Proposal for an NDIS Quality and Safeguarding Framework

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NSW HACC Development Officers Network
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About the NSW HACC Development Officers Network

The NSW HACC Development Officers (HACC DOs) Network is a forum for regional sector development workers who are funded through the disaggregated Home and Community Care (HACC) Program to promote best practice in the development of a strong, cohesive community care system.

HACC DOs are located in all HACC regions in NSW to provide a range of support, resource and information services to organisations funded under the former HACC Program, which is now the Commonwealth HACC Program (for people aged over 65 years and Aboriginal and Torres Strait Island people 50 and over) and the Community Care Supports Program (CCSP) (for people aged under 65 years and Aboriginal and Torres Strait Island people under 50) in NSW. There are approximately 50,000 younger people with disability using CCSP.

The role of the NSW HACC DOs is centred on the development of HACC/CCSP services; however, necessity dictates that they also work with providers of the full range of community care programs, including Disability Services Program (DSP), Community Supports Program (CSP), Home Care Packages (HCPs) and National Respite for Carers Program (NRCP). They work closely with NSW and Commonwealth funding bodies, as well as peak organisations, to further the interests of frail older people and people with disability living in the community, and their carers. Especially in times of reform and transition, HACC DOs play a key role in providing a voice for community care providers as well as information, training and support to individuals and groups on both change management and implementation issues.

The HACC DOs are grateful for the opportunity to comment on the proposed Framework for Quality and Safeguarding in the National Disability Insurance Scheme (NDIS) ["the *Draft Framework*']. The document was thorough and comprehensive; its contents were easy to read and understand, despite the complex subject matter. The consultation process has allowed a range of opportunities for feedback over an appropriate period of time, made simpler by the breakdown of questions throughout the document, which are referenced in the submission below [eg. *Q1.2*]. the HACC DOs look forward to reading the final Decision Paper.

Recommendations

1. That all NDIS participants have the opportunity to access the information and support they need to enable decision-making most appropriate to meet their individual capacity, level of interest and the natural safeguards they already have in place.

2. That the NDIS further develops existing state-funded capacity-building systems that have been effective in assisting people with disability and their communities.

3. That the Australian Government provides a complaints system which effectively supports the rights of all people with disability in their engagements with disability-related supports, regardless of whether they are funded by the NDIS.

4. That the Australian Government resources a network of individual and systemic advocacy services that are accessible to all people with disability and their carers and families, regardless of whether they are funded by the NDIS.

5. That provider registration for the NDIS allows for market involvement by a range of quality providers and appropriate, dignified risk management and support for individuals with disability.

6. That an autonomous Oversight Body be established to manage and promote key components of NDIS for continuous quality improvement of the Scheme and the safeguarding of all people with disability, regardless of whether they receive a funding package.

Recommendation 1

That all NDIS participants have the opportunity to access the information and support they need to enable decision-making most appropriate to meet their individual capacity, level of interest and the natural safeguards they already have in place.

Information is the basic tenant of decision-making, the building block of individual capacity and a fundamental right of every Australian with disability under the *UN Convention for the Rights of Persons With Disabilities* ("the *UN Convention*"), to which Australia is a signatory, and the *National Disability Strategy*[1] which gave life to the National Disability Insurance Scheme.

Therefore, under the NDIS, the discussion about available information must start at initial eligibility screening to assist individuals to identify their information needs and to locate the sources appropriate to their disability and communication needs. This must occur for all individuals seeking disability-related assistance from the NDIS, irrespective of whether they receive a Tier 1 funding package. Information to promote the safety and community support of all individuals with disability should be available via Tier 2 Information, Linkages and Capacity Building (ILC) services. For those receiving a Support Plan, the detailed assessment and planning process will then need to further explore the capacity of the person with disability and/or their carers to access information independently and to make informed decisions, including their ability and/or interest in self-managing their supports now and in the future.

The most important features of an NDIS information system [Q1.1] are:

- General information openly available to people with disability who want to remain anonymous while gathering factual, current details about the NDIS, before deciding to make contact with the National Disability Insurance Agency (NDIA) ie. websites, brochures, newspaper/radio/tv ads and interviews, posters and signs, public events and guest speakers;
- Contact points for individuals with specific questions via a range of communication styles/media, both anonymous and identified ie. phone including TTY, email/web, face-to-face including permanent shopfronts in the community and advertised outreach events, such as information stands in shopping centres [eg. list of NDIA offices, ILC services and LACs];
- Specific guidance for participants in the NDIS on elements of the process and various ways of engaging with them, by phone, written correspondence, email, skype or face-to-face [eg. factsheets and rules, list of approved providers, list of community visitors and abuse helplines, list of advocates and complaints helplines] ***see also Recommendations 3, 4, 5****;*
- Resources and tools for individuals who want to be more active in managing their supports, develop their personal skills and/or share their experiences with others in a range of formats and available in both private and public environments [eg. forms/templates, checklists, case studies, blogs, physical and virtual forms, training etc] ***see also Recommendation 2*****.**

Information content to address participants' questions relating specifically to safety and quality may include:

- Context: How does NDIS work? What are my rights? Where am I in the process? What's the next step? What's the endpoint?
- Privacy: Who has my information? What are they doing with it? What are my rights?;
- Harm and Abuse: What is it? What are my rights? Who can I talk to about it? How do I know if I am safe to be alone with a certain worker? What can I do if it's happening to me or someone I know?;
- Choosing Support: What to expect from services. What should I look for when choosing my provider/s?;
- Feedback: What if I have a good idea? How do I make a complaint if I'm unhappy? What are my rights? Who can help me?

