

Discussion Paper

Calling for development of a

National Supported Decision Making Framework

Prepared on behalf of the Australian Supported Decision Making Network

April 2016

The Australian Supported Decision Making Network

This paper has been prepared by the Australian Supported Decision Making Network (the ASDMN). The ASDMN began during 2012 to facilitate the implementation of supported decision making in Australia. The ASDMN currently has more than 100 members including people with disability and their families as well as members drawn from a wide range of agencies including service delivery, advocacy, government, academics and community sectors working in disability, older persons and mental health across Australia. Government members contribute on the basis that their input is not taken to commit their government to a particular course of action. The ASDMN has become a focus of expertise in supported decision making because of members' association with trial projects, research, and implementation of changed legislation. The network has met regularly over the past 3 years to share information on the latest work in SDM, consider wider policy issues and collaborate on the effective introduction of SDM across Australia.

Development of this paper was undertaken by a small reference group of members, led by the ACT Disability, Aged and Carer Advocacy Service. The paper has been endorsed for release by ASDMN members.

In early 2015 the Network wrote to Premiers and the Prime Minister advising them of the intention to prepare this discussion paper. Responses from jurisdictions acknowledged the contribution that a National Framework could make to achieving outcomes for people whose decision making ability is questioned.

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National Supported Decision Making Framework

Discussion Paper

This discussion paper describes supported decision making, what it is, how it works and why it's important. It calls for the development of a National Framework for supported decision making which would establish Australian practice. A National Framework is required because SDM has implications for a broad range of policy areas across multiple levels of government that reach into people's private lives.

Supported decision making supports people to exercise their ability to make legal and day to day decisions. Ensuring people have the support they need to engage in decision making is central to Australia's obligations under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)¹. In addition much Australian policy now recognises that people with disability have the right to choice and control in their lives, including the NDIS, reforms of mental health legislation, reforms of guardianship law, the National Disability Strategy and consumer directed care for older Australians. Currently, while high level policy statements recognise the right to exercise will and preference, the support needed by those whose decision making ability is impaired to exercise those rights is largely missing. There are isolated examples of good practice.

Supported decision making has applicability across a wide population including people with disability, people who experience mental health issues and people who experience aging conditions such as dementia. While we all access support for some decisions (from family, friends or professionals), people who are perceived to not have capacity for decision making are commonly denied the additional support that they need and decisions are made by substitute decision makers instead.

The breadth of the impact of supported decision making indicates the need for a National Framework to align responses across multiple disciplines and jurisdictions. It would also ensure consistent application of, and access to SDM. The elements of the National Framework are identified below and include ensuring that clear responsibility for legislation, regulation, policy and practice is articulated. It is the responsibility of governments at all levels to collaborate with other stakeholders in developing and delivering a National Framework for supported decision making.

The term 'supported decision making' (SDM) refers to a very broad range of practices and concepts. What is understood by the term 'supported decision making' has been shaped across a range of sectors, including the law, health, human rights and community sectors, each with its own interests and motivations.

The United Nations Office of the High Commissioner for Human Rights (OHCHR)² describes SDM as "the process whereby a person with a disability is enabled to make and communicate decisions with respect to personal or legal matters."³ The United Nations Committee on the Rights of Persons with Disabilities has called for the replacement of guardianship systems with supported decision making

¹ According to the UNCRPD persons with disabilities include those who have "long term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."

² The United Nations Office of the High Commissioner for Human Rights is a part of the United Nation's secretariat which promotes and protects human rights. See: <http://www.ohchr.org/EN/Pages/WelcomePage.aspx> for more information.

³ United Nations Human Rights Council, 2009, para. 45.

responses and articulated features of a supported decision making regime which would be consistent with international human rights law.⁴

The Australian Law Reform Commission Report into Equality, Capacity and Disability in Commonwealth Laws⁵ proposes National Decision Making Principles which provide a basis for change. A National Framework for SDM would engage policy makers, governments and other stakeholders in articulating a common vision for implementation of the National Decision Making Principles.

