

# Office of the Public Advocate (Qld)

## Systems Advocacy

### Submission to the Department of Social Services

*Review of the National Disability Advocacy  
Program*

**June 2016**

# Introduction

The Public Advocate of Queensland commends the Department of Social Services (DSS) for reviewing the National Disability Advocacy Program (NDAP) and appreciates the opportunity to provide comment. Consistent with the functions of the Public Advocate, this submission focusses on upholding the rights of people with impaired decision-making capacity.

## The Public Advocate (Qld)

The Public Advocate was established by the *Guardianship and Administration Act 2000* (Qld) to undertake systems advocacy on behalf of adults with impaired decision-making capacity in Queensland.<sup>1</sup>

The primary role of the Public Advocate is to promote and protect the rights, autonomy and participation of Queensland adults with impaired decision-making capacity in all aspects of community life. More specifically, the functions of the Public Advocate include:

- promoting and protecting the rights of the adults with impaired capacity for a matter;
- promoting the protection of the adults from neglect, exploitation or abuse;
- encouraging the development of programs to help the adults reach the greatest practicable degree of autonomy;
- promoting the provision of services and facilities for the adults; and
- monitoring and reviewing the delivery of services and facilities to the adults.<sup>2</sup>

There are a number of health conditions that may contribute to impaired decision-making capacity in adults. They include, but are not limited to, intellectual disability, acquired brain injury, mental illness, ageing conditions such as dementia, conditions associated with problematic alcohol and drug use, and other related conditions. These conditions are referred to throughout this submission as cognitive and/or psychosocial impairment.

Many people living with cognitive and/or psychosocial impairment may, at some point in their lives, if not on a regular and ongoing basis, experience impaired decision-making capacity. A significant number of these individuals may require support with decision-making that includes accessing and analysing information, determining and weighing up available options, and communicating choices and decisions. They may also require support to navigate societal systems, and to understand their rights and ensure they are upheld.

It is important to note that not all people with cognitive and/or psychosocial impairment have impaired decision-making capacity. Decision-making capacity is dependent on a range of factors including situational issues and personal experience of illness or disability. Further, impaired decision-making capacity does not operate in a global way in people's lives. It may, for instance, be evidenced in only one or a few facets of life (such as finances or health care), and its influence may vary considerably from the subtle to the substantial.

Adults with impaired decision-making capacity comprise a substantial group in Australian society. In 2016, the Office of the Public Advocate estimates the potential population of adults with impaired

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<sup>1</sup> *Guardianship and Administration Act 2000* (Qld) ch 9.

<sup>2</sup> *Ibid* s 209.

decision-making capacity living in Queensland to be 118,739 (1 in 40 people).<sup>3</sup> Given that at least 70 per cent of current participants of the National Disability Insurance Scheme (NDIS) have a cognitive and/or psychosocial disability,<sup>4</sup> it is highly likely that, at full implementation of the scheme, significant numbers of NDIS participants may have some degree of impaired decision-making capacity. Many of these participants may require the support of independent advocates for decision-making, navigating systems, and promoting and protecting their human rights.

## The 2015 Review of the National Disability Advocacy Framework

In 2015, the Public Advocate made a submission to the *Review of the National Disability Advocacy Framework* (the 2015 Review). The submission made a number of recommendations which inform this submission and are summarised below.

- The National Disability Advocacy Framework (the Framework) must reflect a strong focus on human rights, and include clear and explicit references to the guiding principles of the United Nations *Convention on the Rights of Persons with Disabilities* (UNCRPD).
- The independence of advocacy, along with the appearance of independence, must be prioritised and protected in all instances to mitigate against conflict of interest and the minimisation of customer matters requiring advocacy, and to facilitate transparency and accountability of service providers.
- Advocacy for people with disability must be contemporary and progressive. The Framework must, for instance, recognise and reflect the pivotal shifts that are occurring in promoting and protecting the legal capacity of people with disability who may have impaired decision-making capacity.
- Access to advocacy for people with disability living with compounding disadvantage must be strengthened, as must the overall responsiveness of the advocacy system for people with disability generally.
- The Framework must have broad scope (that is, it must apply to all people with disability, not just participants of the NDIS) and accommodate all types of advocacy required by people with disability.
- The Framework must facilitate transition to the new service environment. A comprehensive advocacy system that effectively and equitably responds to people with disability is the shared responsibility of multiple government agencies and will require a co-ordinated and integrated strategy.
- The definition of disability advocacy must be simultaneously broad and sufficiently detailed to address the gamut of issues that people with disability may encounter, including abuse, discrimination and exploitation.
- The Framework must be based on evidence and allow for the systematic collection, management and analysis of data to inform and evaluate the quality and effectiveness of the NDAP.

The Public Advocate's 2015 submission is located at Appendix One.

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<sup>3</sup> Office of the Public Advocate (Qld), *Potential Population for Systems Advocacy* (January 2016) <[http://www.justice.qld.gov.au/\\_\\_data/assets/pdf\\_file/0006/457539/fs02-potential-population-v5.00.pdf](http://www.justice.qld.gov.au/__data/assets/pdf_file/0006/457539/fs02-potential-population-v5.00.pdf)>.

<sup>4</sup> National Disability Insurance Agency, *Quarterly Report to COAG Disability Reform Council* (31 March 2016) <<http://www.ndis.gov.au/about-us/information-publications-and-reports/quarterly-reports>>.

# The position of the Public Advocate (Qld)

The Public Advocate strongly supports advocacy as an essential mechanism for promoting and protecting the rights of people with disability in line with the UNCRPD.<sup>5</sup> Both individual and systems advocates play a critical role in upholding the key rights and principles in the UNCRPD, including promoting accessibility to services and physical premises,<sup>6</sup> as well as to justice;<sup>7</sup> addressing discrimination<sup>8</sup> and promoting reasonable accommodation;<sup>9</sup> supporting participation in all aspects of life;<sup>10</sup> ensuring equal recognition before the law and supporting legal capacity;<sup>11</sup> promoting an adequate standard of living;<sup>12</sup> and preventing and eliminating harmful treatment.<sup>13</sup> This office encourages the Australian Government to uphold advocacy as a critical, independent and non-negotiable safeguard for people with disability, and asserts that it must be adequately resourced and promoted as part of an integrated disability system within Australia.

The Public Advocate commends the DSS on a number of positive inclusions in the 2016 *Review of the National Disability Advocacy Program Discussion Paper* (the Discussion Paper). Of note are the emphases on:

- the equal enjoyment of human rights and full community participation for people with disability;
- the incorporation of six types of advocacy into the Framework;
- the need for increased responsiveness to the issues, requirements and preferences of people with disability;
- the importance of a sound evidence base on which to evaluate the effectiveness of advocacy supports and services;
- addressing access to, and gaps in coverage of, advocacy services, particularly with respect to people with disability living in isolated areas and/or experiencing additional disadvantage (such as people with disability from culturally and linguistically diverse and indigenous backgrounds);
- the provision of advocacy to people with disability who are not part of the NDIS; and
- the changing cultural and demographic trends impacting upon the delivery of advocacy services.

Irrespective of these generally positive inclusions, the 2016 Discussion Paper does not appear to have resolved issues identified in the 2015 Discussion Paper. The 2016 Discussion Paper has little detail about the proposed program, including any evidence to support the planned direction. It is therefore difficult to prepare a comprehensive submission.

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<sup>5</sup> United Nations, *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007 [2008] ATS 12 (entered into force 3 May 2008) <<http://www.un.org/disabilities/convention/conventionfull.shtml>>.

<sup>6</sup> Ibid preamble.

<sup>7</sup> Ibid art 13.

<sup>8</sup> Ibid preamble.

<sup>9</sup> Ibid art 2.

<sup>10</sup> Ibid arts 25, 27, 29.

<sup>11</sup> Ibid art 12.

<sup>12</sup> Ibid art 28.

<sup>13</sup> Ibid arts 15, 16.

This submission responds to the five key issues identified in the Discussion Paper. The goal of this submission is to support the establishment of a NDAP that is:

- strongly human rights and evidence based;
- effective, independent and responsive to the individual needs of people requiring disability advocacy;
- accessible; and
- adequately resourced.

## Threshold issues for the National Disability Advocacy Program

### Mapping the system

Revisions to the disability advocacy system in Australia should be undertaken on the basis of a comprehensive and evidence-based review of the current system that includes mapping the current state of the system.

