



Joint Standing Committee on the National Disability Insurance Scheme

Inquiry into Transitional Arrangements for the National Disability
Insurance Scheme

August 2017

About the Office of the Public Guardian

The Office of the Public Guardian (OPG) is an independent statutory office which promotes and protects the rights and interests of adults with impaired decision-making capacity, and children and young people in the child protection system.

The purpose of OPG is to advocate for the human rights of our clients. For our adult clients, this means advocating for their rights, access to services, independence and choice as part of a supported decision-making model. For our clients who are children and young people, this means advocating for their rights, access to services and where appropriate, their independence and choice.

Advocacy means understanding the lives and views of our clients with the aim of promoting and protecting their human rights. Advocacy can mean working to prevent or address discrimination, abuse or neglect. Advocacy does not mean taking over a client's life or problems. Advocacy does not mean taking over the roles and responsibilities of other government agencies or service providers.

The OPG provides an important protective role in Queensland by administering a community visitor program, which provides statewide monitoring, oversight and advocacy services to:

- adults with impaired decision-making capacity residing in government funded facilities, authorised mental health services, forensic mental health facilities, disability facilities and some hostels, and
- children and young people in the child protection system including in out-of-home care (foster care, kinship care, residential care), or at a visitable site (residential facilities, detention centres, corrective services facilities, authorised mental health services, disability facilities).

When appointed by the Queensland Civil and Administrative Tribunal 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. The *Public Guardian Act 2014* and *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.

The OPG works to protect the rights and interests of adults who have 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* are upheld. The OPG's 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 and attorney systems.

Further information about the work of the Office of the Public Guardian can be found at www.publicguardian.qld.gov.au

Submission to the inquiry

Position of the Public Guardian

The Office of the Public Guardian (OPG) welcomes the opportunity to provide a submission to the Joint Standing Committee on the National Disability Insurance Scheme (the Committee) inquiry into transitional arrangements for the National Disability Insurance Scheme (the inquiry). The views contained in this submission are that of the OPG and do not purport to represent the views of the Queensland Government.

This submission addresses the inquiry's terms of reference where they relate to the experiences of the OPG and our clients, and raises additional issues for the Committee's consideration which the OPG considers significant to the inquiry.

The OPG believes it has a strong contribution to make to this inquiry, given that across Queensland, it provides guardianship to over 3,000 clients and undertakes monitoring and advocacy for over 6,000 clients in its Community Visitor program. The vast majority of these clients experience a cognitive disability.

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

Overview and recommendations

The OPG strongly commends the inquiry and supports proposals that will bring improvements to National Disability Insurance Scheme (NDIS). Overleaf is a summary of the recommendations the Public Guardian sees as critical to the success of the Scheme in Queensland, if it is to truly ensure 'choice and control' and that it does not, unintentionally, infringe the human rights of its participants.

The NDIS represents one of the most significant disability support reforms in recent Australian history, and provides a unique opportunity to advance the lives of people with disability. The OPG commends the Committee for inquiring into the Transitional Arrangements for the NDIS, which is of critical importance for the OPG's clients, particularly those who are visited and advocated for by the community visitor program.

The Public Guardian recommends:

- A mechanism is required to ensure that a participant's previous service provider transfers relevant service histories for the participant to a new service provider, funded by the NDIS.
- Immediate actions are taken to resolve the 'Catch 22' for clients who are dual diagnosis (mental illness and disability) and residing in a mental health facility, whereby NDIS planning cannot commence without a residential address, but an address cannot be identified unless an appropriate NDIS service-provider can be identified through the planning process. The inadvertent consequence is the 'indefinite' detention of the person in a mental health facility.
- The NDIA should promote the use of advocates to assist with planning as an alternative to seeking the formal appointment of a guardian.
- The NDIA should ensure that advocacy agencies are funded not only for 'participant readiness', but to support the person through the entire NDIS planning and plan activation process
- A system must be developed to determine how the NDIS will advise the Public Guardian of new visitable disability sites that the OPG will be required to visit pursuant to the *Public Guardian Act 2014*.
- Given the high incidence of persons with cognitive impairments who are participants within the NDIS (up to 70%), community visitors should be provided for, and fully funded within the NDIS Quality and Safeguards framework complaints scheme.
- The Quality and Safeguards under full transition to the NDIS should provide for, and fully fund, a community visitor program within its complaints model.
- Planning meetings should be conducted with participants in person and interpreters should be utilised for non-English speaking participants.
- A mechanism exists to ensure that participants who move out of the care of a formal service-provider to, for example, the home of a private carer or family, are still subject to the same monitoring and oversight that participants in the care of a formal provider receive from the community visitor program after being transitioned to the NDIS (given they will no longer be residing at a 'visitable site' under the Queensland *Public Guardian Act 2014*).

Boundaries and interface of NDIS service provision

The Committee has inquired into the boundaries and interface of NDIS service provision, and other non-NDIS service provision, with particular reference to health, education and transport services. The OPG has observed numerous issues in this area in relation to planning, appointment of a guardian for the purposes of the NDIS, and service delivery in regard to accommodation.

