public guardian

Submission to the Review of the National Disability Advocacy Framework

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Introduction

On 1 July 2014 a new independent statutory body—the Office of the Public Guardian (OPG)—was established to protect the rights and wellbeing of vulnerable adults with impaired decision making capacity, and children and young people in out-of-home care (foster care, kinship care), residential care and youth detention.

The OPG combines the roles that were previously undertaken by the Adult Guardian and Child Guardian and has special responsibilities to support and protect the rights of children and young people in the child protection system. The OPG supports children in care through two specific programs; the community visitor program for children in care, which aims to ensure children and young people in the child protection system are safe and well and are being properly cared for, and the child advocacy program, which gives children in care an independent voice, ensuring their views are taken into consideration when decisions are made that affect them.

Children and young people in out-of-home care have particular needs that must be addressed in order to ensure their safety and improve their emotional, physical and psychological well-being.

The Charter of Rights for a child in care under the *Child Protection Act 1999*, section 74 and Schedule 1 describes the core rights that apply to every child and young person who is in the child protection system and includes the right to be provided with a safe and stable living environment and to be placed in care that best meets their needs and is culturally appropriate.

The OPG also works to protect the rights and interests of adults who have an impaired capacity to make their own decisions, recognizing that everyone should be treated equally, regardless of their state of mind or health.

Our charter with respect to adults with impaired capacity is to:

- Make personal and health decisions if we are their guardian or attorney
- Investigate allegations of abuse, neglect or exploitation
- Advocate and mediate for people with impaired capacity, and educate the public on the guardianship system.

The OPG also provides an important protective role in Queensland by administering a community visitor program to protect the rights and interests of the adult if they reside at a visitable site.

The *Public Guardian Act 2014* and *Guardianship and Administration Act 2000* set out our legislative functions and powers and the *Powers of Attorney Act 1998* regulates the authority for adults to appoint substitute decision-makers.

Position of the Public Guardian

The Office of the Public Guardian (OPG) welcomes the opportunity to comment on the review of the National Disability Advocacy Framework (the Framework).

The OPG supports the intention of the NDAF to provide an agreed structure consistent with the United Nations *Convention on the Rights of Persons with Disabilities* (the Convention), that operates to enable state and federal governments to support people with disability to protect their rights and overcome barriers. However, it is noted from the outset that there are concerns regarding the *Discussion Paper, Review of the National Disability Advocacy Framework* (Discussion Paper) which forms the basis for the consultation. The Discussion Paper is significantly lacking in specificity and detail regarding implementation and evaluation of the current Framework. Given the 'high level' nature of the Discussion Paper and limited information provided within the Discussion Paper, OPG has been restricted in its ability to provide a comprehensive response regarding the review of the Framework.

A summary of the recommendations of the OPG are set out on pages 10 to 11.

The OPG would be pleased to lend any additional support as development of this Framework is progressed. Should clarification be required regarding any issues raised, the OPG would be happy to make representatives available for further discussions.

General Comments on the Framework

Background

In Queensland, the OPG undertakes individual advocacy and the Office of the Public Advocate (OPA) undertakes systems advocacy, on behalf of people with impaired decision-making capacity. The OPA protects and promotes the rights, autonomy and participation of all Queenslanders with impaired decision-making capacity through statutory systems advocacy. The OPG represents the rights and interests of individual adults with impaired capacity around matters, including disability services and supports.

Funded advocacy systems are critical to breaking down individual and systemic barriers that face people with disability. There are two main functions that state-funded or operated advocacy systems can perform. Firstly, they can enable the assertion and enforcement of the rights of people with disability. Secondly, they can underpin the personal autonomy of the person with disability by acting as an alternative to the more restrictive and last resort option of imposing a substitute decision-maker, such as a guardian.[1]

Advocacy is essential to give effect to, and realise, the human rights of persons with disability. Not only can advocacy assist in opening doors for people with disability to participate in everyday life, but it can address injustices and power imbalances, improving not only the quality of services provided, but by changing attitudes within the community and systems.

The OPG is fully supportive of a Disability Advocacy Framework that places accessibility, responsiveness and independence at the heart of funded and non-funded disability advocacy, and

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[1] Eilionoir Flynn, 'Making human rights meaningful for people with disabilities: advocacy, access to justice and equality before the law', *The International Journal of Human Rights* (2013) 17:4, 491-510 at 492

ensures that people with disability are satisfied with the advocacy provided and have better outcomes in their lives as a result.