A mapping process is particularly important given the ad hoc development of disability advocacy in Australia. Funded advocacy for Australians with disability emerged in the decades post de-institutionalisation,<sup>14</sup> and sprang up in response to local identified need rather than as a planned and co-ordinated strategy for advocacy service provision. As a result, and as identified in the Discussion Paper, the contemporary advocacy system has considerable gaps in geographical coverage, responsiveness of the system and availability of advocacy types.<sup>15</sup>

The current review of the Framework and the NDAP provide an opportunity to develop a comprehensive disability advocacy strategy that will support the sector in the new NDIS environment and into the future. This strategy needs to incorporate a clear vision about the future of the NDAP that includes the models of advocacy it will fund, the locations of services, the accessibility needs of smaller and more remote communities, and the technological and outreach mechanisms required to strengthen access. Finally, the strategy requires a plan in order to reach the desired end-state, which should include activities that will grow the capability of the sector, including the range of advocacy services, their coverage, responsiveness and accessibility. Before such a strategy can be developed, it is important to first know what the program is currently funding, what advocacy services are available and where.

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**Recommendation:** *The DSS should undertake a comprehensive review of disability advocacy provision in Australia to accurately identify what types of advocacy are available where, understand the nature of the gaps that currently exist, develop a targeted evidence-based strategy for addressing those gaps, and make informed decisions about where to invest limited funding.*

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<sup>14</sup> Disability advocacy was recognised as a programme area in the *Disability Services Act 1986* (Cth).

<sup>15</sup> Department of Social Services, *Review of the National Disability Advocacy Program: Discussion Paper* (April 2016) 2, 4.

## Resourcing advocacy

If the disability advocacy system is to achieve the DSS' vision for a responsive, evidence-based, integrated and effective NDAP,<sup>16</sup> it must be appropriately resourced.<sup>17</sup>

Australia's system of advocacy for people with disability is widely considered to be underfunded; even with multiple advocacy providers operating in each state,<sup>18</sup> advocates report being unable to meet the considerable demand for their services. Some advocacy organisations in Queensland, for example, report operating on a skeleton, part-time staffing contingent, carrying caseloads beyond resources, and regularly turning people with disability away because they have no capacity to take up new issues. Some advocacy agencies in Queensland also report that, because of limited resources, only the most urgent and sometimes life-threatening cases can be accepted. This situation leaves advocacy services with a chronic inability to absorb non-critical issues brought by people with disability but which are nonetheless important for protecting their human rights. Additionally, instead of funding keeping pace with demand, advocacy agencies have informed this office that funding has stayed static despite substantial increases in the costs of operation. This situation has resulted in a reduction in the capacity of some advocacy organisations to respond to the issues brought by people with disability.

The inadequate resourcing of the disability advocacy sector particularly is concerning given the anticipated increase in the number of people who will receive disability services when the NDIS is fully implemented.<sup>19</sup> These issues take on even greater significance given the challenges facing people with disability as a result of the paradigm shift from provider-driven to user-driven services under the NDIS. While greater choice and control for consumers of disability services has the potential for improved quality of life,<sup>20</sup> it also brings increased responsibility for negotiating plans and contracts with vendors and providers. As a consequence, the NDIS will result in a contract culture that requires greater direct engagement by people with disability, and may require increased involvement of advocates, particularly for those individuals who lack capacity to engage effectively in complex negotiations and/or to seek remedy for faulty products or poorly delivered services. A rapidly growing consumer base and increasing marketplace complexity demand that funding for advocacy be increased to a level commensurate with these shifts.<sup>21</sup>

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**Recommendation:** *The review of the NDAP should include a review of the resourcing of the disability advocacy sector and its ability to meet demand in the new NDIS environment.*

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<sup>16</sup> Ibid 3.

<sup>17</sup> The need for appropriate resourcing of advocacy is supported in Recommendation 16 of the Senate Community Affairs References Committee's report on *Violence, Abuse and Neglect Against People with Disability in Institutional and Residential Settings, Including the Gender and Age Related Dimensions, and the Particular Situation of Aboriginal and Torres Strait Islander People with Disability, and Culturally and Linguistically Diverse People with Disability* (November 2015) xx <[http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/Violence\\_abuse\\_neglect/Report](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Violence_abuse_neglect/Report)>.

<sup>18</sup> See Disability Advocacy Network Australia, *Advocacy Organisations* <<http://www.dana.org.au/home/advocacy-groups/>>.

<sup>19</sup> 450,000 Australians are expected to benefit from the NDIS by full roll-out. See National Commission of Audit, *7.2 The National Disability Insurance Scheme* <<http://www.ncoa.gov.au/report/appendix-vol-1/9-2-national-disability-insurance-scheme.html>>.

<sup>20</sup> The NDIA argues that increased choice and control, along with greater levels of independence, lead to improved life experiences. See National Disability Insurance Scheme, *Promoting Independence for People with Disability* <<http://www.ndis.gov.au/about-us/governance/IAC/iac-advice-independence>>.

<sup>21</sup> See above n 17 regarding the need for significant investment in funding for advocacy to keep pace with the increase in numbers of people accessing the NDIS.

## Models of advocacy

### Issues for people with impaired decision-making capacity

This office supports the inclusion of the six types of advocacy identified in the Discussion Paper. We do, however, have concerns about some aspects of the model, and raise three points for particular consideration with respect to promoting and protecting the rights of people with impaired decision-making capacity.

#### Self-advocacy

Self-advocacy is an important inclusion in the NDAP. While this Office strongly supports self-advocacy as a strategy for empowering people with disability<sup>22</sup> and developing their capabilities,<sup>23</sup> we recognise that this form of advocacy should not be relied upon as the primary advocacy mechanism for some people with impaired decision-making capacity. For example, people with profound cognitive or communicative disability are likely to have difficulty recognising the importance of and need for advocacy in a situation, and may have considerable difficulty gathering evidence and presenting it in ways that can effect change. Self-advocacy is also based on the presumption that the relationship between customer and service provider is sufficiently equal to promote the resolution of issues. This is not always the case, particularly in circumstances where significant power imbalances exist (for example, where people with disability receive their accommodation, support and care from one provider).

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***Recommendation:** The Framework and the NDAP should acknowledge the limitations of self-advocacy, and ensure that alternative forms of advocacy are readily available to people with impaired decision-making capacity.*

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#### Systems advocacy

The importance of systems advocacy should not be underestimated in the NDAP. Systems advocacy focusses on influencing the legislative, policy and practice aspects of systems, and provides a cost-effective way of addressing issues affecting large numbers of people with disability.

Most Australian states and territories have legislation that provides for the appointment of statutory officers to undertake systems advocacy for adults with impaired decision-making capacity (such as the Public Advocate in Queensland). We note, however, that there appears to be no plan for the establishment of a Public Advocate, or equivalent, at the federal level.

While this office, along with its counterparts in other states and territories, sometimes comment about systems issues affecting adults with impaired decision-making capacity in the broader Australian context, state-based Public Advocates do not have power to source information and data beyond their jurisdictions. Unless the Australian Government formally recognises the role of state-based Public Advocates in the NDIS and other federally-based systems such as aged care, the Public Advocates' ability to access information and advocate in the interests of people with impaired decision-making capacity who are receiving services within those systems will be significantly

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<sup>22</sup> See, for example, Thomas G Ryan and Sarah Griffiths, 'Self-Advocacy and its Impacts with Adults with Developmental Disabilities.' (2015) 55(1) *Australian Journal of Adult Learning* 31-53.

<sup>23</sup> See, for example, S Carrington and N Lennox, 'Advancing the Curriculum for Young People who have an Intellectual Disability. Advocacy in Health: A Pilot Study.' (2008) 32(2) *Australasian Journal of Special Education* 177.

limited. Alternatively, the Australian Government may prefer to establish a Commonwealth Public Advocate or equivalent statutory office to fulfil those functions. Either of these approaches would further demonstrate the Australian Government's ongoing commitment to establishing systems and agencies that promote and protect the rights of vulnerable people with disability in line with the UNCRPD.<sup>24</sup>

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**Recommendation:** *The Australian Government should either formally recognise the role of state-based Public Advocates to undertake systems advocacy for adults with impaired decision-making capacity who receive services in federally-based systems, or establish a Public Advocate or equivalent independent statutory office with jurisdiction to advocate at the federal level.*

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## **Inclusion of the *National Decision-Making Principles***

Consistent with the principles of the UNCRPD and contemporary discourse about decision-making, the Australian Law Reform Commission's report *Equality, Capacity and Disability in Commonwealth Laws*<sup>25</sup> promotes the need for government-funded services to shift their focus from what people cannot do, to the supports that should be provided to enable them to make decisions and exercise their legal capacity.