A National Framework would also contribute to delivery of outcomes under the National Disability Strategy⁶ which recognises as areas for future action: the need to review restrictive legislation and practices from a human rights perspective (2.4) and ensure supported decision making safeguards for those people who need them are in place, including accountability of guardianship and substitute decision makers (2.12).

What is Supported Decision Making?

In Australia SDM is emerging across the community in a number of forms. Some Australian SDM projects have identified a range of shared steps involved in SDM, including:

- Building capability to recognise the role of decision making, the right to equality and self-determination
- Learning about decision making
- Recognising and expressing a decision
- Identifying and establishing support
- Exploring a decision
- Accessing information to inform a decision
- Advocating for the decision
- Fulfilling the decision
- Ongoing support for another decision.

Although this gives us some idea about what is involved in the practice of SDM, these steps also demonstrate that the supports a person uses will be decision and time specific, and will need to be adjusted according to the complexity of the decision. Some people may need support for all of the steps, others may only need support with one of the steps. As a safeguard, supported decision making should be available to people when and where they need it and be provided in a manner that optimizes their understanding and their decision making ability and participation.

Supported decision making can:

- Be an alternative or an adjunct to guardianship or administration
- Enable people to retain their legal capacity through being an alternative to enduring documents or powers of attorney as well as enable people to make arrangements of their choosing to be implemented in the future if required (advance directives).

⁴ UN Committee on the Rights of Persons with Disabilities General Comment No 1 (2014) paragraph 25

⁵ <https://www.alrc.gov.au/publications/equality-capacity-disability-report-124>

⁶ <https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/national-disability-strategy-2010-2020>

- Be a means by which a person can exercise their decision making ability with support; such as in mental health care and treatment decisions where it can be an alternative to involuntary treatment orders
- Enable people to access a range of other rights including having equal access to healthcare; by being active participants in health care decisions
- Support access to housing, legal, financial, telecommunications and other services
- Extend into people's personal lives to make decisions around who they live with, their supports and services, meaningful employment and the activities they participate in
- Enable people to have self-determined relationships, to enjoy a right to privacy and dignity, and the fulfilment of other social and cultural rights.

Developing a National Framework for SDM

People who have impaired decision making ability, whose decision making ability is simply not recognised or whose decision making ability is declining may all benefit from access from SDM which is tailored to their individual needs and circumstances. The Framework should establish flexible, innovative responses able to meet this diversity.

The ALRC has recommended a set of National Decision Making Principles which provide a sound foundation for the Framework. The Principles are:

Everyone has the right to make decisions that affect their life and have those decisions respected.

Persons who may require support in decision making must be provided with the support necessary for them to make, communicate and participate in decisions that affect their lives.

The will, preferences and rights of the person who may require decision making support must direct decisions that affect their lives.

Decisions, arrangements and interventions for persons who may require decision making support must respect their human rights.⁷

The ALRC recognises that there may be some circumstances when another person may be required to make a decision and terms this 'representative' decision making. Representative decisions are still made on the basis of will preferences and rights of the individual rather than the best interest model currently used by substitute decision makers. There are emerging models of practice both nationally and internationally that recognise decision making ability on a spectrum which requires a spectrum of responses between autonomous decision making and substitute decision making. The Framework needs to articulate good practice across this spectrum and provide practical guidance for implementation consistent with the principles.

These principles must also translate into other legislative, regulatory and policy frameworks and practices. The Framework should describe both the formal and informal implementation of SDM and the role of supporters.

⁷ Accessed at <http://www.alrc.gov.au/publications/equality-capacity-disability-report-124> on 18 Dec 2015

The Framework should articulate a common understanding of SDM which will enable a consistent, repeatable and accessible practice throughout Australia.