Information will be key to providing protections to NDIS participants. Individuals' insight and capacity for self-protection cannot be assumed prior to detailed conversation during their assessment and planning process. The NDIA, through its quality and safeguarding systems, including the role of the Support Planner, has a particular responsibility to establish parameters for and with each participant, and to link them to information that facilitates protections described in the *UN Convention*, to

> *… take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse.*[2]
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> *[****See Recommendations 4 & 5****]*

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[1] https://www.dss.gov.au/sites/default/files/documents/05_2012/national_disability_strategy_2010_2020.pdf

[2] http://www.un.org/disabilities/convention/conventionfull.shtml Article 16 - Freedom from exploitation, violence and abuse

However, this must be appropriate and proportionate to individual circumstances. The information system must be respectful of the achievements of people with disability and their carers prior to entering NDIS, which have been developed through lived experience, creativity and often necessity. This includes the natural safeguards people already have around them from informal supports, such as family and friends. It is important to acknowledge and respond to a range of individual capacities, experiences and interests in levels of empowerment, risk-taking and self-management of disability supports in the information available. For instance, two individuals of similar age, education and disability type may display extremely different levels of confidence to make decisions due to the support and encouragement of family, which might suggest a need for more or less focus on capacity building in their Support Plans [***See capacity building services in Recommendation 2***].

In order to ensure accessibility [Q1.2], the NDIS information system must begin with the full range of communication requirements established under the *UN Convention*:

> *"Communication" includes languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology*[3]

For instance, there is genuine concern in the community that information about the NDIS is largely limited to online platforms currently and there is a universal trend to use websites to limit the costs of information distribution. Websites are efficient storage and clearinghouses for information for both providers and participants, and indeed the public in general, but are inaccessible to many people with disability, particularly those without specific aids or supports. These reasons include, but are not limited to:

- communication disabilities, such as intellectual or vision impairment;
- physical disabilities, such as inability to sit for periods of time or use a computer;
- emotional or physical energy of people with disability and carers, who are exhausted by their day-to-day lives and cannot cope with the additional strain of independent web-surfing;
- language and literacy, including limited translation options and/or excessive complexity of information content;
- socio-economics and low ownership of IT devices, internet subscription.

Recognising this, and with Australia's agreement to enable people with disability "*to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice"* under the *UN Convention*[4], information must be provided in accessible formats and technologies appropriate to different kinds of disabilities and available in a timely manner and without additional cost:

- In the written word [on paper, on CD/DVD or on websites]: in plain English, using explanatory pictures where appropriate, translated into community languages, in large print, without watermarks or other art that does not add to the meaning, in braille; and
- In the spoken voice [on the phone, in person, on CD/DVD or via websites]: in plain English, using explanatory non-verbal communications where appropriate, with interpreters available for community languages, including signing for people who are hearing impaired.

Recommendation 2

That the NDIS further develops existing State-funded capacity building systems that have been effective in assisting people with disability and their communities.

Given the limited timelines to prepare people with disability for the NDIS, and in order to maximise the efficiency and effectiveness of its investment in capacity building, the NDIS must utilise the outcomes of projects by local State and Territory jurisdictions, including the learnings and outcomes of completed pilots, research findings, tools and resources, as well as facilitating the continuation of current projects that are successfully working with people with disabilities and their families.

For instance, NSW was already moving towards individualised funding as part of a wider reform agenda to implement person centred approaches in disability services prior to plans by the Council of Australian Government (COAG) for an NDIS. NSW Government, through the Department now known as NSW Family and Community Services Ageing, Disability and Home Care (ADHC), has promoted and resourced individual empowerment of people with disability through the Living Life My Way Framework[5] since statewide consultations in 2012, and is now expanding individual funding under Stronger Together 2, the second part of NSW Government's ten year plan for disability supports[6],

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[3] http://www.un.org/disabilities/convention/conventionfull.shtml Article 2 - Definitions

[4] http://www.un.org/disabilities/convention/conventionfull.shtml Article 21 - Freedom of expression and opinion, and access to information

[5] http://www.adhc.nsw.gov.au/__data/assets/file/0007/271843/Living_Life_My_Way_Framework.pdf

[6] *Stronger Together: A new direction for disability services in NSW 2006-2016* underpins the transformations to the disability sector in NSW. Under Stronger Together 2, people with disability using services funded by the NSW Government under the National Disability Agreement (specialist disability services) were able to convert the value of those services into a portable, individualised arrangement from 1 July 2014.

and *Ready Together: a better future for people with disability in NSW*[7], which will culminate in the full rollout of NDIS in 2018. Projects have included:

- *Living Life My Way – putting people with disability at the centre of decision making* [2011-12]: statewide consultation-based research on the best way to implement self-directed supports and individualised budgets in NSW.[8]
- *Yarnin' about Disability – sharing what Aboriginal people told us [2013]:* consultation-based research about the unique transition needs of Aboriginal people with disability and their communities.[9]
- Supported Decisions Pilot [2013-14]: a joint project between ADHC, the NSW Trustee, the Guardian and Public Guardian to provide information and tools to a sample group of individually funded people with disability in Western Sydney.[10]
- Ability Links NSW [2013-] *due for evaluation in 2016*: a network of regional workers intended to be an access point for support in NSW for people with disability, with a community development focus. Linkers support people to access or make use of both funded and unfunded resources, prioritises accessing mainstream community and personal resources before seeking funded support for a person.[11]
- Getting Prepared – NSW Capacity Building for People With Disability [2014-15]: funding for eight statewide organisations to provide workshops and tools to prepare people with disability for NDIS, including information about the transition processes in NSW.[12]

The Getting Prepared projects focus on a number of special needs groups [***see also Recommendation 3***], including rural and remote Aboriginal Communities[13], new and emerging CALD communities[14] and people with a physical disability[15]. These projects also draw on speakers from the Ambassadors and Champions Program, a unique peer support model involving selected individuals with disability who aim to inspire confidence through their personal experiences of using individualised funding[16].

The NSW Consumer Development Fund - My Choice Matters is included on the Getting Prepared list, but was established before the other projects, with an investment of $5 million. Auspiced by the NSW Council for Intellectual Disability, My Choice Matters aims to assist all people with disability and their carers to develop more Choice, Voice and Control in the achievement of quality lives, with or without NDIS funding. The project's strategic framework[17] was developed based on feedback through the Living Life My Way consultations, consultations with stakeholders (such as the Ministerial Reference Group on Person Centred Approaches, The NSW Disability Council, a range of Advocacy and Information Services), and Australian and international literature on capacity building, and the project advisory committee of people with a range of experiences of disability and caring[18]. Each of the four outcomes areas has an entry point on the My Choice Matters website, which is directed appropriately and respectfully towards people with disability:

- Get More Skills: 1 day seminars to launch My Choice Matters, explain the changes in disability and start people visualising the future and thinking about individual goal-setting, self-management of supports etc; a follow up series was tailor-made for groups under-represented at the general sessions.[19]
- Run Projects: grants of up to $5000 to assist a person with disability with a personal capacity building initiative; the step-by-step easy application process is assisted by a workbook and designated staff support worker.[20]
- Become a Leader: series of free training developed and delivered by, leadership professionals, including people with a disability; participants attend two days and or six monthly workshops.[21]
- Share Stories: DVD interviews with people with disability; this will soon include the publishing of reports from Run Projects participants.[22]

The work of My Choice Matters reflects a complex matrix of learning opportunities, initiatives and intended outcomes for building the capacity of people with disability and families within a diversity of communities and limited resources. The complexity of the interwoven outcomes is best described in the Strategic Framework:

> *Within the broader outcomes there will be many individual "learning journeys". For example, some people might attend some Get More Skills workshops, before signing up to a Leadership initiative, then Run a Project, and finally share their story with others. Some may only sign up for one workshop, while others will*

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[7] http://www.adhc.nsw.gov.au/__data/assets/file/0007/280276/ReadyTogether_booklet_web.pdf
[8] http://www.adhc.nsw.gov.au/__data/assets/file/0018/262530/Stage_3_consult_report_Aug2012.pdf
[9] http://www.adhc.nsw.gov.au/__data/assets/file/0009/294534/YarnUps_OutcomesReport.PDF
[10] http://www.adhc.nsw.gov.au/__data/assets/file/0003/279039/SDMP_fact_sheet_Oct2013.pdf
[11] https://www.adhc.nsw.gov.au/individuals/inclusion_and_participation/ability_links_nsw
[12] http://www.adhc.nsw.gov.au/__data/assets/file/0009/280269/Getting_Prepared_Information_Sheet.pdf
[13] http://www.adnnsw.org.au/projects
[14] http://ecsc.org.au/our-programs/cald-disability-consumer-capacity-building-project
[15] http://www.pdcnsw.org.au/index.php?option=com_content&view=article&id=47&Itemid=97
[16] http://www.adhc.nsw.gov.au/__data/assets/file/0006/275397/Ambassadors_and_Champions_fact_sheet_Sep2013.pdf
[17] http://www.mychoicematters.org.au/images/final_strategic_framework.pdf
[18] http://www.mychoicematters.org.au/advisory-group.html
[19] http://www.mychoicematters.org.au/get-more-skills.html
[20] http://www.mychoicematters.org.au/run-your-project.html
[21] http://www.mychoicematters.org.au/become-leader.html
[22] http://www.mychoicematters.org.au/share-your-story.html

> *know exactly what project they would like to run to build their capacity. There may be those who will only ever participate in Tweets. This reflects that people are at different stages of learning about the possibilities, have different interests and different dreams about their lives. The framework is flexible enough to enable people to use it in different ways.*[23]

My Choice Matters actively encourages individual empowerment and risk-taking. Every aspect of the project reflects good practice in communicating with people with disability, including sound options on the website for those who cannot read, printed resources in a range of languages[24] and workshops specifically designed to target CALD and Aboriginal communities[25]. Each outcome area entry on the website has a DVD introduction in plain English, with a sign interpreter. The website also features:

- Additional click-ons to enable registration for event/workshops and the newsletter.
- Our Stories: interviews with participants on various topics and experiences.[26]
- Resources: listed under headings consistent with the aims of the project to be accessible, relevant and appealing [A Good Life, Care and Support, New Skills, Your Community, Planning and Goal Setting].[27]

In June, My Choice Matters will be launching a new learning tool, My Learning Matters, which brings together over sixty resources under fifteen topic areas, with interactive features.[28] The ongoing evaluation of My Choice Matters is being conducted by the Centre for Applied Disability Research at the University of NSW[29].