The Australian Law Reform Commission proposed a set of *National Decision-Making Principles* as an initial step to reforming Commonwealth, state and territory laws and legal frameworks on decision-making. The *National Decision-Making Principles* are:

- **Principle 1 – The equal right to make decisions:** All adults have an equal right to make decisions that affect their lives and to have those decisions respected.
- **Principle 2 – Support:** People who require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives.
- **Principle 3 – Will, preferences and rights:** The will, preferences and rights of people who may require decision-making support must direct decisions that affect their lives.
- **Principle 4 – Safeguards:** Laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for people who may require decision-making support, including to prevent abuse and undue influence.<sup>26</sup>

The *National Decision-Making Principles* should be included in the Framework to ensure that advocacy services operating under the NDAP maximise the participation and right to autonomy of people with impaired decision-making capacity, and assist them to make their own choices in the advocacy process.<sup>27</sup>

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**Recommendation:** *The National Decision-Making Principles should be incorporated into the Framework and NDAP.*

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<sup>24</sup> United Nations, *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007 [2008] ATS 12 (entered into force 3 May 2008) art 33 <<http://www.un.org/disabilities/convention/conventionfull.shtml>>.

<sup>25</sup> Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws*, Report No 124 (2014).

<sup>26</sup> *Ibid* 64.

<sup>27</sup> Individual autonomy is a general principle of the UNCRPD. See article 3(a).



# Improving responsiveness

## Growing sector capability

Some cohorts of people with disability – for instance, people from Aboriginal or Torres Strait Islander backgrounds who live in remote areas of Queensland, and people living with diagnoses of intellectual disability, mental illness and dementia – live with multi-faceted disadvantage. Dealing with complex issues relating to specific populations living in challenging situations often requires deep knowledge and/or lived experience of culture and/or disadvantage. Advocacy organisations typically grow rich bodies of local knowledge, networks and relationships, along with expertise in the relevant advocacy types as part of their long-term engagement in local communities and with particular cohorts of people with disability.

Ideally every advocacy service would be able to respond professionally, sensitively and knowledgeably to all people with disability, irrespective of culture, contextual complexity or the nature of issues presented. The small size of many advocacy organisations, however, makes developing robust knowledge and expertise across all disability cohorts and advocacy models difficult, if not unrealistic.

Despite these limitations, this office recognises that the review of the Framework and the NDAP presents an opportunity to grow the capability of the sector and improve service responsiveness. The Framework and NDAP need to strike a balance between recognising and preserving the local knowledge, expertise and networks grown by Australian advocacy agencies over several decades and supporting those services to grow their capability to ensure the system delivers the highest possible degree of responsiveness to every person with disability who accesses it.

One way to do this would be to ensure that knowledge and expertise can be easily shared between advocacy services across Australia. This could be achieved by establishing a collaborative consortium of advocacy services currently providing individual and systems advocacy to people with disability. Membership in the consortium would need to be open to all disability advocacy services, irrespective of funding source, cohort expertise or preferred advocacy model.

This collaborative consortium could perform a number of functions, including:

- establishing, growing and maintaining a cross-jurisdictional network of advocacy agencies that provide individual and systems advocacy to people with disability;
- strengthening advocacy sector capability by promoting collaboration and co-ordination of activities, and the expansion of innovative service delivery through, for instance, the use of technology;
- conducting network meetings with agencies (including via tele/videoconferencing) to discuss emerging issues, share information and updates, and develop advocacy strategies and resources;
- auspicing annual conferences and free workshops to strengthen the knowledge and skills of advocates;
- developing and publishing advocacy training materials and resources for professional advocates;
- collecting, managing, analysing and publishing the data provided by advocacy agencies;
- liaising and sharing information and data with the government departments responsible for funding advocacy across Australia;

- developing advocacy resources for people with disability (for example, web-based applications that promote advocacy services and streamline access to them); and
- sourcing research funding and co-ordinating priority research projects on key advocacy-related issues for people with disability.

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***Recommendation:** The DSS should consider developing a collaborative consortium of disability advocacy services to grow the capability of the disability advocacy sector through enhancing and sharing the knowledge and skills of advocates around Australia and promoting collaboration between services.<sup>28</sup>*

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## Improving access to advocacy supports

### The importance of community education and referral relationships

People with disability need clear pathways to independent advocacy. Often when people with impaired decision-making capacity have a need for advocacy, neither they nor members of their support networks, recognise this need. Even when they do, many would not know how or where to access disability advocacy supports and services.

This situation reflects the experience of many disadvantaged people in the community with legal problems. The legal assistance sector has long recognised the need for community legal education to help people identify that they have a legal problem, inform them about their rights and responsibilities and how to get legal help.<sup>29</sup> The Commonwealth Government, through its legal assistance funding program to legal aid commissions and community legal centres across Australia, has required these organisations to provide community legal education as part of their suite of services and has set performance measures for this activity.<sup>30</sup>

We suggest that the NDAP should recognise the importance of disability advocacy services providing “community advocacy education” as part of their suite of services to ensure that people with disability, their support networks and service providers can identify when they need disability advocacy and how to access those services. Disability advocacy services would need to develop strategies to support strong relationships with disability support services, other disability service providers and community visitors to establish referral pathways for people with disability who need advocacy services. Some ways they could do this would be to provide information and training to workers in these referral networks about disability advocacy services and how they can assist people with disabilities to promote and protect their rights. They should also develop simple and accessible information explaining their services for clients and their supporters and how they can be contacted.

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***Recommendation:** The importance of community advocacy education should be acknowledged in the Framework and the NDAP, and agencies that are funded under the NDAP should also be funded to deliver community advocacy education.*

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<sup>28</sup> The Public Advocate acknowledges the challenges that accompany this approach, such as asking advocacy services to share information under conditions of competitive tendering. These complexities will need to be addressed by the DSS.

<sup>29</sup> See, for example Legal Aid Queensland, *Community Legal Education Strategy 2016-17*, 3.

<sup>30</sup> Council of Australian Governments, *National Partnership Agreement on Legal Assistance Services*.

There are obvious benefits for disability advocacy services that engage with networks such as the Queensland Community Visitor Program. Community Visitor Programs are widely recognised as valuable mechanisms for identifying issues facing people with impaired decision-making capacity. The program serves as a key outreach mechanism for people residing in authorised mental health facilities, forensic disability services, and community-based supported accommodation services, and plays an important role in the prevention and cessation of abuse and neglect that can occur in institutional settings.<sup>31</sup> The external scrutiny provided by community visitors – along with the requirement to identify issues and report them to a statutory agency<sup>32</sup> – means that many people with impaired decision-making capacity who live in closed environments may have their issues identified and resolved without ever having to seek out an advocacy service. The Community Visitor Program can provide valuable referrals, assisting people with impaired decision-making capacity to make contact with independent advocates where required.

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*Recommendation: The Framework and the NDAP should acknowledge the importance of advocacy services developing referral relationships and networks.*

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## Additional mechanisms for improving access to advocacy

### Ensuring advocacy is free

One of the strengths of the current disability advocacy system is that people with disability have access to free advocacy. This is particularly important given that low income and poverty are issues for many people with disability.<sup>33</sup>

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*Recommendation: The Framework and NDAP should explicitly state that advocacy for people with disability will continue to be available free of charge during and after the implementation of the NDIS.*

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### Utilising technology

The Public Advocate supports the use of contemporary communication technologies to facilitate access to advocacy.

Strengthening access to, promoting the sharing of information between, and improving the efficiency of advocacy services across Australia will require the resourcing of a range of contemporary communication technologies including teleconferencing, videoconferencing, Skype, TTY communication, web-based applications,<sup>34</sup> and the use of social media.

The use of technology will be particularly important for consumers of advocacy services living in rural and remote Australia. Thus funding for advocacy in these areas will need to go beyond resourcing the advocacy services themselves to ensuring that facilities located in isolated

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<sup>31</sup> See, for example, Carolyn Frohmader (cited in Xavier Smerdon, 'Independent Inquiry Call Over Yooralla Abuse' (Pro Bono Australia News, 25 November 2014) [24] <<http://www.probonoaustralia.com.au/news/2014/11/independent-inquiry-call-over-yooralla-abuse#>>).

<sup>32</sup> In Queensland, this agency is the Office of the Public Guardian. The Public Guardian receives reports from the Community Visitor Program and sends them to the relevant service providers (see *Public Guardian Act 2014* (Qld) ss 47(1), 47(3)).

<sup>33</sup> Jennifer Mays, 'Disability, Citizenship, and Basic Income: Forging a New Alliance for a Non-Disabling Society' in Jennifer Mays, Greg Marston and John Tomlinson (eds), *Basic Income in Australia and New Zealand: Perspectives from the Neoliberal Frontier* (Palgrave Macmillan, 2016) 207.

<sup>34</sup> For instance, an app that assists people with disability to identify advocacy services that are closely aligned with their advocacy needs.

communities (such as neighbourhood centres and libraries) have adequate information and communication technology (ICT) infrastructure to support alternative forms of service delivery.

Further, the DSS could establish funding for the development of an innovative, technology-based advocacy model that maximises access for people with disability to all advocacy types.