Stakeholders – community engagement

The range of stakeholders for a National Supported Decision Making Framework is very broad. They include:

- People living with disability that leads their decision making ability to be questioned regardless of diagnosis, age, gender, culture, language.
- Family, friends and supporters of people with disability
- The Australian, state and territory governments
- Local governments
- Legal systems
- The National Disability Insurance Agency
- The disability and mental health service sectors (public, private and NGO)
- The Australian services sectors including legal, health, housing, education, retail, financial, employment and community
- All members of the Australian community

Engagement for each stakeholder group will vary. Ownership of the Framework would ideally include commitment from all governments on behalf of the Australian community. A genuine co-design approach, driven by a lead agency and SDM champions, to development of the Framework would involve diverse strategies to ensure the voice of each stakeholder group is heard and informs development. International experience highlights the importance of identifying an agency with responsibility for ensuring SDM practice is sustained and available to those who need it.

Safeguards – reporting, regulation and oversight

Supported decision making is itself a safeguard of the assumption of a persons' decision making capacity and their right to make decisions. Recognising that in an SDM model, the decision belongs to the decision maker and responsibility for the decision is retained by the person, safeguards need to be described at a number of levels.

Safeguards for the SDM process should:

- Ensure that SDM practice is consistent with the Principles
- Enable SDM to be measured and evidenced
- Clarify legal risks, assurances and remedies available to decision makers and supporters
- Include a quality framework
- Provide oversight of SDM processes, including review mechanisms
- Clearly articulated responsibility for oversight

Safeguards for people using SDM should:

- Ensure that all people have access to SDM when and where they need it
- Include training and skills development for decision makers, supporters and organisations including responsibilities, boundaries of role and access

- Ensure that the use of SDM enables people to live a rich and varied lifestyle and develop skills while promoting personal and social wellbeing
- Balance duty of care and dignity of risk

Safeguards for supported decisions should:

- Ensure that safeguard responses are proportionate to the context of the decision being made and the impact in a person's life
- Include good practice guidance that ensures decisions are fully informed

While guardianship and administration systems are generally viewed as necessary safeguards for protected persons, it is important to remember that in the Australian context there is no long term study which measures the impact of guardianship in people's lives, and describes the ways in which guardianship is both a safeguard and a risk to safety or wellbeing of individuals.

The introduction of SDM provides an opportunity to put in place a safeguarding framework which prioritises the will, preferences and rights of a person in the context of promoting personal and social wellbeing.

Risk

The goal of decision making strategies cannot be to eliminate all risk. Rather it might best be expressed as maximising the person's decision making potential and autonomy while keeping risk to an acceptable level.

It is important to recognise that existing mechanisms designed to keep people safe, including mechanisms which limit involvement in decision making, have the potential to be, of themselves, risky. A decision that a person cannot take part in an activity that may present physical risks for instance, may introduce risks associated with the persons mental health and co-existing difficulties, self-esteem, social isolation, emotional regulation and increase the likelihood of other risk taking behaviours. The benefits of SDM which have been identified through work to date include reduced risk of exploitation, abuse and neglect; greater autonomy; greater self-esteem; confidence and skill. These, along with dignity of risk and a person's right to make their own decisions, need to be balanced against perceptions of risk based in duty of care obligations. This balance may be achieved by enshrining supported decision making in law and policy, giving it comparable status to duty of care, and requiring evidence of supported decision making being unsuitable before substitute or representative decision makers are appointed. This change in focus, such that duty of care is not seen as sufficient rationale for representative decision making will be key to full implementation of SDM, based in a presumption of decision making ability. The National Framework provides an opportunity to articulate a new approach to risk in decision making which presumes capacity and ensures that safeguards which enable decision making are developed.

Language – consistency, availability and equal access

The Framework is an opportunity to establish consistent language to describe SDM which would underpin consistency in law, practice and participation. Areas needing further exploration include

- Formal and informal decision making
- Legal capacity and decision making ability

- Support for decision making and support with decision making
- Assisted decision making, co-decision making and supported decision making

Resources – capability building and funding

Implementation of the ALRC Principles ensuring SDM is available to those who need it does not come without cost. Governments will ultimately bear some responsibility for establishing and supplying supported decision making, oversight and monitoring. In addition, different levels of the community can enable supported decision making by changing existing practices to ensure people's right to participate in decision making. It should be recognised that Guardianship, for example, does not come without cost. There will be some new resources needed for SDM, but also some realignment of existing practices so that they become consistent with the CRPD.