One of the service challenges experienced by the OPG since the introduction of the NDIS is that numerous guardianship applications have been brought to the Queensland Civil and Administrative

Tribunal (QCAT) to formally appoint a guardian for young people with cognitive impairment who are living in aged care, due to the limited availability of age-appropriate accommodation. Anecdotally, some of these applications have been made due to a lack of, or poor, planning processes during the person's transition into the NDIS.

Of particular concern is the number of applications for guardianship for NDIS-related matters that have been made for Aboriginal and Torres Strait Islander people with cognitive impairment in rural or remote communities. Some of the referrals to the OPG for considering guardianship appointments are based on a perception that the person must have a formally appointed decision-maker involved throughout the NDIS process. Extensive advocacy work has been conducted by the OPG with eligible participants living in aged care facilities to achieve less restrictive options for the person than the appointment of a statutory guardian. A critical aspect of this process has been the linking of the service user with an advocate and services.

The result is the unnecessary appointment of a substituted decision-maker for a substantial period in a person's life; this in fact contravenes the principles of 'choice and control' embodied by the NDIS.

Anecdotally, the OPG has also observed situations where, once the NDIS plan has been approved by a private guardian who is a family member, the guardian terminates the service provider's contract. The guardian then takes on the responsibility of caring for the participant (and effectively providing services) themselves. Where a participant is moved to a private dwelling, and/or to the home of the private guardian, the participant also arguably falls outside of the quality and safeguard oversight of the community visitor program as the private dwelling would no longer be necessarily deemed a 'visitable site' under the *Public Guardian Act 2014* (PGA). In certain situations, private care arrangements may be preferable, however there may be instances where the scheme is providing a perverse incentive for this to occur in improper circumstances.

In the OPG's experience, there have also been issues with hostel accommodation service providers not being properly informed about their obligations under the NDIA. For example, the OPG has observed that some hostel accommodation service providers were informing participants that they were required to engage a particular provider as their NDIS service provider in order to live at the accommodation.

In the last three months, the OPG has observed the NDIA encouraging participants with high needs to reside in co-tenancy arrangements. This encouragement takes the form of a line item within a participant's plan, which provides funding for participants to seek and consider alternative accommodation arrangements. This may impede on the participant's ability to exercise full choice and control under the NDIS, with the result that participants may be placed in co-tenancy arrangements that are inappropriate to their needs and personal circumstances.

The OPG has observed that when participants are transferred to a new service provider under the NDIS, there is no mechanism to ensure that the previous service provider transitions highly relevant information, such as non-verbal communication methods and support, or service histories, to the new service provider. This exchange of information is critical to ensuring that the participant receives a timely and effective transition of relevant services, many of which may be vital to their daily needs.

It is unclear as to how the NDIA will advise the Public Guardian of new visitable disability sites to ensure that these sites are visited by community visitors under the PGA. As above, this information exchange will be vital to ensuring that the OPG is aware of visitable disability sites within the jurisdiction of the community visitor program and able to conduct visits in a timely manner. It should also be noted that many participants under the NDIS are not at visitable sites and are therefore not subject to the oversight of the OPG's community visitor program, a critical monitoring and advocacy function in Queensland.

The OPG has made strong representations to the Australian Government (through the Department of Social Services) that the community visitor function will be the critical bridge to the NDIS' Complaints Commission. Given that almost 70% of Scheme Participants have a cognitive impairment, it is unrealistic to expect these clients to initiate and pursue their own self-advocacy with the Complaints Commission, in particular those who are non-verbal. Additionally, experience has shown the vulnerability of people with disability to abuse in accommodation and respite services. This is the reason why, in Queensland, the monitoring and oversight function of the OPG is regarded as such a critical facet of the rights-protection for people with disability in the service-system. A Complaints Commission cannot be expected to substitute the 'monitoring' that is required to identify and action potential abuse.

In addition, the OPG has observed that some residential service accommodation are de-registering from level 3 accreditation to level 2 accreditation under the *Residential Services Accreditation Act 2002* (Qld) to avoid compliance obligations, and therefore would no longer be considered visitable sites under the PGA.

Consistency of NDIS plans and delivery of services

The Committee has inquired into the consistency of NDIS plans and delivery of NDIS and other services for people with disabilities across Australia. The OPG has observed a number of issues in this area, including particular challenges faced by people with impaired capacity during the planning process.

In the OPG's experience, participants who are accommodated in authorised mental health services and residential services are required to have an NDIS plan before they are able to leave the service, because NDIS funding is needed to secure disability accommodation and services. However, to be eligible for an NDIS plan, an individual is required to have an address in the community. This creates a 'catch twenty-two' situation as a participant requires a plan under the NDIS in order to obtain an address and transition back into the community. This is extremely concerning for the Public Guardian, as in some cases it will effectively result in the indefinite detention of participants who are subject to forensic orders. The following is a de-identified case example of an OPG client's experience.