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**Recommendation:** *The DSS should resource technologies both within advocacy organisations and regional, rural and remote communities so that adults with impaired decision-making capacity can access a full range of advocacy services and select those best suited to their needs and circumstances.*

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## Improving the advocacy evidence base and co-ordination on systemic issues

The Discussion Paper highlights the need for a more robust evidence base in relation to advocacy activities in Australia and to support improvements in the lives of people with disability.<sup>35</sup> The Discussion Paper does not outline the nature of the data currently being collected from advocacy services or the methodology and mechanisms by which it is being collected. This makes it difficult to make recommendations for improving data collection and strengthening the evidence base.

Even without this information, it is apparent that there is minimal collection and analysis of data in the broader disability advocacy space. Advocacy services used by people with disability are funded by a number of government departments at both federal and state/territory levels, and the data being requested by these agencies is not consistent across funding bodies. This situation means that, at best, the DSS is capturing and reporting only partial data about the advocacy being delivered to people with disability.

One way to support a standardised system of data collection would be to establish a National Data Collection Framework (NDCF) across all advocacy organisations used by people with disability (including NDAP services, state/territory funded advocacy services, community legal centres, and legal aid services). An NDCF would require the relevant funding bodies to create a multi-agency partnership, and collaborate on data content and methodology. Collection, management and analysis of data could be undertaken by any one (or all) of these agencies, a Commonwealth Public Advocate, or an agency assigned to co-ordinate the collaborative consortium.

Assigning data management to a single entity addresses another of the questions in the Discussion Paper: sharing data between stakeholders. The agency or co-ordinating body responsible for managing the data could publish the findings and disseminate them to private and public stakeholders. This entity could also play a role in strengthening the advocacy evidence base by establishing research partnerships and undertaking research that explores the effectiveness of advocacy from the perspective of people with disability.

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**Recommendation:** *Government should collaborate on, and commit to, a comprehensive and systematic data collection strategy and research framework for disability advocacy as a priority so that the collection of baseline data from all advocacy services can occur before full roll-out of the NDIS.*

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<sup>35</sup> Above n 15, 5.

## The interface with the NDIS and addressing conflict of interest

One of the key principles underpinning effective advocacy is that of independence. Advocacy services must not only be independent, they must also be seen to be independent. What this means is that there should never even be the potential for a suggestion that the service is not independent. Consequently, it is the view of this office that any framework that permits disability service providers to also offer disability advocacy services is fundamentally flawed because advocacy must be free of conflict of interest and must uphold independence and the appearance of independence in all circumstances.

The principle of independence recognises that employees' actions are driven not only by explicit directives (policy and procedure) but also by organisational culture.<sup>36</sup> Advocates employed by organisations that are also delivering services to people with disability will be entrenched, often unknowingly, in the practices of the organisations in which they work and risk 'capture' by that culture which may result in them not have sufficient awareness or confidence to advocate effectively for people with disabilities.

Additionally, advocates who are employed by the organisation against which their customers are lodging complaints will experience a conflict of interest. Employees have a responsibility to protect the standing and reputation of the organisation and yet as advocates they are expected to strongly assert the rights of customers, actions which may ultimately result in sanctions against the organisation by external agencies. In doing their jobs well, effective advocates may become organisational liabilities. It is reasonable to suggest that advocates may find themselves having to choose between doing the best possible job for consumers or continued employment. At the very least, the perception of this conflict undermines the advocates and the services that they offer.

The Public Advocate cannot envisage any circumstance in which advocacy bodies seeking to operate as service providers under the NDIS could demonstrate they have mechanisms in place that would address the risk and perception of conflicts of interest. We would strongly advise against funding services to perform these dual and conflicting roles.

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***Recommendation:** The DSS must maintain disability advocacy as an independent body of services free of conflicts of interest; advocacy services should not be funded to deliver disability services under the NDIS.*

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## Understanding and improving access to justice

This office acknowledges the particular vulnerabilities of people with disability to a wide range of legal problems.

Many of the legal problems faced by people with disabilities are also legal problems experienced by other members of the community (for example, criminal charges, civil debts, tenancy issues). Legal Aid Commissions, community legal centres, Aboriginal and Torres Strait Islander Legal Services and family violence prevention legal services across Australia are funded by the Commonwealth Government to provide legal assistance services to financially disadvantaged and vulnerable people in the community. Many people with disabilities access these agencies for help with their legal

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<sup>36</sup> Edgar H. Schein, *Organizational Culture and Leadership* (John Wiley & Sons, 4<sup>th</sup> ed, 2010).

problems. However, in terms of improving access to justice, we note the findings of the 2014 Productivity Commission Inquiry Report into *Access to Justice Arrangements* which estimated that additional funding of \$200 million a year needs to be invested in legal assistance services to maintain existing services and to address services gaps impacting access to justice for disadvantaged Australians.<sup>37</sup> This funding shortfall is likely to impact those most vulnerable seeking access to justice, such as people with disability.

We are concerned that the rollout of the NDIS will significantly impact the way support services are provided to some people with disabilities and this in turn will create new issues and gaps in the supports available to help people with disability gain access to justice.

We are also concerned about the potential impacts where funding for support packages under the NDIS is provided directly to the clients to purchase the support services they need. We recognise that there may only be a very small proportion of NDIS participants who will be funded in this way; however, we are concerned that the risks, in terms of legal issues arising from these arrangements, are significant. In addition, the consequences for the quality of life and health of NDIS participants when there are issues with the quality or delivery of services, are also potentially serious.

These new funding arrangements will fundamentally change the relationships that people with disability have with their service providers. Essentially, people with disabilities will be entering into private contracts for the purchase of personal services. Many people in this group will have little, if any, experience contracting services from third parties. This lack of experience will make them particularly vulnerable to being taken advantage of. But at the very least, some people with disability are likely to not have much knowledge about the types of conditions that should be included in these agreements to protect their interests and will have to bear the consequences of that lack of knowledge. These contractual arrangements are likely to pose significant problems for the purchasers of the services (the people with disabilities) when there are issues with the contractual compliance of the service providers. For example, when problems arise with the quality or delivery of services under these arrangements, we are concerned that the purchasers will be 'on their own' in a legal sense. That is, they may need to take their own legal steps to enforce their service agreements, or to seek to recover monies paid for services that were not provided. These NDIS participants may need to access legal services to protect and enforce their rights.

This office is unaware whether legal assistance providers will be funded or prepared to assist NDIS participants who present with these legal problems. We would be interested to receive a clear outline from the DSS about how it anticipates these processes for contracting to purchase services will play out in practice and what supports and protections the department is putting in place for NDIS participants.

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***Recommendation:*** *Given the potential risks to people with disability in an NDIS marketplace and its emerging contract culture, the position and funding of legal advocacy in the NDAP must be clarified and prioritised.*

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<sup>37</sup> Australian Government Productivity Commission, *Access to Justice Arrangements: Productivity Commission Inquiry Report Overview*, No 72 (5 September 2014) 30.

# Summary of recommendations

The following is a list of recommendations made in this submission.

**Recommendation:** The DSS should undertake a comprehensive review of disability advocacy provision in Australia to accurately identify what types of advocacy are available where, understand the nature of the gaps that currently exist, develop a targeted evidence-based strategy for addressing those gaps, and make informed decisions about where to invest limited funding.

**Recommendation:** The review of the NDAP should include a review of the resourcing of the disability advocacy sector and its ability to meet demand in the new NDIS environment.

**Recommendation:** The Framework and the NDAP should acknowledge the limitations of self-advocacy, and ensure that alternative forms of advocacy are readily available to people with impaired decision-making capacity.

**Recommendation:** The Australian Government should either formally recognise the role of state-based Public Advocates to undertake systems advocacy for adults with impaired decision-making capacity who receive services in federally-based systems, or establish a Public Advocate or equivalent independent statutory office with jurisdiction to advocate at the federal level.

**Recommendation:** The *National Decision-Making Principles* should be incorporated into the Framework and NDAP.

**Recommendation:** The DSS should consider developing a collaborative consortium of disability advocacy services to grow the capability of the disability advocacy sector through enhancing and sharing the knowledge and skills of advocates around Australia and promoting collaboration between services.

**Recommendation:** The importance of community advocacy education should be acknowledged in the Framework and the NDAP, and agencies that are funded under the NDAP should also be funded to deliver community advocacy education.

**Recommendation:** The Framework and the NDAP should acknowledge the importance of advocacy services developing referral relationships and networks.

**Recommendation:** The Framework and NDAP should explicitly state that advocacy for people with disability will continue to be available free of charge during and after the implementation of the NDIS.

**Recommendation:** The DSS should resource technologies both within advocacy organisations and regional, rural and remote communities so that adults with impaired decision-making capacity can access a full range of advocacy services and select those best suited to their needs and circumstances.

**Recommendation:** Government should collaborate on, and commit to, a comprehensive and systematic data collection strategy and research framework for disability advocacy as a priority so that the collection of baseline data from all advocacy services can occur before full roll-out of the NDIS.