There are also disability information and advocacy organisations and peaks currently funded by ADHC, who develop and disseminate resources that contribute to the capacity of people with disability to exercise choice and decision making [***see also Recommendation 4 re systemic advocacy***]. For example, there is a comprehensive database of providers across NSW available online or by phone through IDEAS – Information on Disability, Education and Awareness Services.[30] Again, information is provided in various formats, including visual and audio, different size prints and language options. IDEAS held a two-day expo in the NDIS Trial site last year that was visited by 3000 people, and are planning another this year. Exhibitors included NDIA, providers of assistive technology, local disability providers, statewide peaks and My Choice Matters, as well as various workshops for people with disability and their carers.[31]

Although there are differences in the funding arrangements for Consumer Directed Care, the NDIS might also draw on some of the capacity building resources developed for people in aged care, including HomeCareToday website. It provides information, resources and peer supports to assist older people to make the most of the benefits and opportunities of CDC, including personal stories, an online forum and a peer education program.[32]

Recommendation 3

That the Australian Government provides a complaints system which effectively supports the rights of all people with disability in their engagements with disability-related supports, regardless of whether they are funded by the NDIS.

The introduction of the NDIS has highlighted the need for a new, national system for handling complaints by people with disability. In order to provide a safeguard for the rights of people with disability [in the Corrective stream of the *Draft Framework*], it must be independent from providers of support [Q2.2.1], including the NDIA, due to real or perceived conflict of interest, including:

- without the appropriate knowledge and attitudes, incompetent and/or exploitative practice may not necessarily be deliberate, but is poss, especially in the beginning, when everyone is still learning how NDIS works;
- systems in other areas of consumer law are indicators of need;
- the fundamental power imbalance between provider and consumer exists despite the high capacity and skills of some individuals with disability;
- many providers may not have the capacity self-manage complaints appropriately;
- it is unrealistic to expect that autonomous businesses would value a complaints system as the authors of the *Draft Framework* do [Option1]:

> *In the NDIS, having an effective complaints system will be more advantageous to providers*

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[23] http://www.mychoicematters.org.au/images/final_strategic_framework.pdf Pg 7
[24] http://www.mychoicematters.org.au/multiple-languages.html
[25] See current list at http://www.mychoicematters.org.au/what-s-on-2/registration-form.html
[26] http://www.mychoicematters.org.au/our-stories/
[27] http://www.mychoicematters.org.au/resources-and-links.html
[28] http://www.mychoicematters.org.au/blog/announcing-my-learning-matters.html
[29] http://www.cadr.org.au/reports-papers/my-choice-matters-evaluation-interim-report
[30] http://www.ideas.org.au/
[31] See IDEAS – TV wall on http://www.ideas.org.au/
[32] http://homecaretoday.org.au/consumer

> *because they will be operating in a competitive market. The ability to demonstrate flexibility and to resolve complex issues to meet participants' needs will help them improve their service offer and their reputation.* [p 51];

- review by an *industry-initiated complaints body* [Option 2], is not viable, as many providers, especially those who are new to disability, are unlikely to belong to disability-specific peaks;
- it cannot be assumed that generalist professional bodies are appropriately skilled to manage complaints involving persons with disability.

The functions of an independent complaints body described in the *Draft Framework* [pg 54] are appropriate, and best achieved the expansion of existing disability commissioner models in States and Territories[33] [including offices of Ombudsman, Option 3b] and development of a national network which draws on the expert advice of the joint Disability Commissioners group in their 2014 factsheet. This model includes the requirement for providers to report annually on the number, nature and outcomes of complaints and a central body with specific powers [Q2.2.3].[34] The complaints body should also have a key role in the Developmental stream of the *Draft Framework*, providing education[35] and capacity building [***see also Recommendation 2***].

The current regulatory framework in NSW includes the NSW Ombudsman, presently vested with extensive powers regarding

> *"handling and investigating complaints about disability services, inquiring into major issues affecting people with disabilities and disability service providers, reviewing the care, circumstances and deaths of people with disabilities in care, coordinating Official Community Visitors in their visits to licensed boarding houses and supported accommodation; and monitoring, reviewing and setting standards for the delivery of disability services."*[i]

NSW Ombudsman's powers are vested in state based legislation, such as the *Disability Services Act 1993 which has been replaced by the Disability Inclusion Act 2014, Community Services (Complaints, Reviews and Monitoring) Act 1993, Youth and Community Services Act 1973, and Youth and Community Services Regulation 2010.*

The Ombudsman is also engaged in varied systemic activities informed by:

- their direct contact with people with disabilities, their families, representatives, and advocates;
- handling of complaints, investigations, and reviews of deaths;
- contact with Official Community Visitors [Q2.2.4]; and
- monitoring of the delivery of disability services.