Case example 1

A client of the Public Guardian has been at an authorised mental health service for several years pursuant to a forensic order. The client has a dual diagnosis of both an intellectual disability and a mental health condition, and there is ongoing disagreement between disability and health funding agencies as to which diagnosis gives rise to the client's high support needs. The client cannot access increased limited community treatment or transfer from the authorised mental health service into the community without disability funding and support. In addition, the client's kinship group resides in an area where the NDIS is yet to roll out. Therefore he is unable to transfer into the community unless he moves away from his kinship group, isolating him further.

OPG participants have had plans developed in planning meetings that have been facilitated by telelink rather than in person. It can be very difficult for participants with impaired capacity to effectively and meaningfully engage in planning meetings facilitated by this method. It can also be difficult for the NDIA planner to ascertain the views and wishes of a participant who is non-verbal via this method. This puts non-verbal clients, who are in greater need, at a major disadvantage. In addition, interpreters are not always provided to assist planners in communicating with non-English speaking participants. In the OPG's experience, interpreters provide a vital service which helps planners to better understand the views and wishes of non-English speaking participants and are not always provided. In-depth face-to-face conversations with participants and more specialised training for planning staff will help to ensure the development of NDIS plans that are tailored to meet the individual participant's needs in accordance with their views and wishes.

The OPG has observed that participants have received inconsistent services from Local Area Coordinators (LACs) depending on the region in which the participants are located. While, in some areas where the NDIS has been rolled out, the OPG has found the services and advocacy provided by LACs to be very helpful; this has not been the case in all areas. It is important that there is consistent service delivery across Queensland to ensure that all participants receive equal opportunities to engage with the NDIS.

The OPG has experienced matters where there is confusion about the role and obligation of service providers to engage in advocacy on behalf of a participant under the NDIS. For example, if there are two service providers in a participant's life and advocacy or other engagement is required, it is unclear which service should be engaged if there is no agreement in place. Currently, OPG is resolving these issues at the local level, but this has the potential to become a significant issue as the NDIS moves toward full transition and the need for advocacy increases.

In some cases the OPG has found it challenging to identify a participant's service provider, which impacts on the OPG's ability to advocate for clients in the NDIS. The OPG has been informed that the NDIA will not provide this information to states and territories due to privacy reasons. The following is a de-identified case example of an OPG client's experience.

Case example 2

The OPG has a client who, prior to becoming an NDIS participant, was receiving music therapy 1-2 times each week. However, since becoming a participant, the NDIA has only approved 10 hours per year in the participant's plan. As this music therapy service is not in scope for the NDIS, the participant incurs gap-fees. Seeking a resolution, the OPG approached the contracted service provider to seek contact details for the LAC. This request was denied due to privacy reasons.

The NDIA only pays a certain amount of funding per therapy session, which can be less than the actual cost of each session. The cost of a service such as music therapy often depends on the number of service providers available and how competitive on price they are. In places with limited or no services, the cost of such services are much higher and is passed on to the participant. This is an example of rural and remote disadvantage that has been observed in regional areas of Queensland.

Risks and NDIS decision-making processes, particularly in relation to the Disability Reform Council and COAG

While the terms of reference concern matters during transition, decisions made by bodies such as the Disability Reform Council and COAG during this period, particularly in relation to Quality and Safeguards mechanisms under the NDIS, will significantly impact our clients' ability to access, and make complaints under the NDIS at full scheme. Therefore, the OPG strongly recommends that bodies involved in NDIS decision-making processes, recognise the essential role that community visitors will need to play within an NDIS Quality and Safeguards complaints scheme in relation to monitoring, advocating for issue resolution, and supporting persons with impaired cognitive capacity to exercise their rights.

NDIS quarterly reports indicate that more than 70 per cent of participants have some form of cognitive impairment. It is clear from the experience of the OPG (not just through its community visitor function, but that of approximately 3,150 guardianship clients per annum), that it is unrealistic to assume that people with a cognitive impairment (especially clients who are non-verbal), can self-advocate and access these mechanisms. Indeed this erodes any concept of choice and control for these participants. Effectively, without community visitors, there is no mechanism for people with a cognitive impairment (in particular non-verbal clients) to 'get to the front door of the Complaints Commission' and raise their concerns without access to community visitors.

In 2016-17, Queensland community visitors made 5,224 visits to adult visitable sites in which they identified 1,931 issues. A significant proportion of these matters related to personal safety and security, including complaints of abuse or assault. Further, at the request of the QCAT, community visitors identified large numbers of issues relating to the inappropriate use of restrictive practices. Quite simply these matters would not have been brought to the attention of local area coordinators or a Complaints Commission, without the vehicle of a community visitor scheme. It is feasible to assume that the abuse of the fundamental human rights of adults with impaired capacity identified in these cases would neither be observed, nor addressed without the presence of community visitors in these facilities.

The OPG strongly recommends that the Quality and Safeguards under full transition to the NDIS provides for, and fully funds, a community visitor program within its complaints model. The OPG firmly believes that given the high incidence of persons with cognitive impairments who are participants within the NDIS, if no provision is made for community visitors within the complaints scheme, the scheme will not work. Without a professional and fully funded community visitor program within the NDIS, there will only be a small subset of NDIS participants to whom the Complaints Commission is able to offer rights-protection.