**Recommendation:** The DSS must maintain disability advocacy as an independent body of services free of conflict of interest; advocacy services should not be funded to deliver disability services under the NDIS.

**Recommendation:** Given the potential risks to people with disability in an NDIS marketplace and its emerging contract culture, the position and funding of legal advocacy in the NDAP must be clarified and prioritised.

## Conclusion

As Public Advocate, I am committed to promoting and protecting the rights, autonomy and participation of Queensland adults with impaired decision-making capacity in all aspects of community life.

To that end, I support the development of a responsive, well-resourced, accessible, independent and evidence-based disability advocacy system that operates as a potent safeguard for people with impaired decision-making capacity and, more generally, for people with disability.

I am grateful for the opportunity to provide comment on the review of the NDAP and commend the Australian Government on its continued engagement with the sector about the program. I look forward to providing comment on a comprehensive NDAP proposal in the near future should there be an opportunity to do so.

Should additional information be required about any aspect of this submission, I would be pleased to discuss the submission further.

Mary Burgess  
**Acting Public Advocate**  
**Office of the Public Advocate (Qld)**

### Office of the Public Advocate

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# Appendix One: Submission to the Review of the National Disability Advocacy Framework

## Introduction

I commend the Australian Government for initiating a review of the National Disability Advocacy Framework (the Framework) and appreciate the opportunity to provide comment. Consistent with the functions of the Public Advocate, this submission has at its premise an important focus on upholding the rights of adults with impaired decision-making capacity.

## The Public Advocate (Qld)

The *Guardianship and Administration Act 2000* (Qld) establishes the Public Advocate as an independent statutory authority. As Public Advocate for Queensland, I am responsible for promoting and protecting the rights, autonomy and participation of adults with impaired decision-making (the adults) in all aspects of community life through statutory systems advocacy.

More specifically, the functions of the Public Advocate are:

- promoting and protecting the rights of the adults with impaired capacity for a matter;
- promoting the protection of the adults from neglect, exploitation or abuse;
- encouraging the development of programs to help the adults reach the greatest practicable degree of autonomy;
- promoting the provision of services and facilities for the adults; and
- monitoring and reviewing the delivery of services and facilities to the adults.<sup>38</sup>

In 2015, the Office of the Public Advocate estimates that there are approximately 115,745 Queensland adults with impaired decision-making capacity (or 1 in 42 adults).<sup>39</sup>

The primary factors that can impact decision-making capacity include (but are not limited to) intellectual disability, acquired brain injury, mental illness, ageing conditions such as dementia, and conditions associated with problematic alcohol and drug use.

It is important to note that not all people with these conditions will have impaired decision-making capacity. Further, impaired decision-making capacity does not necessarily impact all areas of an adult's life, and may fluctuate in response to situational issues.

It is likely, however, that many people with intellectual, cognitive or psychiatric disability (hereafter referred to as cognitive impairment) may, at some point in their lives if not on a regular and ongoing basis, experience impaired decision-making capacity in respect of a matter.

Regardless of whether a person is deemed to have impaired capacity by law, many people with cognitive impairment will nonetheless require support with their decision-making, including access to and the analysis of information, determining and weighing up available options, and

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<sup>38</sup> *Guardianship and Administration Act 2000* (Qld) s 209.

<sup>39</sup> Office of the Public Advocate, *The potential population for systems advocacy* (Fact Sheet, Office of the Public Advocate (Queensland), April 2015).

communicating decisions. More generally, many people with disability may also require support to understand their rights and ensure that they are upheld.

It is also important to note that many of these individuals may become participants of the NDIS.

## Interest of the Public Advocate (Qld)

The introduction of the NDIS represents a significant step towards addressing the deficiencies of state- and territory-based disability service systems within Australia and a meaningful advancement toward the social inclusion of people with disability. A key principle in enabling this is the focus on affording people with disability greater choice and control. It is essential, however, to ensure that such autonomy exists within a context that accommodates and supports people whose capacity to make decisions may be impaired.

An analysis of the available information on NDIS participants indicates that in early 2015 there were 5,004 NDIS participants who may have some form of cognitive impairment. This correlates to 66% of all participants (excluding the South Australian trial site).<sup>40</sup> In view of these statistics and relevant to this submission is the importance of recognising that people with cognitive impairment require different developmental strategies for building their capability in navigating the system, getting the outcomes they want, and exercising their rights. They are also at a much higher risk for abuse, neglect and exploitation.

Acknowledging that all rights apply equally to people with disability, regardless of whether they have decision-making capacity or not, the United Nations *Convention on the Rights of Persons with Disabilities* (the UNCRPD)<sup>41</sup> places a particular onus on Australian governments to provide people with disability the support they need to exercise their rights. The UNCRPD affirms the rights of people with disability and confers the obligation to uphold these rights to all state parties who are signatories to this pivotal document. Importantly, as a signatory to the UNCRPD, the Australian Government has committed to applying this covenant in developing and improving its legislation, policy, programs and services.

The Framework itself acknowledges the role of the UNCRPD in guiding the implementation of the Framework noting that “the framework complements [mechanisms including the UNCRPD] by providing a structure that governments will work within to enable and support people with disability to safeguard their rights and overcome barriers”.<sup>42</sup>

In reviewing the Framework, I strongly support an ongoing focus on conceptualising its provisions from a human rights perspective with clear and explicit reference to the UNCRPD and the principles espoused therein. Ensuring a human rights focus enables the Framework, as an integral document underpinning the future system of advocacy supports, to guide and direct the structural and cultural shifts that are required at a broader societal level. These societal changes are essential to ensuring that people with disability are afforded the dignity of engaging with services and supports in a manner reflective of their non-disabled contemporaries.<sup>43</sup>

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<sup>40</sup> National Disability Insurance Agency, ‘Quarterly Report to COAG Disability Reform Council’ (Report, 31 December 2014) <[http://www.ndis.gov.au/sites/default/files/documents/Report\\_to\\_the\\_Disability\\_Reform\\_Council\\_2014-15\\_Q2\\_Q2.pdf](http://www.ndis.gov.au/sites/default/files/documents/Report_to_the_Disability_Reform_Council_2014-15_Q2_Q2.pdf)>.

<sup>41</sup> *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, [2008] ATS 12 (entered into force 3 May 2008).

<sup>42</sup> ‘National Disability Advocacy Framework’ (Department of Social Services, August 2012), p 1.

<sup>43</sup> Dowse, L. (2001) Contesting Practices, Challenging Codes: Self advocacy, disability politics and the social model. *Disability & Society*, Vol.16, No.1, pp 123-141.

The importance of ensuring recognition for human rights, and providing reasonable accommodation to ensure that individual rights are supported and upheld, underpins my submission.

Recommendation:

- ♦ The Framework must be conceptualised from a human rights perspective, with explicit reference to the United Nations *Convention on the Rights of Persons with Disabilities*, and clear statements that will guide and direct the role of advocacy services in facilitating the necessary structural and cultural shifts required at a broader societal level.

## Limitations inherent in the review process

The Discussion Paper notes that “there have been significant changes in the disability environment since the Framework was endorsed in 2012”.<sup>44</sup> The Discussion Paper also highlights the importance of the National Disability Advocacy Framework by noting that it is “the structure that governments work within to enable and support people with disability to protect their rights and overcome barriers”.<sup>45</sup>

In light of the importance accorded to this document and the weight that it appears to hold with respect to upholding rights and guiding the provision of advocacy supports, it is concerning that the Discussion Paper lacks sufficient detail to support a full and robust review process. For example, there is limited information regarding the implementation of the Framework to date nor any reference to particular areas that may be presenting a barrier to its effectiveness in achieving the desired outcomes.

These limitations make it difficult to assess the efficacy of the Framework. They also present a significant challenge to providing constructive and informed feedback to support improvements that may assist, if required, in more effectively translating the Framework’s provisions to practice within the context of the contemporary disability policy and service provision environment.

Furthermore, while the Discussion Paper references decisions made by the Council of Australian Government’s Disability Reform Council in respect of advocacy<sup>46</sup>, there is no detail provided about these decisions with the exception of high-level descriptors that offer little by way of context to the review. While the detail of these decisions may be known to agencies such as my own, many people with disability and their families/carers may not have access to this information.

It is also concerning that the way in which the Discussion Paper is presented suggests that the review process is being undertaken in support of the agreed funding arrangements in respect of advocacy supports, which in and of itself may fundamentally compromise the basic tenets of advocacy.

While the Discussion Paper suggests that the potential impact on the administration of advocacy services is still being assessed and notes that details of these arrangements are “still to be worked out”<sup>47</sup>, these references offer little by way of enabling considered responses and recommendations that might assist in the development of a new Framework.