Some of the responses are formal, in the form of inquiries and reviews and informal [ie. liaising with ADHC and other services on key disability plans, standards, and policies].

Akin to the NSW Ombudsman, in addition to receiving complaints, the Australian Human Rights Commission, headed by the Disability Discrimination Commissioner, *"conducts public inquiries, negotiates disability guidelines and standards, support organisations to develop Disability Inclusion Plans and run community education programs."*[ii]

Currently, there are three pieces of legislation, which each have different coverage:

- In NSW currently, complaints relating to disability discrimination may be received by the NSW Ombudsman pursuant to the *Community Services (Complaints, Reviews and Monitoring) Act 1993* and the Anti-Discrimination Board under the *Anti-Discrimination Act.*
- On the Federal level, the Australian Human Rights Commissions accepts complaints regarding disability discrimination in line with the *Disability Discrimination Act 1992.*

In order to achieve consistency nationally, the new system requires a singular Act which contains all these powers and strengthens investigative powers. In terms of powers to make binding decisions, State and Federal complaints instrumentalities mentioned above are already vested with these powers. However, if the NDIS is seeking to encourage a truly inclusive society and work with people in unfunded Tiers, the complaints system must encompass all supports and services used by people with disabilities, not just those financed by NDIS, in one body [Q2.2.2].

The NSW Ombudsman, for instance, is known, trusted and respected as the independent defender of disability rights, but it can currently only act in specific areas of public sector and funded service delivery. The powers and resources of the NSW Ombudsman and its peers could be enhanced through "*the introduction of an 'unconscionable conduct' (or exploitation) offence"*, as suggested by the joint Disability Commissioners group:

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[33] The *Disability Inclusion Act 2014* (NSW) provides for "responsibilities of the State during and following the transition to the National Disability Insurance Scheme" s3(f). Part 4 of the Act deals with Disability Standards conditional on financial assistance being provided to an entity delivering disability services. It is reasonable to presume that State funding administered to the same target group under the *National Disability Insurance Scheme Act 2013* would not be subject to Part 4 of this Act.

[34] http://www.ombo.nsw.gov.au/__data/assets/pdf_file/0004/14692/Safeguards-and-NDIS_Nov14_web.pdf

[35] The NSW Ombudsman, for instance, has already established an appropriate role in educating people with disability about their rights under the NDIS and complaints processes in the Hunter Trial site.

> *The creation of an offence for exploiting people with disability would serve as a 'safety net' for all service delivery arrangements, including those that will fall outside of the safeguards proposed for providers registered under the NDIS*[36]*.*

The new system should give all people with disability the equal right to protection and a clear requirement for the NDIS to fund beginning-to-end complaint-to-resolution advocacy support, including greater funding for complaints handling officers. We believe that the Oversight Body needs to be accessible to people with disability and appropriately staffed in order to facilitate complaints from people with disability, who are heavily reliant on the service provider and fear retribution. [see the *Shut Out Report* for examples]

Recommendation 4

That the Australian Government resources a network of individual and systemic advocacy services that are accessible to all people with disability and their carers and families, regardless of whether they are funded by the NDIS.

The Council of Australian Governments (COAG) recently made the first crucial step in the development of a rights-based system to support people with disability in its commitment to advocacy:

> *The Council agreed that the NDIS will fund decision support, safeguard supports and capacity building for participants, including support to approach and interact with disability supports and access mainstream services.*
>
> *The Council agreed that systemic advocacy and legal review and representation will be funded outside of the NDIS. A review of key policy directions and principles in the National Disability Advocacy Framework, in light of the NDIS, will be informed by targeted consultations from April to July 2015, with a final report to the Disability Reform Council by December 2015.*[37]

It is a requirement of the current *National Disability Advocacy Framework* to separate advocacy from the disability support 'system' and to protect people with disability from conflict of interest; however, the COAG statement above suggests that only NDIS participants will be able to access decision supports. Community attitudes and NDIS-inspired markets will clearly impact on all people with disability and their carers. Indeed, the *NDIS Act 2013* includes Objects in Section 1 beyond just funded supports:

> *(a) in conjunction with other laws, give effect to Australia's obligations under the Convention on the Rights of Persons with Disabilities done at New York on 13 December 2006 ([2008] ATS 12); and*
> *(c) support the independence and social and economic participation of people with disability;*
> *(h) raise community awareness of the issues that affect the social and economic participation of people with disability, and facilitate greater community inclusion of people with disability*[38]

In order to ensure people with disability have their views taken into account in decision making in the NDIS and the community generally, they must have access to the three types of output listed in section 13 of the *National Disability Advocacy Framework*:

> *(a) Individual advocacy that is tailored to meet the individual needs of people with disability including a focus on the needs of people with disability experiencing multiple disadvantage;*
> *(d) Disability advocacy that promotes community education and awareness of disability issues and rights;*
> *(e) Systemic advocacy that positively contributes to legislation, policy and practice that will support the agreed outcomes.*

Action 2.11 of the *National Disability Strategy 2010-2020* is to "*support independent advocacy to protect the rights of people with disability."*[39] Advocacy is undeniably a part of the effective implementation of the NDIS:

> *"The role of advocacy in representing the interests of people with disability is to be acknowledged and respected, recognising that advocacy supports people with disability by:*
> *a. promoting their independence and social and economic participation;*
> *b. promoting choice and control in the pursuit of their goals and the planning and delivery of their supports;*
> *c. maximising independent lifestyles of people with disability and their full inclusion in the mainstream community." (*National Disability Insurance Scheme Act 2013*).*

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[36] http://www.ombo.nsw.gov.au/__data/assets/pdf_file/0004/14692/Safeguards-and-NDIS_Nov14_web.pdf

[37] Disability Reform Council Communique 24/4/15 http://mitchfifield.dss.gov.au/media-releases/coag-disability-reform-council-communiqu

[38] NATIONAL DISABILITY INSURANCE SCHEME ACT 2013 (NO. 20, 2013) - SECT 3
http://www.austlii.edu.au/au/legis/cth/num_act/ndisa2013341/s3.html

[39] https://www.dss.gov.au/sites/default/files/documents/05_2012/national_disability_strategy_2010_2020.pdf Pg 41

The review of the *National Disability Advocacy Framework (the Framework)* within the new context of the NDIS is both timely and appropriate; however, it is not so much the Framework itself that requires review, but rather the National Disability Advocacy Program and related resource allocations by government to enable full implementation of its long-term goal:

> *People with disability have access to effective disability advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights enabling full community participation.*[40]

Individual and systemic advocacy for people with disability should be funded separately from support packages. A person should not have to pay for the cost of an occasional need for advocacy from their funding package which is intended to cover their support needs. Individual advocacy must be available when needed, where needed and at no cost to the person with disability or carer/s who require help with a complaint. This means the provision of an appropriate number of advocates, as well as funding to make their services accessible and to meet Work Health and Safety requirements for both the clients with disability and the advocacy staff, including:

- location in safe and accessible offices for people with disability who can visit them;
- availability of technology to assist individuals with communication disabilities;
- assistance with travel costs, if needed, by people with disability to visit the office or other sites during the process of advocacy;
- operation outside business hours for people with disability who are working and/or where necessary to address specific complaints;
- availability of in-home advocacy services for housebound clients.

Indeed, the *NDIS Act*[41] and the *Draft Framework* acknowledge that "*NDIS participants will face some particular challenges exercising their rights without help from others"* [pg 46]. This requires comprehensive funding for <u>independent</u> advocacy, both individual and systemic.

In regard to *systemic advocacy,* the National Disability Advocacy Framework states:

> *Systemic advocacy seeks to introduce and influence longer term changes to ensure the rights of people with disability are attained and upheld to positively affect the quality of their lives. Strategies may include: advocating for changes in legislation, policy and practices of service delivery; advocacy development; community education; community and advocacy sector development and <u>lobbying</u>.*[42]

Recently five national disability peaks were funded through the 2014 DSS Grants. There are concerns across the sector about the ability of such a limited number of organisations to effectively to effectively contribute to policy development, safeguarding of rights of people with disability, as well as systemic advocacy on specific issues. Specialist peaks are needed to ensure understanding of, and appropriate responses to, groups of people with disability in the community who are recognised in the *National Disability Advocacy Framework* as having 'Multiple Disadvantage': xxx

> *A person experiences multiple aspects of disadvantage concurrently caused by the intersection of disability and other forms of disadvantage such as, but not limited to, gender, age, education, sexuality, geographic location, ethnicity and cultural background.*[43]

There were some excellent organisations funded previously with knowledge and skills in specific disabilities such as vision impairment, deafness, autism and brain injury, who would have provided a voice for people with disability in an effective complaints system, including:

- giving advice to government and statutory bodies in the development and review of legislative mechanisms and support materials, including identification of gaps in the law, contradictions or lack of clarity in information and ideas for improvement;
- promotion of complaints systems and related programs, such as information on websites, newsletter articles and good new stories about complaints successes;
- encouraging appropriate use of complaints systems, including training people with disability in self-advocacy skills and providing family advocacy skills to carers who are advocating for a relative with disability.

The range of special needs groups within the disability community must be considered in the upcoming review of the National Disability Advocacy Program, as well as the fact that many advocacy providers and disability peaks are at risk of losing their funding, as resources are being relocated from NSW jurisdictions to the NDIS[44].

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[40] National Disability Advocacy Framework https://www.dss.gov.au/sites/default/files/documents/08_2012/attachment_a.2_-_national_disability_advocacy_framework.pdf

[41] NDIS Act 2013 Part 2, General Principles of the Act 4 (13)

[42] National Disability Advocacy Framework https://www.dss.gov.au/sites/default/files/documents/08_2012/attachment_a.2_-_national_disability_advocacy_framework.pdf

[43] National Disability Advocacy Framework https://www.dss.gov.au/sites/default/files/documents/08_2012/attachment_a.2_-_national_disability_advocacy_framework.pdf

[44] The *Heads of Agreement between the Commonwealth and NSW Governments on the National Disability Insurance Scheme*, signed in December 2012, and the *Intergovernmental Agreement on the National Disability Insurance Scheme Launch* specify that funding for disability and community

Recommendation 5

That provider registration for the NDIS allows for market involvement by a range of quality providers and appropriate, dignified risk management and support for individuals with disability.