Need for a nationally consistent approach to 'disability advocacy' in its broadest sense

It is key that there is a nationally consistent approach to disability advocacy. The Framework should align with the human rights articulated in the Convention, and enable people with disability to have a voice along the continuum of engagement with the National Disability Insurance Scheme (NDIS) and other service systems.

As a national Framework, it should be the umbrella under which all forms of advocacy are supported not only under the NDIS, but more broadly across government and service systems: whether formal or informal, representative or self-advocacy; legal or non-legal; at the individual, service, agency and systems levels. It is therefore recommended that the Framework expressly provide for recognition and inclusion of the broad spectrum of advocacy supports, (regardless of funding sources), in the concept of disability advocacy. This includes recognition of the full continuum of advocacy from informal self-advocacy, individual advocacy, legal advocacy, through to recognition of formal systemic advocacy. Providing for all forms of advocacy under the Framework, validates not only advocacy supports that will be funded under the NDIS, but also recognises the broader nature of disability advocacy (whether funded or otherwise) that are critical to providing people with disability with a voice within broader systems and the community. The Framework should therefore articulate and specify exactly what is envisioned by 'disability advocacy' in order to ensure inclusion of all advocacy support within its remit.

Centrality of choice and control of disability advocacy by persons with disability

Choice and control by persons with disability over the way in which their advocacy is provided should be fundamental principles that underpin the Framework. Advocacy can enable a person with disability to have a voice in society that is governed by power imbalances, whether at the personal or structural level. Advocacy provides a means for a person with disability who feels disadvantaged by a power imbalance to have someone backing them, and 'in their corner'. As such, a critical outcome of the Framework should be the ability of people with disability to clearly access and understand information regarding advocacy funding, and how they can choose and manage advocacy they need.

Under the NDIS, advocates can support a person with disability to help give a voice to the person's needs and rights as they engage with the National Disability Insurance Agency (NDIA). They can assist a person with disability to understand what they need to do, understand their rights, be heard by others, navigate and understand the NDIS, and help resolve issues with systems (such as the NDIA and/or service providers). The outcome should be enabling the person as far as possible to participate in community life and decision-making in their life.

Advocacy to support equal recognition before the law and provide access to justice

Disability advocacy is critical to providing persons with recognition of their human rights under the Convention. The Framework should ensure that advocacy supports are provided to persons with disabilities to ensure their rights to equal recognition before the law (Article 12) and access to justice (Article 13). It is recommended that greater clarity be provided under the Framework articulating these key rights.

Recognition of the fundamental human right of people with disability to exercise legal capacity and be supported in decision-making where required (including effective communication supports) should be included as foundational elements of the Framework. Under Article 12, where people with disability are identified as having impaired decision-making capacity, advocacy support should be identified and made available to support that person's decision-making. It is the obligation of Government under the Convention to ensure that appropriate and effective supports are provided to protect and support the right of a person with disability to make their own decisions.

A complementary right to equal recognition before the law, is ensuring that people with disability have access to justice. The right to access to justice was not clearly recognised in its own right until the adoption of the Convention.[2] One reason for inclusion of this right in the Convention is that it is well known that people with disability are not only more likely to experience legal problems, they are also more vulnerable than the general population to a wide range of legal problems.[3] Provision should be made under the Framework that prioritises people with disability having access to legal advice and representation, which can assist in supporting and upholding the rights of people with disability.

The need for legal advocacy is heightened by the introduction of the NDIS. It is critical that individuals be able to access independent legal and non-legal advocacy to not only navigate the NDIS, but also to deal with urgent matters as they arise. The role of legal authorities and advocates should be recognised as an important safeguard for people with disability, and as a mechanism to address individual and systemic barriers to accessing justice due to disability, by helping people with disability to voice their issues and complaints, and seek redress.

Need for clarity regarding funding of disability advocacy supports

While the OPG notes the decision of the Disability Reform Council (DRC) that the NDIS will fund 'decision supports', 'safeguard supports' and 'capacity building for participants', (including support to approach and interact with disability supports and access mainstream services where these activities are additional to the activities funded through the National Disability Advocacy Program), it is not entirely clear as to how these funding areas are to be defined or whether they are limited. It is also noted that the DRC agreed that systemic advocacy and legal review and representation would be funded outside of the NDIS.