This submission will therefore provide comment to the extent that it is possible to do so. It will also highlight areas in which further information regarding the implementation of the Framework is

<sup>44</sup> ‘Discussion Paper – Review of the National Disability Advocacy Framework’ (Department of Social Services, June 2015), p 2.

<sup>45</sup> Ibid, p 2.

<sup>46</sup> Ibid, p 3.

<sup>47</sup> Ibid, p 3.

urgently required to inform a more cohesive analysis of the extent to which the Framework can be appropriately contextualised and operationalised within the evolving environment in which people with disability will access supports and services.

Further, unless otherwise specified, the information discussed in this submission should be assumed to be inclusive of the broad spectrum of advocacy supports ranging from self-advocacy to individual advocacy to systemic advocacy. Being able to access necessary advocacy supports regardless of where they may be situated along this continuum is an important feature of disability advocacy and should be supported regardless of any decisions that may be made in respect of the funding sources for different types of advocacy support.

## Position of the Public Advocate (Qld)

### The importance of independent advocacy

Access to advocacy plays a critical role in supporting vulnerable people to voice their issues and make complaints.<sup>48</sup> Under the future system of advocacy supports, inclusive of those proposed to be funded by the NDIS, there must be a commitment to ensuring that independent advocacy remains available and easily accessible to individuals and that the level at which advocacy is funded is adequate to meet the need and demand for advocacy services.

While, in some circumstances, advocacy is required to facilitate access to the disability service system where decisions of eligibility or administration have denied access to, or inaccurately assessed the level of, support required by an individual, it must be recognised that the need for advocacy is far broader than this single service system.

More often than not, the need for advocacy exists alongside the provision of disability supports and is not limited to those who access specialist disability services. People with disability engage with a broad range of systems in seeking to achieve necessary outcomes. An individual's ability to successfully navigate this complex web of systems may be impacted by numerous compounding personal, environmental and social factors.

In 2012, the Law and Justice Foundation of New South Wales published a report on access to justice and legal needs in Australia. This report ultimately found that "people with a disability are not only more likely to experience legal problems but are, in fact, more vulnerable to a wide range of legal problems".<sup>49</sup>

The number of legal problems that people with disability face may increase with the introduction of the NDIS. It is crucial for individuals to be able to access advocacy supports to not only navigate the NDIS but also to deal with urgent matters as they arise. The absence of these supports can result in negative and undesirable outcomes for people. It may also trigger emergency and/or crisis situations that require expensive tertiary interventions.

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<sup>48</sup> See, for example, Deane (cited in 'Draft Report on Caring for Older Australians' (Transcript of Proceedings at Brisbane on Friday, 25th March 2011, at 8.29 am, Australian Government Productivity Commission (AGPC), 2011e), pp 737 - 738, <[http://www.pc.gov.au/\\_data/assets/pdf\\_file/0019/107443/20110325-brisbane.pdf](http://www.pc.gov.au/_data/assets/pdf_file/0019/107443/20110325-brisbane.pdf)>); Colin Goble, "Like the Secret Service isn't it." People with Learning Difficulties, 'Perceptions of Staff and Services: Mystification and Disempowerment' (1999) 14(4) *Disability & Society* pp 449-461; Nursing Home Deaths Spark Concerns Over Aged Care Complaints System' (ABC News, 7 November 2013) <<http://www.abc.net.au/news/2013-11-07/nursing-home-deaths-spark-concerns-over-aged-care-complaints-sy/5075260>>; 'Elder Abuse' (Second Report of Session 2003-04, Vol. 1, House of Commons Health Committee (HCHC)), 29.

<sup>49</sup> Christine Coumarelos, Deborah Macourt, Julie People, Hugh M McDonald, Zhigang Wei, Reiny Iriana and Stephanie Ramsey, 'Access to Justice and Legal Needs Volume 7' (2012) at 18 <<http://www.lawfoundation.net.au/ljf/app/&id=FC6F890AA7D0835ACA257A90008300DB>>.

Advocacy is likely to play an important role in supporting people through NDIS processes and in building an individual's capability. While legal advocacy and advocacy in support of upholding the rights of people with disability may not be 'funded' by the NDIS, ensuring its availability will be critical to the success of the NDIS, particularly in respect of safeguarding participant rights.

It is essential that advocacy services remain independent and that the value of upholding this independence is not diminished. Independent advocacy can help ensure that systems and services remain accountable for their actions. It can also mitigate against conflict of interest situations arising such as in circumstances where a support worker is asked to escalate an issue that a person with disability has with the service provider.

Having access to independent advocacy also reduces risk for people with disability. Given the often isolated and closeted nature of personal support, issues raised by a person with disability may go 'unheard', be 'trivialised', or may not be given the necessary ongoing attention to ensure that an issue is addressed to the person's satisfaction.

Furthermore, facilitating access to high-quality, independent advocacy is necessary to strengthen the voices of vulnerable people. It can act as an important safeguard and assist in keeping systems transparent and accountable.

To enable the necessary outcomes and appropriately mitigate potential risks, the Framework must ensure that, regardless of funding sources and mechanisms, the provision of advocacy supports remains independent of the service provision environment.

Recommendations:

- ◆ The Framework must recognise the importance of independent advocacy as a critical safeguarding mechanism for people with disability.
- ◆ The availability of independent legal advocacy (inclusive of legal advice and representation) and advocacy that ensures a focus on supporting and upholding the rights of people with disability must be an integral component of the Framework.
- ◆ Further, while positioning the role of advocacy as being independent of all relevant systems (inclusive of the NDIS), the Framework must still direct recognition for and adherence to its applicability across these systems.

## Ensuring advocacy is contemporary and progressive

The Discussion Paper recognises the dynamic environment within which the evolution of the disability service system is occurring. However, in addition to the changes arising through the implementation of the NDIS, the shifts in contemporary thinking with respect to promoting and protecting the right of people with disability to equal recognition before the law must also be recognised by the Framework.

Arguably, the proper resourcing and implementation of disability advocacy such that it appropriately recognises and supports the capacity of the person to make decisions about and effect change in respect of their own lives has the potential to diminish the need for expensive and intrusive interventions such as guardianship and may reduce the cost of disability support services over time.

The presumption of capacity is integral to any system of support for people with disability. However, capacity has traditionally been viewed, particularly from a legal perspective, as a deterministic and absolute concept. That is, a person either has capacity or they do not. In this respect, the

determination of capacity or otherwise is the current gatekeeper to a person retaining their decision-making rights.<sup>50</sup>

Conversely, contemporary discourse uses the term ‘supported decision-making’ to refer to a process by which a range of supports may be used to enable a person to make their own decisions and retain their legal capacity. Ensuring that the person who is affected by the decision remains at the centre of the decision-making process is intrinsic to the provision of decision-making support.

The practice of supporting a person to make their own decisions occurs every day, often in an informal way. This is not to say, however, that these practices occur without issues or challenges. Despite the challenges, which need to be better understood and addressed, people have the right to make their own decisions wherever possible, and to be provided with support to do so if required.

The provision of decision-making support as a means by which to assist people to communicate, make decisions and exercise their legal capacity aligns with the paradigm shift declared by the UNCRPD. It is increasingly recognised that the focus must shift from what a person cannot do to the supports that should be provided to protect and support the right of a person to make their own decisions.

The national decision-making principles proposed by the Australian Law Reform Commission (ALRC) in their 2014 report on *Equality, Capacity and Disability in Commonwealth Laws*<sup>51</sup> represent a significant opportunity to lead the incorporation of the paradigm change brought about by the UNCRPD into Australia’s domestic laws, policies and programs.

In line with this, the review of the National Disability Advocacy Framework provides the opportunity to embrace this contemporary and progressive approach to upholding the rights of people with disability by reflecting the proposed national decision-making principles (presented below) in the new Framework.

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### ***Proposed national decision-making principles***

***Principle 1: The equal right to make decisions*** – all adults have an equal right to make decisions that affect their lives and to have those decisions respected.

***Principle 2: Support*** – Persons who require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives.

***Principle 3: Will, preferences and rights*** – The will, preferences and rights of persons who require decision-making support must direct decisions that affect their lives.

***Principle 4: Safeguards*** – Laws and legal frameworks must contain appropriate and effective safeguards for persons who may require decision-making support including to prevent abuse and undue influence.<sup>52</sup>

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At its essence, supported decision-making involves the participation of, and ultimately decision by, the person concerned.<sup>53</sup> Irrespective of whether the provision of decision-making support is an

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<sup>50</sup> Mary Donnelly, *Healthcare Decision-Making and the Law: Autonomy, Capacity and the Limits of Liberalism* (Cambridge, 2010), p 90.

<sup>51</sup> Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws* Final Report 2014.

<sup>52</sup> *Ibid*, p 64.

