

**Office of the Public Advocate (Qld)**  
**Systems Advocacy**

**Submission to the Department  
of Social Services**

Review of the National Disability  
Advocacy Framework

**August 2015**

# 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>1</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>2</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 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 National Disability Insurance Scheme (NDIS).

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<sup>1</sup> *Guardianship and Administration Act 2000* (Qld) s 209.

<sup>2</sup> Office of the Public Advocate, *The potential population for systems advocacy* (Fact Sheet, Office of the Public Advocate (Queensland), April 2015).

## 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>3</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>4</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>5</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>6</sup>

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.

<sup>3</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\\_02.pdf](http://www.ndis.gov.au/sites/default/files/documents/Report_to_the_Disability_Reform_Council_2014-15_Q2_02.pdf)>.

<sup>4</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>5</sup> ‘National Disability Advocacy Framework’ (Department of Social Services, August 2012), p 1.

<sup>6</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.

# 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>7</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>8</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>9</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>10</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 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.

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<sup>7</sup> ‘Discussion Paper – Review of the National Disability Advocacy Framework’ (Department of Social Services, June 2015), p 2.

<sup>8</sup> Ibid, p 2.

<sup>9</sup> Ibid, p 3.

<sup>10</sup> Ibid, p 3.

# 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>11</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>12</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.

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

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<sup>11</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)), p 29.

<sup>12</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/lif/app/&id=FC6F890AA7D0835ACA257A90008300DB>>.

‘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>13</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 a 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.

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<sup>13</sup> Mary Donnelly, *Healthcare Decision-Making and the Law: Autonomy, Capacity and the Limits of Liberalism* (Cambridge, 2010), p 90.



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>14</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>15</sup>

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At its essence, supported decision-making involves the participation of, and ultimately decision by, the person concerned.<sup>16</sup> Irrespective of whether the provision of decision-making support is an informal process or authorised by law, the person retains their autonomy and legal powers of decision-making.<sup>17</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.

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<sup>14</sup> Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws* Final Report 2014.

<sup>15</sup> *Ibid*, p 64.

<sup>16</sup> Victorian Law Reform Commission, *Guardianship: Consultation Paper 10* (released March 2011), p 117.

<sup>17</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.

## 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>18</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>19</sup> Ensuring that the limitations of current systems in respect of persons experiencing multiple disadvantage are attended to is an important focus area.

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.

<sup>18</sup> ‘National Disability Advocacy Framework’ (Department of Social Services, August 2012), p 1.

<sup>19</sup> Ibid, p 1 and p 3.



## 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 National Disability Advocacy Program (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.

### Recommendations (cont):

- ◆ 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 coordinated 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-focussed 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>20</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>21</sup>

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.

<sup>20</sup> ‘National Disability Advocacy Framework’ (Department of Social Services, August 2012), p 1.

<sup>21</sup> ‘Discussion Paper – Review of the National Disability Advocacy Framework’ (Department of Social Services, June 2015), p 2.

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>22</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.

<sup>22</sup> 'Discussion Paper – Review of the National Disability Advocacy Framework' (Department of Social Services, June 2015), p 3.

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>23</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>24</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>25</sup> it would appear that the process by which the foundation document for the provision of advocacy supports, 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>26</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.

<sup>23</sup> ‘Discussion Paper – Review of the National Disability Advocacy Framework’ (Department of Social Services, June 2015), p 3.

<sup>24</sup> ‘National Disability Advocacy Framework’ (Department of Social Services, August 2012), p 4.

<sup>25</sup> Ibid, p 5.

<sup>26</sup> Ibid, p 3.

## 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 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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