High quality supports

High quality supports work together with the person's natural safeguards – their family and friends, local community, as well as enforceable safeguards, i.e. programmes designed to serve persons with disabilities which are to be *effectively monitored by independent authorities*. [Article 16(3), UNCRPD]

High quality supports involved all people with disability in decision making including people with disability who are on Guardianship orders, Community Treatment Orders (mental health) or financial management orders, who would otherwise be excluded from decision making, by having another person substituted for themselves. This is an unacceptable practice for the National Disability Insurance Scheme. Therefore the Quality and Safeguards should make reference to and specifically state that one of its aims and philosophies is to implement the recommendations of the papers *Substitute Decision Making: Time for Reform*[iii], which calls for a review and complaint process of decisions made by substitute decision makers and UNCRPD Shadow Report which advocates for the establishment of a "*comprehensive system focused strongly and positively on promoting and supporting people to effectively assert and exercise legal capacity, and on safeguarding against abuse and exploitation in both informal and formal supported and substituted decision-making arrangements.*"[iv]

Self-management and choice [Q2.4.1, Q2.4.2]

Ultimately, individual participants should decide who can provide support to them in the NDIS. Police checks can assist in the choice, but should not prevent choice. The Law Society inducts solicitors who have a criminal record. Similarly people with disability need to be permitted the dignity of risk of choosing their own support person. However, it is not clear what level of criminality would result in an automatic banning. We are in support of barring persons with a history of violent offences. However, we note that there needs to be an appeal process where the onus is on the person who has been barred to satisfy the Oversight Body that they have sufficiently mended their way. Additionally, the Oversight Body may provide some support and supervision for those workers who are accepted on these grounds. The Oversight Body to manage Barred Worker List, Community Visitors receive reports about and investiage Serious incidents.

With regards to staff screening, service providers are supportive of a Blue Card type system which includes an extensive background check. We are in favour of this sort of system because it allows for workforce flexibility necessary for the success of the NDIS, as the new card will allow workers to work for more than one service at a time due to quick and simple verification process. With the Blue Card, the service provider needs to log into a portal to check the currency of the card; which is much more efficient than the current system in NSW which requires every service provider to run their own police check even though one could have been at a different service only a day ago. Furthermore, the Blue Card would allow people who self-manage to easily and quickly check new workers which removes a significant barrier from self-administration.

Provider registration [Q2.1.1, Q2.1.2, Q2.1.3]

Provider registration needs to be added to the functions of the Oversight Body which is charged with protecting rights of people with disability, in order to free up the NDIA to focus on scheme administration especially during the critical establishment phase.

The Proportionality principle with regards to disability standards appears logical at first blush as the principle relies on an assessment of inherent risk in an activity such that those activities that attract less risk should be held to a lesser standard. However, in practice once people become more comfortable with a service provider and a particular activity they are more likely to increase their risk taking behaviour; so a service provider who is licensed for a lower level activity may find themselves actually delivering a much more involved, dare we say risky service without adequate knowledge and safeguards. This is the reason why recommend assessing each service by activity/provider/participant/environment in a matrix as they are co-dependent factors.

One could argue that knowing that person and their needs over a prolonged period time equips the service provider to respond appropriately. This may very well be the case in an agency that has the capacity to invest in development of the staff and service model but cannot be presumed for smaller sole-person provider organisations which are likely to fit into the ground floor standard.

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care services will be transferred to the NDIS. Available at: http://www.nsw.gov.au/ndis (last accessed: 25/02/2013) clause 33, which specifies that "[f]ollowing commencement of the full NDIS, the NSW Government will not provide any residual specialist disability services or basic community care services."

Outlined above are our reasons for recommending a relatively high standard which applies to all service providers who *work exclusively with people with disability*; which is equivalent to or stronger than the NSW Disability Standards. The notion of "working exclusively with people with disability" is expansive and would include a gym that advertises specific classes for people with disability. On the other hand, if a person with disability chooses to go to a gym and assume the risk inherent in that activity, then there is no requirement for the gym to meet the Standards. If a person is not able to make a decision about the acceptability of risk in a particular activity, a substitute decision maker or a support person needs to be present for the entirety of the activity.

Small service providers who do not have retained earnings to pay for accreditation are at a disadvantage in the current NSW Disability Standards system which requires them to pay a Consultant to review their service against the standards. However, AHDC has recognised this and established a fund which current grant recipients may access to pay for accreditation. There needs to be a mechanism similar to Aged Care where the review does not attract a fee as it is conducted by a Government agency, the Aged Care Commissioner. Having funded independent reviewers would encourage entry into market of other like service providers (local community centres, education providers, allied health providers) which would increase choice and quality of services for people with disability.

Many disability service providers are finding the shift from their current block funding model to an individualised funding package model as evidenced in NDS's *State of the Sector Report 2014* which states that very few service providers know their actual costs of service delivery, have adequate workforce or have aligned their current model with the services funded by the Scheme. Services have received tailored support from Sector Consultants through the Industry Development Fund in order to prepare for the NDIS transition. This project needs to continue through to actual roll-out in order to ensure that people with disability have high quality services to purchase.