<sup>53</sup> Victorian Law Reform Commission, *Guardianship: Consultation Paper 10* (released March 2011), p 117.

informal process or authorised by law, the person retains their autonomy and legal powers of decision-making.<sup>54</sup>

The right to legal capacity, support for decision-making and effective communication must be articulated as a foundational element for effective disability advocacy.

Recommendations:

- ◆ Upholding the right of people with disability to make their own decisions and to decide the way in which, and when, they access and apply advocacy supports should be integral to the development of the new Framework.
- ◆ The national decision-making principles proposed by the ALRC should be incorporated into the National Disability Advocacy Framework.

## Compounding disadvantage and accessible advocacy

While recognising that the Framework extends beyond the NDIS, the funding of many advocacy supports is proposed to be facilitated through the NDIS. With this in mind, it is important to contextualise any consideration of the efficacy of the Framework by acknowledging that many people with disability experience challenges that limit the extent to which they are able to independently navigate the systems within which supports and services are provided.

The Framework recognises this by stating that “people with disability often face barriers and attitudes that impede their ability to participate in society resulting in poorer life outcomes”.<sup>55</sup> It is similarly recognised that many people with disability experience additional disadvantages that can further limit their ability to achieve necessary outcomes. This is particularly relevant for those people with disability who have a cognitive impairment or impaired decision-making capacity.

Currently, there is a lack of available information for people with disability, in particular people with cognitive impairment, about their rights and how to pursue grievances and make complaints. Information, where it is available, is often not provided in a format that is suitable for people with cognitive impairment or they are not provided with the support they need to understand this information. Individuals can also experience fear in speaking out against the systems from which they are accessing support and this fear is exacerbated by the heavy reliance on service providers who provide support across multiple aspects of everyday living.

NDIS participants with cognitive impairment will need a significant investment in supports to help build their individual capability, particularly when considering the issue of how best to enhance, develop and/or maintain natural safeguards.

Ongoing recognition for these issues is an important component of the Framework. The Framework must ensure that it provides for a system that not only supports people to exercise their rights but also supports people to understand that they have rights.

These challenges are well known in the disability sector and recognition for the existence of multiple disadvantage is reflected in the Framework.<sup>56</sup> Ensuring that the limitations of current systems in respect of persons experiencing multiple disadvantage are attended to is an important focus area.

<sup>54</sup> Terry Carney, ‘Participation and Service Access Rights for People with Intellectual Disability: A Role for Law?’ (2013) 38(1) *Journal of Intellectual and Developmental Disability*, p 60.

<sup>55</sup> ‘National Disability Advocacy Framework’ (Department of Social Services, August 2012), p 1.

<sup>56</sup> *Ibid*, p 1 and p 3.

Further, the importance of accessible and inclusive advocacy supports is paramount to ensuring that all people with disability are able to benefit from the NDIS equally, regardless of their circumstances. To this end, I would recommend that the 'Principles' of the Framework are strengthened with respect to the extent to which they recognise and require attendance to these issues.

Recommendations:

- ◆ The Framework should emphasise that all services, whether funded to provide advocacy supports or not, have a responsibility to ensure clear and accessible information about individual rights to better enable all people with disability, particularly those with impaired capacity, to engage with service providers in an effective manner without fear of retribution.
- ◆ The Framework must also recognise the importance of ensuring accessibility and responsiveness for those who experience multiple disadvantage.

## The scope of the Framework's application

Having been engaged in the consultation process on advocacy and the NDIS in April 2013, I retain a number of concerns about the proposed reach of the Framework that the Discussion Paper does little to address. For example, the Discussion Paper refers to the decision by the Council of Australian Government's Disability Reform Council in relation to advocacy supports that would be funded by the NDIS versus those that will be funded outside the NDIS. However it fails to elaborate on how this impacts the context within which advocacy will be provided despite stating that the review is being undertaken because of the changes to the disability environment that have occurred since it was endorsed in 2012.

At the time of the 2013 consultation underpinning the decision reached by the Disability Reform Council, it was proposed that the NDIS would only fund agencies for the advocacy supports now referred to as 'decision supports', 'safeguard supports' and 'capacity-building for participants' where these activities are clearly additional to the activities that are funded through the NDAP.

Statements made at that time suggested that advocacy supports were likely to be available to people with disability regardless of whether they are NDIS participants or not (an approach that I am supportive of). However, there was little acknowledgment at that time for the fact that the agencies funded by the NDAP do not provide full state/territory-wide coverage within each of the jurisdictions. Neither was it acknowledged that the NDAP does not include specific support for cohorts that are known to face additional barriers in accessing services (for example, Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse backgrounds).

Given that the need for advocacy is usually situation-specific and therefore difficult to 'plan' for, the Framework must ensure that the expectations that it sets clearly articulate a broad reach for the provision of advocacy supports.

There is an urgent need to clarify the application of the Framework within the broader context of human service delivery, and to confirm the arrangements that will be put in place to ensure that all people with disability, regardless of whether they are NDIS participants or not, will be able to access advocacy supports as and when they are needed.



To this end, it is vitally important that the Framework provides for a system that encompasses the full spectrum of advocacy from self-advocacy to individual advocacy to systemic advocacy, as it does now. Despite the Disability Reform Council decision in respect of the way in which different types of advocacy might be funded, the Framework needs to be positioned as a foundational document that guides funding arrangements rather than funding arrangements defining the scope of advocacy supports.

#### Recommendations:

- ◆ The scope of the Framework must ensure that advocacy supports, regardless of their funding source, include the full continuum of advocacy from self-advocacy to individual advocacy to systemic advocacy.
- ◆ The Framework must retain a clear emphasis on the need for improvements in the availability and quality of advocacy supports.
- ◆ The Framework must make it clear that access to advocacy supports is not contingent on being a NDIS participant.
- ◆ Furthermore, it should be clear that although NDIS participants may choose to access advocacy supports as part of their NDIS funding arrangements, even when this is *not* specifically provided for in their plan, advocacy supports must still be obtainable in response to emerging unplanned situations that may arise.
- ◆ The Framework must be developed in a manner that positions it to underpin and guide funding arrangements and the provision of advocacy supports; funding arrangements should not define the scope of advocacy.

## Supporting transition to the new service environment

It is important to recognise that although the Australian Government has committed to the NDIS being fully implemented from 1 July 2019, it is likely that those systems that are supplementary to the NDIS, and yet integral to its success in achieving outcomes for people with disability, may require longer than this to adjust to the demand for support and services likely to emerge into the future.

People with disability have needs that extend across numerous service systems, including (but not limited to) education, housing, health and disability. People with disability also interact with the criminal justice system both as perpetrators and victims. In many cases, however, needs are not met and/or are met in a limited way with little consistency or cohesion across the different service systems.

The consultation process in 2013 suggested that there may be a decrease in the demand for advocacy over time as individuals would no longer need to petition for adequate resources. While this may be a reasonable assumption in respect of disability supports that are able to be accessed through the NDIS, this proposition fails to take into account the reliance of the NDIS on other service systems. To this end, it fails to recognise that people with disability who are ineligible for the NDIS as well as eligible NDIS participants may still require advocacy supports to negotiate access to services that have been identified to be the responsibility of other service systems.

A comprehensive system that appropriately, effectively and equitably responds to people with disability, with or without impaired decision-making capacity, is the shared responsibility of multiple government agencies and requires a co-ordinated and integrated approach. While the NDIS operates within the context of these other systems, which exist to address needs not necessarily attributed to

an individual's disability, it is not evident how greater responsiveness by these systems will be promoted for people with disability. It is therefore likely that the importance of providing advocacy supports to enable people with disability to navigate within and across the NDIS and complementary human service systems will become even more salient into the future.

There is a critical and immediate need for all levels of government, across all sectors, to invest in a sustainable social system that ensures access to social, economic, civic and specialist resources for people with disability, their families and support networks. This is a primary way to promote inclusion, protect rights and interests, minimise disadvantage, and reduce risks of abuse, neglect and exploitation.

A more inclusive and outcomes-focused approach to the delivery of human services would generate increased opportunities for improvement and integration within and across systems, thus enabling more appropriate support to be provided to people with disability.

The Framework must recognise that Australia is in a state of transition and ensure its applicability across the broad range of sectors that people with disability might engage with. Similarly, the availability and responsiveness of advocacy supports must be strongly espoused in the Framework to ensure that the rights of people with disability are not inadvertently compromised as a result of having a limited understanding of their rights and how to navigate systems to access support to exercise their rights.

#### Recommendations:

- ◆ The Framework must be a contemporary, 'forward-thinking' document that sets achievable goals for the future while recognising the evolving nature of disability service provision and the need for corresponding development and growth in those systems that are complementary to the disability service system.
- ◆ The Framework must articulate the importance of supporting people with disability to understand their rights, and to exercise them.

