



Review of the National Disability
Advocacy Program
Queensland Office of the Public Guardian submission

June 2016

Role of the Office of the Public Guardian

The Office of the Public Guardian (OPG) is an independent statutory body established to protect the rights and well-being of vulnerable adults with impaired decision-making capacity; and children and young people in out-of-home care (foster care, kinship care, residential care), or residing in residential sites, detention or mental health services.

The OPG 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; and to children and young people in out-of-home care, or residing at various sites, including disability residential sites, authorised mental health services, or detention centres.

The OPG also supports children and young people in care through the child advocacy program. This program gives children in care an independent voice, ensuring their views are taken into consideration when decisions are made that affect them, thereby implementing a key element of the United Nations *Convention on the Rights of the Child*. Both the child visitors and child advocates provide an oversight mechanism to ensure that the Charter of Rights for a child in care under the Child Protection Act 1999 are upheld. This includes upholding the rights of children and young people 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, recognising that everyone should be treated equally, regardless of their state of mind or health. The OPG has a direct role in implementing obligations and ensuring rights as prescribed by the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD) are upheld.

The *Public Guardian Act 2014* and the *Guardianship and Administration Act 2000* set out the OPG's legislative functions, obligations and powers. The *Powers of Attorney Act 1998* regulates the authority for adults to appoint substitute decision makers under an Advanced Health Directive or an Enduring Power of Attorney.

Our legislative obligations with respect to adults with impaired capacity are to:

- make personal and health decisions if the Public Guardian is their guardian or attorney
- investigate allegations of abuse, neglect or exploitation
- advocate and mediate for adults with impaired capacity, and educate the public on the guardianship system, and
- provide a community visitor program for adults residing in government funded facilities and some private hostels.

When appointed by the Queensland Civil and Administrative Tribunal (QCAT) as guardian, the Public Guardian routinely makes complex and delicate decisions on health care and accommodation and guides adults through legal proceedings in the criminal, child protection and family law jurisdictions.

Position of the Public Guardian

The Office of the Public Guardian (OPG) welcomes the opportunity to provide a submission on the review of the National Disability Advocacy Program (NDAP).

It is critical that all people with disability have access to individualised and effective advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights, and access to full participation in the community. The OPG strongly supports funding of disability advocacy organisations through the NDAP for advocacy related to the National Disability Insurance Scheme (NDIS), as well as advocacy for disability issues outside of the scope of the NDIS within mainstream society. While people with disability need advocates to address issues that may arise within the NDIS, it is critical that funding be available for disability advocacy within the broader community regarding individual and systemic matters outside the scope of the NDIS, such as housing and employment.

Dedicated and consistent funding arrangements for advocacy organisations is one factor that has the potential to guard against insufficient and inappropriate support being available for people with disability who struggle to navigate complex systems, and voice their needs. For people who need decision-making support such as those with intellectual or cognitive impairments, or mental illness, the funding of an advocate to assist in navigating the NDIS and mainstream systems can mean the difference between being supported to voice their own needs, as against having a substitute decision-maker appointed to speak on their behalf. There is a real risk that inadequate funding of advocacy support under the NDIS may lead to the unintended consequence of an increase in appointments of substitute decision-makers for those individuals who struggle with decision-making on their own. The default to such guardianship appointments, in lieu of appropriate advocacy support, would appear to be contrary to the philosophy underpinning the NDIS of consumer choice and control.

In order to meet the advocacy needs in a rapidly changing and diverse disability environment, proposed funding models should incentivise collaboration between existing funded organisations to enable the sharing of specialist disability advocacy expertise and knowledge. To facilitate this, funding models could include inducements for innovative use of technology and other resources that ensure increased access to specialist disability advocacy to people living in regional and remote areas.

The OPG is therefore fully supportive of funding advocacy to organisations that promote accessibility, are responsive and independent. People with disability should have access to advocates who can support them to address individual and systemic barriers, and give people with disability the satisfaction that whatever type of advocacy provided, they have obtained better outcomes in their lives and social barriers to full and equal participation in society have been addressed.