Recognising that wider community development and social inclusion activities will promote SDM, a National Framework could establish capability building resources and principles for funding of supported decision making. Without establishment funding SDM is less likely to become well embedded and widely available in the community.

Innovation

The Framework should support innovation by

- Recognising SDM as a tool to build decision making ability, respond to fluctuating decision making ability and prepare for declining ability.
- Upholding principles of co-design so that models are responsive to experiences of all stakeholders, particularly decision makers and their supporters.
- Identifying mechanisms for continuous improvement

Innovation within the Framework itself may be achieved through inclusion of a structured review mechanism (perhaps biennially) which enables new research and practice insights to be built into the Framework.

Sustainability

Community wide capacity building which recognises that everyone has a responsibility to enable decision making where and when it is needed will be pivotal to sustainability of SDM. Embedding SDM will require relationships between SDM and legal decision making mechanisms to be clearly articulated. The National Framework could consider the relationship between SDM and advance directives, enduring power of attorney, and appointments of substitute decision makers (including guardians and trustees) under varied legal frameworks. This will have implications for other policies that intersect with these mechanisms, for example Health Law.

Through enactment of a legislative response to SDM, sustainability models could emerge.

CRPD preferences freely given decision support over paid support. Whilst the decision supporter role will ideally be freely given, sustainability will require investment in:

- Outreach for socially isolated people
- Mentoring and coaching

- Community wide training and skills development for decision makers and decision supporters
- Oversight and monitoring
- Gathering the evidence base
- Evaluation and innovation

A National Framework would establish mechanisms for sharing of expertise and SDM resources, reporting on implementation of SDM and action plans which would sustain momentum of implementation.

Successful development and implementation of the Framework will require a community development approach, which includes genuine engagement of disability peoples' organisations, carers and others in the community sector.

Evaluation

Frameworks should be consistent with the national decision making principles, the National Disability Strategy and the UNCRPD.

The experience of people with disability must be at the centre of an evaluation process. In addition, understanding the perspectives, motivations and challenges for decision supporters will contribute to sustainability.

A National Framework would establish the high level evaluation framework and mechanisms for data collection and reporting to inform evaluation, as well as feedback loops which ensure that evaluation findings inform further development of SDM practice.

What comes next

This paper has sought to identify the key issues on which implementation of supported decision making rests. These issues require both attention and investment to explore them in greater depth, provide more detailed analysis, and reach a common understanding which will contribute to implementation of the ALRC recommendations for law reform as well as the development of a National Framework for SDM and full implementation of supported decision making across Australia.

All levels of Government in Australia need to make a commitment to establishing the SDM Framework. The National Supported Decision Making Network will work cooperatively with Governments in development of the Framework. Initial actions might include

- Establishment of a national advisory committee on supported decision making tasked with driving the SDM agenda forward
- Identifying and recruiting high profile champions for the National Supported Decision Making Framework.
- That Governments respond to the ALRC Capacity Inquiry regarding law reform and commit to a community development approach, working with civil society, to implementation of SDM
- Establish mechanisms for integration of community practice through pilot projects around the country in collaboration with academic research and policy/legislation development
- Development of an integrated evidence base through further research that recognises the expertise and experience of people with disability, their families and supporters, the community sector, as well as the academic sector in growing knowledge about SDM.
- A national supported decision making conference which brings together a wide range of stakeholders for an in depth discussion of supported decision making issues

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 NDIS¹

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.

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

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

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

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.³

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.

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

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

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. 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.

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

⁴ National Disability Insurance Scheme Act 2013, section 145.

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>

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
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ACT Mental Health Consumer Network



Advocacy for Inclusion



Community Mental Health Australia

Disabled People's Organisations Australia (DPO
Australia)



Inclusion Australia



Mental Health Australia



Mental Health Community Coalition ACT (MHCC
ACT)

National Ethnic Disability Alliance



People With Disabilities ACT (PWDACT)



People with Disability Australia (PWDA)



Schizophrenia Fellowship of NSW (SFNSW)

