, and be available to people on the ground, be responsive to participant concerns and feedback and have good local connections to people, including in rural and remote areas. To ensure that this occurs, there are a number of measures that could be integrated into best practice service systems and quality assurance and improvement processes, including:

- ▶ There is a critical need for consistent and discrete advisory structures at a local or regional level that ensure that there is a good preventative pathway for issues and concerns about the NDIS rollout to be brought to the attention of the agency.
- ▶ Over time and progressively, NDIA employees, particularly NDIA planners should participate in structured and interactive 'values creation' workshops, which are aimed at cultural change. These workshops would allow employees to hear participant feedback and experiences on interaction with the NDIA firsthand, and require employees to identify actions to enhance interaction and resolve issues.
- ▶ Mechanisms for communication with NDIA staff need to be redesigned to ensure that participants and their families are able to communicate directly with knowledge holders and decision makers without undue delay or stress associated with overly complex email systems, long phone delays, and other communication barriers.
- ▶ There is an urgent need for the original planning process, conducted in person with planners to be reinstated so that it is in line with the public information provided to participants regarding planning. The 'First Plan' process that is currently being employed is contrary to the objects and intent of the NDIS and creating significant alarm and concern for participants.
- ▶ Senior NDIA staff should participate in the regular 'grassroots' engagement processes with NDIS participants, such as those described above for the IAC. They should be available during these engagement processes to take questions from NDIS participants and address concerns immediately or through a follow-up process.
- ▶ There should be an online feedback location that acts as an issues register with a guaranteed and transparent response time and process. Currently there is nowhere for people to raise issues and concerns and discuss or ask questions. An identified NDIA senior 'troubleshooter' role could use this as an 'early warning' system to ensure that issues are promptly addressed as well as assist in channelling and diverting the many damaging, problematic and inaccurate views that are currently being expressed on external online discussion forums.

While many of these measures need to be addressed directly by senior management of the NDIA, it is critical that COAG support the NDIA towards greater quality improvement and best practice service delivery.

THE BOARD OF THE NDIA

We strongly support the continuation of an independent Board for the NDIA under legislation. We recognise that the NDIA board should be composed of individuals with significant expertise in such matters as financial management, governance and insurance schemes in order to effectively govern the scale of the NDIS. The Board needs to be robust for the task ahead but we argue that Board skillsets go well beyond industry and financial management.

NDIS governance must reflect the unique blended nature of the agency which is not purely an exercise in industry and financial management focusing on profit and shareholders. Many of the issues important to the success of the NDIS cannot be understood adequately simply from an economic, market or financial perspective. NDIA board members are also the custodians of the vision, objects and principles of the NDIS and require specific technical and disability knowledge, skills, expertise and lived experience. In addition to securing the long-term viability of the NDIS, it is the responsibility of the Board to ensure that the NDIS remains person centered in approach and delivery, reflects the diversity of people with disability, gives effect to Australia's obligations under the Convention on the Rights of Persons with Disabilities (CRPD) and achieves its social and economic inclusion goals.

The Board requires both disability and financial expertise and this requires a strong focus on identifying individuals with disability and lived experience who hold the expertise required for such a robust Board. It must not be assumed that people with disability do not have the significant disability, governance, financial and industry expertise required, and our organisations are well placed to assist in identifying highly experienced and qualified people with disability for the NDIA Board. The integrity of the NDIS is at stake if the Board proceeds to favor corporate insight over disability acumen and excludes the skills and expertise of people with disability and lived experience.

Strong representation of people with disability on the NDIA Board is also critical to provide leadership which is unwavering in its commitment to achieving the maximum possible opportunity for all people with disability in Australia to thrive and realise their human rights.

A strong governance structure which is inclusive of people with disability will need ongoing and regular mechanisms to receive advice and be accountable to NDIS participants.

NDIS INDEPENDENT ADVISORY COUNCIL

Under the NIDS Act 2013, the Independent Advisory Council (IAC) provides the NDIA Board with independent advice that the Board must consider when performing its governance role.⁴

We acknowledge the important role of the IAC and the commitment of the IAC membership. However, given the NDIS has progressed beyond trial sites to transition to full implementation, we believe the role of the IAC would be more 'fit for purpose' if it had solid 'grassroots' linkages to people with disability, including NDIS participants and future participants.

⁴ National Disability Insurance Scheme Act 2013, section 145.

The NDIA Board needs ongoing regular advice and accountability to and from an IAC whose membership is also accountable and open to frank, fearless and genuine advice that comes directly from the ‘grassroots’. This could be achieved if the IAC had stronger links to advocacy organisations and representative organisations of people with disability, or Disabled Peoples Organisations (DPOs) where membership and governance involves NDIS current and future participants. The IAC could also move to be constituted by people nominated by a DPO from each State and Territory.

In addition, the IAC needs to have resourcing and capacity to conduct regular, open and planned discussions, either general or topic specific, with randomly selected NDIS participants to more thoroughly examine the participant experiences, and to ensure a solid evidence base for its advice to the Board.