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

General Comment

In Queensland, advocacy on behalf of individuals with impaired decision-making capacity can be undertaken by the OPG, while the Office of the Public Advocate (OPA) undertakes statutory systems advocacy. The OPG represents the rights and interests of individual adults with impaired capacity regarding a variety of matters, including disability services, accommodation and supports. The OPA protects and promotes the rights, autonomy and participation of all Queenslanders with impaired

decision-making capacity through its statutory systems advocacy role. However, while both the OPG and OPA have an advocacy role, similar to their interstate counterparts, state and territory governments are not funded and resourced to comprehensively service the entire country, which makes externally funded advocacy systems critical to breaking down individual and systemic barriers that people with disability face.

There are two main functions that funded advocacy systems can perform. Firstly, they can enable the assertion and enforcement of the rights of a person with disability. Secondly, they can underpin the personal autonomy of the person with disability by supporting the person to have their voice heard and be supported to self-advocate, rather than be having a substitute decision-maker, such as a guardian, appointed to formally act on their behalf.¹

Choice and control by persons with disability regarding the way in which their advocacy is provided should be a fundamental principle underpinning any proposed funding model. 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 advocacy can address injustices and power imbalances, improving not only the quality of services provided, but by changing attitudes within the community and systems.

Models of advocacy

The Review of the National Disability Advocacy Program Discussion Paper (the Discussion Paper) proposes that the focus of funding of advocacy organisations should be upon the human rights of the person with disability and their needs, rather than the model of advocacy ‘available’ in their local area.

If people don’t know their rights, and if they can’t understand the NDIS or mainstream systems, or feel threatened by power imbalances, an advocate not only provides information about the person’s rights, but also *uses* that information or knowledge to advocate on the person’s behalf, or supports the person to self-advocate. Such advocacy gives a voice to the otherwise silent participant, who may not even understand that they have certain rights, let alone, know how to wield or protect those rights.

Funded advocacy should have a commitment to protection and promotion of human rights

Underpinning these models should be a strong commitment to *protecting and promoting the human rights* of people with disability. Models should align with the human rights articulated in the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD) enabling people to have a voice that is specific to the unique Australian context of the NDIS, as well as provide advocacy to address issues within other service systems.

Funded advocacy should be driven by choice and needs of people with disability

Firstly, the OPG acknowledges the tireless work that so many disability advocates and their organisations currently undertake in areas of individual, systemic, citizen, family, self-advocacy and legal advocacy. These advocates work faithfully to develop relationships of trust and understanding, while advocating on issues specific to people with disability, and their families and carers. Their work has been pivotal in transforming many people’s lives, as well as bringing about systemic change in the disability sector in Queensland and Australia.

While many organisations are currently funded for disability advocacy, the OPG considers that models of advocacy should be driven primarily by the needs of people with disability. To this end, it should be

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

noted that some people with disability deliberately choose locally known and small advocacy groups to speak on their behalf, while others prefer to use larger organisations that specialise in particular fields. From the OPG's perspective, people with disability are likely to prefer organisations that understand the specific issues and barriers that they face as individuals, and deliberately choose disability specific advocates for their proven understanding and commitment to addressing barriers that people with disability face to full participation in the community. Similarly, some advocates may only be small operations, but their unrelenting commitment to sustaining a relationship with the person and their family, and supporting the person with disability, are the reason that the advocate is repeatedly asked to provide advocacy support. A revision of funding models should therefore recognise that many of these organisations only exist because they already have substantial grass-roots support within the disability community.

Funded models of advocacy should therefore be driven by what best helps those individuals with disability to address the particular barriers that they face, whether the issue locally driven, NDIS based, or to address larger systemic issues. Development of funding models should take into consideration how existing organisations with proven expertise and experience in this field, coupled with support from the disability community can continue to be recognised and funded.

Funded advocacy models that incentivise collaboration of expertise

Development of models of support should encourage a nationally consistent approach to disability advocacy that ensures that people are not disadvantaged if they live in regional or remote locations. Consideration could therefore be given to encouraging collaboration between Commonwealth, State and non-government organisations to meet advocacy needs and providing innovative ways of supporting people to have access to advocacy that meets their specific needs.