It is not clear what will be considered 'decision-making' advocacy support that might be funded under the NDIS. For example, it is recommended that advocacy supports should be available at the assessment stage, however, it is not clear whether this will be the case. It is also not clear whether advocacy support will be provided under the NDIS in order to challenge decisions of the NDIA regarding assessments of 'reasonable and necessary' supports. Further, it is not clear whether complaints regarding the NDIA or service providers will be funded as individual advocacy support. People with disability, particularly vulnerable individuals such as those with impaired capacity, will need advocacy assistance at the assessment and planning stages (to fully understand the planning process and the plan and what is involved), to know their rights, navigate the NDIS process, and to resolve any issues with the NDIA and or service providers.

Without appropriate and adequate advocacy support provided at the outset, the risk for individuals with impaired capacity is that they may either have a nominee or a guardian appointed to make decisions on their behalf. High quality and appropriate advocacy can provide an effective means of supporting a person through the NDIS process from start to finish. It is critical that advocacy be used as an early intervention tool to address decision-making needs at the assessment stage, and resolve

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[2] Eilionoir Flynn, 'Making human rights meaningful for people with disabilities: advocacy, access to justice and equality before the law', *The International Journal of Human Rights* (2013) 17:4, 491-510

[3] Coumarelos, C, Macourt, D, People, J, MacDonald, HM, Wei, Z, Iriana, R & Ramsey, S 2012, *Legal Australia-Wide Survey: legal need in Australia*, Law and Justice Foundation of NSW, Sydney, accessed 6 August 2015 at http://www.lawfoundation.net.au/ljf/app/&id=FC6F890AA7D0835ACA257A90008300DB at 18

issues locally before they escalate, and that advocacy be available as an avenue to provide decision-making supports, rather than resorting to the use of substitute decision-makers.

The Framework should provide principles and outcomes that reflect a commitment to funding of disability advocacy supports, whether individual, systemic or legal in their nature. However, there are serious concerns that it is not clear either under the Framework or the NDIS whether there will be a gap between advocacy support funded through the NDIS, or through other funding packages. In light of this, the OPG agrees with the OPA position in this regard, that a gap analysis be undertaken to ensure that the current range of disability advocacy supports funded and provided (by both the Commonwealth and States/Territories) are mapped to the 'types' of advocacy supports proposed to constitute 'disability advocacy'.

In addition to this, the Framework should prioritize that all people with disability, regardless of whether they are NDIS participants or not, should be able to access advocacy supports as and when they are needed.

Discussion Paper Questions

1. Does the OPG believe the current Framework encompasses the OPG vision of advocacy in the NDIS environment? If not, what changes are required?

The Framework should be centered on the person with disability and their participation in disability advocacy. Further, it should promote and support opportunities for independent individual, systemic and legal advocacy, whether provided formally or informally. It is critical that the independent nature of advocacy be paramount in order to protect against either external influence or the fear of loss of funding or support when the person (or their advocate) speaks out.

While the NDIS will bring many positive benefits and provide many opportunities for people with disability, it is critical that the most vulnerable are not limited in their ability to access or navigate the NDIS through lack of appropriate representation or advocacy. This is of particular relevance to people with impaired capacity, who often experience additional disadvantage or 'multiple' disadvantage as noted in the Framework.

One of the key issues for this vulnerable cohort, is the lack of access to appropriate information about their rights in a format that is accessible to their communication needs, and lack of access to people who are equipped and trained to support people with impaired capacity or who have challenging communication needs. Information is not always available to people in formats that they are readily able to understand, particularly if they have an intellectual or cognitive disability. They often require the support of people to interpret and understand that information. Access to information alone however, is often insufficient. Highly vulnerable people also often need 'a person in their corner', that is, someone that they can trust to support them, particularly if they are intimidated by power imbalances and/or fear of retribution. Such access to accessible information resources should be available at the assessment and planning stages, and include advocacy to support access to understand assessment through to any necessary review mechanisms. They should also be available to assist them to navigate service provision issues with providers.