## Definition of 'disability advocacy'

As noted in the Framework, "disability advocacy provides people with disability the opportunity to participate in decisions that impact their lives to ensure their rights are promoted and protected".<sup>57</sup>

The Discussion Paper defines disability advocacy as "advocacy supporting people with disability to:

- stand up for their rights and choices
- take part in their community
- find employment and training
- feel valued and respected
- achieve their goals
- have their say".<sup>58</sup>

<sup>57</sup> 'National Disability Advocacy Framework' (Department of Social Services, August 2012), p 1.

<sup>58</sup> 'Discussion Paper – Review of the National Disability Advocacy Framework' (Department of Social Services, June 2015), p 2.

The breadth of this description would suggest that it is attempting to cover both individual and systemic advocacy, which is further emphasised in the way that the term is used throughout the 'key elements' of the Framework. However, even this broad definition has the potential to limit the breadth of advocacy in the implicit links that it makes to service options such as employment and training, and by failing to recognise the role of advocacy in addressing issues such as abuse, discrimination, exploitation, etc.

Furthermore, the descriptors agreed by the Council of Australian Government's Disability Reform Council in relation to funded advocacy supports that may be available to people with disability (i.e. decision supports, safeguard supports, capacity building for participants, systemic advocacy, and legal review and representation) have the potential to be even more limiting.

Redefining advocacy by breaking it down in the way proposed by the Disability Reform Council presents a risk that individuals may not be able to obtain the support that they need in a manner that appropriately responds to the issue at hand.

Given previous commitments made by Government to ensure no disadvantage for people with disability as a result of the changing service environment, those people requiring disability advocacy supports should similarly be assured that Government will support a comprehensive system of advocacy that protects their rights and interests.

It is of utmost importance that the Framework sets an inclusive tone and clearly directs a system of advocacy that is both flexible and responsive. The new Framework should ensure that the definitions provided for the advocacy supports covered by the Framework are appropriately inclusive of the broad range of supports currently available to people with disability.

The tone set by the Framework must be equally applicable to NDIS participants as it is to the broader population of people with disability, all of whom may require disability advocacy at some point in their lives. The review of the Framework therefore needs to ensure that the 'language' of advocacy is carefully considered to enable all people with disability to access what they need when they need it.

The process of 'mapping' existing advocacy supports to the arrangements that will be adopted into the future must be open and transparent. Any proposed changes to the types of advocacy that Government will fund into the future must be the subject of a consultation process that seeks to ensure that individual rights are afforded ongoing protection.

The definitions and language ultimately agreed on for inclusion in the Framework must be 'road-tested' to ensure that the Framework mitigates against any risk that people requiring disability advocacy will find themselves having to first advocate simply to obtain the necessary funded advocacy supports.

#### Recommendations:

- ◆ Specific and detailed definitions (that err on the side of over-inclusiveness) for the advocacy supports that are proposed to be funded should be agreed and made publicly available with any proposed deviation from the current range of funded advocacy supports subject to public consultation.
- ◆ There should be clear information about the respective agencies that will fund different ‘types’ of advocacy supports and the avenues through which each can be accessed (e.g. as part of a NDIS participant’s plan, through ‘Information, Linkages and Capacity Building’ servicing approaches, using bulk-purchasing arrangements, etc.).
- ◆ Similarly, there should be clear information about the extent to which individuals themselves are able to choose the way in which advocacy is provided, for example by advocating at an individual, group or systemic level, or via a combination of these.
- ◆ The Framework should make it clear that funded advocacy is not limited to NDIS participants, and articulate the need for clear access points.
- ◆ If a gap analysis has not yet been undertaken, Government should urgently prioritise this to ensure that the current range of disability advocacy supports funded and provided (by both the Commonwealth and the States/Territories) can be mapped to the ‘types’ of advocacy supports proposed to constitute ‘disability advocacy’ into the future.

## Evidence-based review and evaluation

One of the questions in the Discussion Paper asks whether “the principles of the framework [are] appropriate for guiding the delivery of advocacy for people with disability...”.<sup>59</sup> Unfortunately this question is not accompanied by any qualitative or quantitative data upon which to assess progress toward outcomes, or in relation to assessing performance against outputs.

The Discussion Paper also states that “recent public consultation on the NDIS Quality and Safeguarding Framework and the NDIS Information, Linkages and Capacity-Building Framework has already facilitated discussion and ideas on advocacy supports in the NDIS.”<sup>60</sup>

Once again, however, there is a paucity of information about what is being considered in this regard, and the process by which the Australian Government is assessing the merit or otherwise of proposals identified through these consultations. The seeming lack of qualitative and quantitative data to support a robust evaluation of the Framework is a significant concern, especially given that one of the outputs articulated in the Framework refers to “disability advocacy [being] informed by an evidence base and ... provided in an accountable and transparent manner.”<sup>61</sup>

Furthermore, despite the above and a statement indicating that all Governments have agreed to “[ensure] that the funding of disability advocacy is transparent, equitable and accountable” and to “... use ... evidence based data for administration and planning of disability advocacy...”,<sup>62</sup> it would appear that the process by which the foundation document for the provision of advocacy supports,

<sup>59</sup> ‘Discussion Paper – Review of the National Disability Advocacy Framework’ (Department of Social Services, June 2015), p 3.

<sup>60</sup> Ibid.

<sup>61</sup> ‘National Disability Advocacy Framework’ (Department of Social Services, August 2012), p 4.

<sup>62</sup> Ibid, p 5.

that being the National Disability Advocacy Framework, is being reviewed fails to be bound by the same requirements for transparency, accountability and use of evidence-based data.

Urgent attention is required to ensure that the Framework does not simply become a ‘piece of paper’ referenced only at the time of review. The effectiveness of the Framework in achieving its objective of providing “people with disability [with] access to effective disability advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights enabling full community participation”<sup>63</sup> must be subject to rigorous monitoring and analysis.

To this end, there is a need to review the outcomes and outputs that are referenced in the Framework to ensure that they are measurable. Furthermore, there must be clear ‘performance standards’ that map directly to the outcomes and outputs and that are articulated as a requirement of Australian governments, and non-government service providers, in the provision of advocacy supports. Once measurable outcomes and outputs have been defined, and performance benchmarks set, Government should engage in a baseline data gathering exercise against which future performance can be compared.

A system for ensuring the regular collection, collation and analysis of this data should also be developed to enable the provision of advocacy supports to be appropriately monitored for both quality and effectiveness. For example, as noted in previous sections, one of the key tenets of effective advocacy is accessibility. Measuring accessibility should take into account a range of factors ranging from timeliness to the breadth of national coverage to the appropriateness of available advocacy supports in dealing with the issues being addressed to ensuring that people with impaired capacity and/or experiencing multiple disadvantage are provided with the necessary supports to facilitate effective outcomes.

The system that is developed should be used to inform a subsequent evaluation of the effectiveness of the Framework itself in no more than five years post release and implementation.

#### Recommendations:

- ◆ Ensure that the outcomes and outputs in the Framework are articulated in a way that enables performance to be measured over time.
- ◆ Establish a clear baseline as the first stage of implementing a system for monitoring advocacy services; and ensuring the regular collection, collation and analysis of data in relation to the provision of advocacy services.

## Concluding comments

Of primary importance to this process of review is ensuring that the new Framework recognises and promotes the ongoing role of disability advocacy as being more than just another service within the context of the NDIS.

While the NDIS has the potential to generate improved life outcomes for people with disability, disability advocacy permeates into a far broader spectrum of society and the Framework must ensure that people with disability are able to access the necessary advocacy supports to attend to issues that arise across multiple environments.

Even in the current disability service environment, advocates more often than not find themselves involved in negotiating on behalf of, and supporting, individuals in their interactions with a range of

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<sup>63</sup> Ibid, p 3.

authorities and services in relation to matters including lack of access, discrimination, and breaches of human rights, or about complex matters that may involve multiple issues, departments or agencies.

Ensuring accessible, responsive and independent advocacy supports is paramount to an effective system of advocacy and, more importantly, to facilitating outcomes for people with disability.

As the principal document underpinning the design, funding and delivery of advocacy supports, the National Disability Advocacy Framework must be an inclusive document with clear benchmarks to guide its implementation and ensure appropriate translation of principles to practice. It must also embrace the opportunity to guide and direct necessary structural and cultural shifts at a broader societal level.

The Framework must retain its focus on human rights, and include clear and explicit references to the guiding principles of the UNCRPD. It must also recognise and reflect the pivotal shifts that are occurring in promoting and protecting the legal capacity of people with disability who may have impaired decision-making capacity.

The importance of ensuring a contemporary, forward-thinking perspective to the provision of advocacy supports for people with disability cannot be under-estimated.

I appreciate the opportunity to provide comment on the review of the National Disability Advocacy Framework and commend the Australian Government in having initiated this review, even while I retain concerns regarding the limitations of the review process. Should additional information be required, I would be pleased to make myself available at any time to further discuss my submission.



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