There is no 'one type fits all' model that is appropriate for disability advocacy. It may be that funding incentives could be provided for advocacy organisations to collaborate with other advocates who have specific expertise. Primarily, advocacy should be *accessible* to people with any disability, no matter where they live, their culture, background or language. People with disability need opportunities to engage with advocacy supports and services, in a manner that is equivalent to their non-disabled contemporaries. Advocacy models should therefore be *flexible*, and able to adapt to the needs specific to the location, culture or communication needs of the person with disability.

Advocacy that is funded should not be restricted in form or type, but should encompass formal, informal, representative, or support to self-advocate; legal or non-legal; at the individual, service, agency and systems levels. Therefore models of support, whether through the collaboration of one or more advocacy organisations, should provide for funding of a broad spectrum of advocacy supports, across the full continuum of advocacy needs.

Understanding and improving access to justice

The Discussion Paper highlights that people with disability are highly vulnerable to a wide range of legal problems, and are significantly over-represented in the criminal justice system, both as offenders and victims. People with disability often experience barriers to justice, which prevent them from fully participating in legal and justice system processes. The Discussion Paper seeks feedback on the types of legal advocacy needed, and if there are gaps in the supports available to help people with disability to obtain access to justice.

In order for people with disability to have access to legal representation, they first need to know that they have rights, including the right to legal representation. A key barrier to access to justice, is the

lack of understanding or awareness that the person has rights that can be protected, let alone enforced. Legal advocacy can provide a critical link for a person to understand and know that they have certain rights, and then link them with someone who can represent them and pursue those rights at law.

The right to access to justice was not clearly recognised in its own right until the adoption of the CRPD.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 Funded legal advocacy models are pivotal to fulfilling the human rights to access to justice, and equality before the law, as articulated in the CRPD by providing assistance to people with disability to obtain access to legal advice and representation.

A key element of access to justice, is the recognition that people with disability, particularly those with impaired capacity, have the right to equal recognition before the law. This includes the right to be supported in decision-making, for legal or non-legal matters as required. Access to justice, may include legal advocacy, for example, before criminal courts, or civil proceedings such as mental health tribunals. Under Article 12 of the CRPD, where people with disability are identified as having impaired decision-making capacity, provision of advocacy support can be a potent means of protecting and recognising the human rights of a person with disability.

The need for legal advocacy has been heightened by the introduction of the NDIS. Individuals with disability who have problems with their service providers, or with negotiating or reviewing of their plans need access to 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 advocates should be recognised as an important safeguard for people with disability within the NDIS, and as a mechanism to address individual and systemic issues, by helping people with disability to voice their needs and complaints, and seek redress.

Legal advocacy by specialists who understand disability, particularly those with complex needs such as cognitive impairment or intellectual disability, is a further critical need to facilitate a person's access to justice. People with intellectual and cognitive disability in particular, face unique challenges with the justice system. A large proportion of this cohort struggle to speak out against injustices they have experienced, and face significant barriers to speaking out, including speaking out against systems or people who are seen to be in authority. In the experience of many clients of the OPG with impaired capacity, they struggle with a lack of awareness, or understanding of their rights; fear losing services or supports if they speak out; or are ill-equipped to negotiate a formal complaints system, or the justice system, without appropriately qualified and specialized advocacy support.

People with impaired capacity need advocacy support to understand their rights, and also that they have the right to exercise those rights, and be heard. Communicating this takes time and patience, and often specialist skills to assist the person in communication and understanding. Those who experience multiple disadvantage face even greater barriers. They need legal advocates who not only understand how to navigate the legal system, but are equipped with understanding the person's specific disadvantages (disability and otherwise), and have the ability to communicate with the person, assist them to understand that they have a right to decision-making support, and advocacy to access

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/lif/app/&id=FC6F890AA7D0835ACA257A90008300DB> at 18

and navigate the justice system, as they need. Often, this may take a collaborative team support model (of multiple agencies, or advocates working together), in order for legal advocacy to be most effective.

As noted above, funding for legal and non-legal specialist disability advocacy support, is a critical means of avoiding the more restrictive alternative, namely, appointment of a substitute decision-maker for individuals who require decision-making support, and who struggle to navigate systems, such as the NDIS, without support.