NATIONAL DISABILITY AND CARERS ADVISORY COUNCIL

We welcome the establishment of the National Disability and Carers Advisory Council (National Council) and the Disability Reform Council’s reaffirmation of its commitment to the National Disability Strategy 2010-2020 (NDS).⁵ The success of the NDIS is dependent on the accessibility and inclusiveness of mainstream services and supports, and implementation of the NDIS must be achieved in parallel with implementation of the NDS.

The key role of the National Council is to assist in driving implementation of the NDS, including advising on “the full roll-out of the National Disability Insurance Scheme, including the interfaces with mainstream services”.⁶ This means that many issues that are of concern to people with disability in relation to NDIS implementation will have relevance for both the National Council and the IAC. It makes sense, and it will be critical for the advice provided by the National Council to ensure that ongoing engagement mechanisms are established with the IAC, as well as strong engagement mechanisms with people with disability, including NDIS participants and representative and advocacy organisations.

In particular, we highlight our concerns regarding the transition of a number of disability support services and programs into the NDIS where there is no mainstream equivalent for people who are not NDIS eligible but who will continue to require those supports and programs. The ‘continuity of support’ guarantees do not adequately address this issue and is not applicable to all people with disability in this situation. Engagement with us on this issue by the National Council and the IAC is urgently needed to identify solutions to address this.

⁵ COAG Disability Reform Council, Communique, 2 September 2016, https://www.dss.gov.au/sites/default/files/documents/09_2016/drc_communique_2_september_2016.pdf

⁶ ‘National Disability and Carers Advisory Council announced’, Media Release, Hon. Jane Prentice MP, <http://www.janeprentice.com.au/Media/Media-Releases/ID/2459>

NATIONAL DISABILITY REFORM SUMMIT

As a means of rebalancing the publicly expressed concerns regarding the NDIS, and to refocus on ongoing COAG commitment and positive NDIS outcomes, the Disability Reform Council should consider holding a national summit on government efforts to progress disability reform.

Similar to the recent COAG National Summit on reducing violence against women and their children,⁷ a Disability Reform Summit would demonstrate ongoing COAG commitment to disability reform, enable review of progress and highlight best practice across NDS and NDIS implementation. The National Summit would bring together Premiers, Chief Ministers and Disability Ministers, the Australian Local Government Association, business representatives, experts with disability and representatives from disability organisations and advocacy organisations as well as members of the NDIA board, IAC and the National Council. It would be a public, high profile engagement mechanism to consider issues and make recommendations for future progress.

NATIONAL DISABILITY RESEARCH AGENDA

The disability reform agenda, underpinned by the NDS and the NDIS requires investment in a national research agenda that can build a solid evidence base for effective and efficient disability support and inclusive mainstream systems that achieves social and economic gains for people with disability and independence and community inclusion.

It is critical that a disability research agenda has a focus on leadership and agenda setting by people with disability and genuine co-production and innovative collaboration with researchers, including researchers with disability. This approach reflects similar developments in the United Kingdom with the establishment of the Disability Research on Independent Living and Learning (DRILL).⁸ The evidence base developed from such a co-designed and user-led approach would more successfully drive and achieve the disability reform agenda.

⁷ COAG 2016 National Summit, Connect. Act. Change., <https://coagvawsummit.pmc.gov.au/>

⁸ See <http://www.drilluk.org.uk/>

THIS CIVIL SOCIETY NDIS STATEMENT IS SUPPORTED BY:



ACT Disability, Aged and Carer Advocacy Service (ADACAS)



Blind Citizens Australia



ACT Mental Health Consumer Network



Barwon Disability Resource Council (BDRC)



Advocacy for Inclusion



Community Mental Health Australia



Advocacy Tasmania Inc



Deafness Forum of Australia



Developmental Disability WA



Disability Justice Advocacy Inc



Disability Advocacy Network Australia (DANA)



Disability Rights Advocacy Service (DRAS)



Disability Advocacy NSW



Disabled People's Organisations Australia

Disabled People's Organisations Australia (DPO Australia)



Disability Advocacy Victoria



Federation of Ethnic Communities' Councils of Australia (FECCA)



First Peoples Disability Network Australia



**Melbourne East Disability Advocacy
(MEDA)**



Imagine More



Mental Health Australia



Inclusion Australia



**Mental Health Community Coalition ACT
(MHCC ACT)**



Leadership Plus



National Ethnic Disability Alliance (NEDA)



National Mental Health Consumer and Carer Forum (NMHCCF)



Richmond Fellowship ACT Inc



People With Disabilities ACT (PWDACT)



Queensland Advocacy Incorporated (QAI)



People with Disability Australia (PWDA)



Rights Information and Advocacy Centre (RIAC)



Physical Disability Council of New South Wales (PDCN)



Schizophrenia Fellowship of NSW (SFNSW)



Spinal Cord Injuries Australia (SCIA)



Women With Disabilities Australia (WWDA)



**St Vincent de Paul Society Canberra
Goulburn**



**Multicultural Disability Advocacy
Association**



People with disabilities Western Australia (PWdWA)