While the Framework recognizes the existence of multiple disadvantage, greater emphasis should be given within the Framework to placing obligations upon governments and service providers so that they ensure access is provided to information about their rights and quality funded advocacy supports to exercise those rights, particularly for the most vulnerable. It is also critical that the Framework provide an overarching framework across all sectors, so that advocacy is not limited to only those eligible under the NDIS, but ensures a broad approach to ensuring disability advocacy to all persons with disability, across other sectors (such as health and justice).

2. Are the *principles* of the Framework appropriate for guiding the delivery of advocacy for people with disability in a changing disability environment, including in the context of the NDIS? If not, what changes are required?

The principles should ensure that disability advocacy respects personal autonomy and remains independent of vested interests.[4]

It is recommended that the principles recognise the broad range of advocacy forms that underpin what is 'disability advocacy'. In particular, recognition of the importance of voluntary and informal advocacy, along with more formalised individual, legal and systemic advocacy. The risk is that by promoting certain forms of disability advocacy, the Framework may inadvertently undermine less formal forms of individual and community based forms of advocacy if they are not recognised within the broader context of the Framework. Therefore it is recommended that the Framework include a broad-based principle affirming the full nature of disability advocacy, regardless of funding.

It is also essential that the principles give effect to particular rights under the Convention, such as the right to access to decision-making supports (Article 12) and the right to access to justice (Article 13). It is therefore recommended that the Framework clarify principles surrounding the right to support to make one's own decisions, and the right to decide the way in which advocacy supports can be accessed and applied.

The Framework should also address the right to access to justice and legal advocacy. People with intellectual and cognitive disability in particular, face particular challenges with the justice system. A large proportion of this cohort struggle to speak out against injustices they have experienced, and often face significant barriers to speaking out, particularly against systems or people who are seen to be in authority. They often struggle with a lack of awareness of their rights, fear of losing services, or are ill-equipped to negotiate a formal complaints or the justice system without appropriately qualified advocacy support. While the outcomes focus upon the need to ensure that people 'with disability experiencing multiple disadvantage have their needs met', it is crucial that principles underpin this outcome to ensure that people with disability have the right to understand their rights, and the right to exercise those rights. The principles should specify that particularly for those who experiencing multiple disadvantage that they have a right to decision-making support, and advocacy to access and navigate the justice system, where needed.

It is also noted that the principles do not address the issue of training and education, of workers in the disability sector and community regarding disability advocacy and its importance not only to people with disability, but to society as a whole. It is therefore recommended that a principle be considered

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[4] Eilionoir Flynn, 'Making human rights meaningful for people with disabilities: advocacy, access to justice and equality before the law', *The International Journal of Human Rights* (2013) 17:4, 491-510 at 492

to promote the recognition and awareness of the nature and purpose of disability advocacy across disability and other sectors, and within the community.

3. Are the *outcomes* of the Framework still relevant or should different ones be included? If so, what should be included?

The primary outcomes should be whether the person with disability is satisfied with the disability advocacy and have obtained good life outcomes as a result.

A key objective of disability advocacy is to assist in overcoming social barriers, so that people with disability are not disadvantaged on the basis of their disability. This is dependent upon the provision of high quality, independent advocacy that can assist in breaking down these barriers by: supporting the person to be informed of their rights; navigating the disability and other systems; and making complaints or seeking redress.

The Framework should therefore seek to achieve:

- choice and control for people with disability to choose the nature and type of advocacy to protect and promote their rights (whether formal or informal, individual, legal or systemic)
- (where a person lacks capacity to self-advocate), clarity regarding who can act as their advocate, and what the roles and responsibilities of the advocate are
- national consistency to support a broad range of advocacy supports (formal and informal, individual, legal and systemic) to people with disability both under the NDIS and also outside the NDIS
- Under the NDIS that dedicated disability advocacy is available through the continuum of the whole NDIS process, particularly to those who are identified as highly vulnerable, or have impaired capacity
- People with disability are connected to, and provided with, accessible information and tools to support them, and those involved with informal or formal advocacy on their behalf
- clear dedication of funding to support individual, systemic and legal disability advocacy for persons with disability and/or their families and carers, and
- clear dedication of funding to take into account training and workplace development, raising public awareness of disability advocacy in a variety of forms.

4. Are the *outputs* of the Framework still relevant or should different outputs be included?

It is noted that one of the outputs proposed under the Framework is that 'disability advocacy…is informed by an evidence base and is provided in an accountable and transparent manner'. However, the only way that this is able to be determined is through the provision of an evidence based evaluation of funded advocacy supports to ensure that they are appropriate and effective in providing advocacy for which they are funded.