There needs to be flexibility in terms of meeting standards for individuals who self-mange. Those who self-manage need to be able to access separately funded specialised around legal and accounting requirement of self-management.

Recommendation 6

That an autonomous Oversight Body be established to manage and promote key components of NDIS for continuous quality improvement of the Scheme and the safeguarding of all people with disability, regardless of whether they receive a funding package.

An independent, purposed Oversight Body is the only way to provide protection for everyone impacted by NDIS, including the NDIA itself. There are a number of reasons why the disability community, the NDIS and the Australian people generally need an Oversight Body [Q1.7]:

- to ensure that the NDIS is operating efficiently and effectively;
- to ensure the Australian people receive the education they need about NDIS;
- to counteract actual and/or perceived conflict of interest within NDIS[45];
- to provide objective assessment of the success of NDIS, including the success of the new system and market development;
- to ensure the NDIS has the flexibility to respond to the community, to change and to improve over time; and
- to provide feedback and advice to government and the NDIA which is independent of political rhetoric and only for the benefit of people with disability.

The Oversight Body must be the pillar of a system which supports, protects the rights and advocates on behalf of people with disability; not constituted as a large bureaucracy which supersedes State-based mechanisms, but as a consultative body which works to harmonise the work of various jurisdictions in order to provide a voice of people with disability and guidance to Cabinet on:

1. The wellbeing of people with disability both on State and Federal level; and
2. Development of the NDIS in different regions across the country, as no two communities are the same[46]. Ultimately, the NDIS is going to be implemented locally; therefore it is in the best interest of the participants and therefore the NDIS to coordinate service delivery and build capacity of local service to meet the needs of people with disability in their community. This is one of the principles of service delivery under the Article 19 of the *UN Convention*.

Powers and functions of the Oversight Body [Q1.8] should reflect a systemic focus and not get caught up in individual issues[47]. These include:

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[45] For instance, when NDIA allocates funds & their staff develop plans, & very often manage them as well until participants are confident to self-manage or plan management services become available/acceptable..

[46] For example, people with disability in inner city Sydney present with more comorbidities (particularly mental health) than other people with disability living in other parts of NSW.

[47] The HACC DOs support all examples listed, except individual claims for compensation [pg 25], as this this is most appropriately dealt with through the court system

- To review reports from complaints bodies [***see Recommendation 3***] and make recommendations to government;
- To advise on special interest groups, such as:
  - Older people with disability and the interface with the aged care system
  - Younger people with disability in residential aged care
  - CALD and Aboriginal access and participation
  - People with Neurodegenerative conditions
  - People with mental health conditions and the interface with mental health services
  - People with multiple disabilities
- To make recommendations on workforce needs based on figures coming through on worker registrations administered by the Oversight Body ;
- To make recommendations to COAG, State and Federal Disability Ministers about all issues relating to people with disability as elucidated in the *UN Convention* and the *National Disability Strategy 2010–2020;*
- To make recommendations to Government about patterns in provider registrations and where investment needs to be directed [e.g. more allied health in Dubbo, overnight respite in Newcastle];
- To provide targeted advice on the roll-out of the NDIS on issues that come from various regions via local development officers [described below];
- Advise on significant issues relating to disability support services, advocacy and rights, such as:
  - Deinstitutionalisation
  - Housing
  - Social inclusion
  - Health
  - Education
  - Employment
  - Criminal Justice
  - Children and young people
  - Early intervention
  - Squalor and hoarding

The ideal Oversight Body will be constituted by people with disability and sector representatives, such as peaks and researchers. Under this model, each State is to convene a board and elect representatives for the Federal board, with appointments from relevant State and Federal level disability support, rights and advocacy agencies, such as the NSW Disability Council charged with the implementation of the *Disability Inclusion Act 2014 (NSW),* and statewide peak bodies, such as National Disability Services NSW. The Federal Board and State boards will convene working groups on significant issues [as listed above], in order to inform government policy and direct social investment.

The States will require a local presence, perhaps regional community development workers operating under a hub and spokes model, who act as objective conduits who work for the Oversight Body. For instance, over the past thirty years, especially in the NSW HACC system, and to some extent in disability, there have been formal feedback mechanisms to government through a network of interagencies that can discuss systemic issues. The sector was designed to be connected and coherent, and there were people like HACC Development Officers with formal lines of communication to the department – and most importantly - the social justice commitment of the local organisations.

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[i] Disability, NSW Ombudsman, https://www.ombo.nsw.gov.au/what-we-do/our-work/community-and-disability-services/disability-service

[ii] Disability Home Page, Australian Human Rights Commission, https://www.humanrights.gov.au/disability-rights-homepage

[iii] *Substitute Decision Making: Time for Reform,* People with Disability Australia and NSW Mental Health Coordinating Council, 2009, http://www.pwd.org.au/documents/pubs/SB09-SubstituteDecision.doc

[iv] *Disability Rights Now, Civil Society Report to the United Nations Committee on the Rights of Persons with Disabilities*, August 2012, Compiled by Disability Representative, Advocacy, Legal and Human Rights Organisations, August 2012, p 23, http://www.pwd.org.au/issues/crpd-civil-society-shadow-report-group.html