One of the limitations that the OPG faces in providing a comprehensive response to the Discussion Paper is the lack of access to an independent, objective evaluation of the current framework. It is therefore recommended that the Framework provide for a thorough qualitative and quantitative analysis and evaluation following implementation. Without such an evaluation, it is difficult to objectively assess whether the Framework achieves its proposed outcomes, or whether the principles are fulfilled through disability advocacy.

It is therefore recommended that outputs and outcomes be developed so that they are quantifiable or able to be measured through the setting of performance standards or benchmarks. This would also heighten the awareness of Governments and service providers of their obligation to provide appropriate and effective advocacy supports through the monitoring of the performance of disability advocacy services.

In line with the outcomes mentioned above, it is also recommended that a key output should be that disability advocacy brings satisfaction and good life outcomes to people with disability. Further, it is also recommended that an additional output should be included that disability advocacy enables supportive, timely and flexible access to justice.

5. Does the Framework identify what is needed in the current and future disability environment? If not, what changes are required?

It is critical that the Framework takes a broad based approach to disability advocacy, so that ‘disability advocacy’ includes supports for persons with disability under the NDIS, and also outside of the NDIS, across other service systems. The Framework should be centered upon the participation of persons with disability having choice and control over advocacy supports, and whether they are appropriate and effective in addressing individual and systemic barriers that they face due to their disability.

Summary of Recommendations

- The Framework should articulate a clear definition of 'disability advocacy', that recognises and provides for the broad spectrum of advocacy supports (regardless of funding sources), within the concept of 'disability advocacy.' In particular, it should recognise the importance of voluntary and informal advocacy, along with more formalised individual, legal and systemic advocacy.
- The Framework provide an overarching framework for disability advocacy that is relevant across all service sectors so that disability advocacy is not limited to only those eligible under the NDIS, but ensures a broad approach to ensuring accessibility for disability advocacy to all persons with disability, regardless of the system in which the person with disability is seeking advocacy in. The Framework should therefore ensure that all people with disability, regardless of whether they are NDIS participants or not, should be able to access advocacy supports as and when they are needed.
- The principles should ensure that disability advocacy respects personal autonomy and remains accessible, responsive and independent of vested interests.
- The principles should articulate that persons with disability should have choice and control over the way in which their advocacy is accessed and provided.
- The Framework should ensure that advocacy supports are provided to persons with disabilities to ensure their rights to equal recognition before the law (Article 12) and access to justice (Article 13). Greater clarity should be provided under the Framework to articulate these key rights, both as principles and as outcomes. An output should be included that disability advocacy provides supportive, timely and flexible access to justice.
- A principle be included to promote the recognition and awareness of the nature and purpose of disability advocacy across disability and other sectors, and within the community.
- The principles should address the issue of training and education of workers in the disability sector and community regarding disability advocacy, and its importance not only to people with disability, but to society as a whole.
- An outcome of the Framework should be the ability of people with disability to clearly access and understand information regarding advocacy funding and support.
- A key principle and outcome should be included that articulates that disability advocacy should bring satisfaction and good life outcomes to people with disability.
- It is recommended that advocacy supports to be funded under the NDIS should be provided across the continuum of the NDIS process. This should include advocacy assistance at the assessment and planning stages (to fully understand the planning process and the plan and what is involved), to know and understand their rights, navigate the NDIS process, and to resolve any issues with the NDIA and or service providers, and appeal any decisions, including decisions that a person will not receive NDIS funding.
- Greater clarity should be provided regarding how disability advocacy is to be funded, and whether funding will be limited in any way.
- A gap analysis should be undertaken to ensure that the current range of disability advocacy supports funded and provided (by both the Commonwealth and States/Territories) are mapped to the 'types' of advocacy supports proposed to constitute 'disability advocacy'.
- Provision should be made for a thorough qualitative and quantitative analysis and evaluation of the Framework following implementation.

- It is recommended that outputs and outcomes be re-framed so that they are quantifiable or able to be measured through the setting of performance standards or benchmarks.
- Greater emphasis should be given within the Framework to placing obligations upon governments and service providers so that they ensure people with disability are provided with access to information about their rights, and quality funded advocacy supports to exercise those rights, particularly where people are highly vulnerable.