

Review of the National Disability Advocacy Program

June 2016

The NSW Ombudsman's role in relation to services and supports for people with disability

Our submission is informed by our extensive work in relation to people with disability and disability services over the past 14 years, and our consultations with the disability sector. Under the *NSW Community Services (Complaints, Reviews and Monitoring) Act 1993*, the responsibilities of our office include a range of key functions targeted at improving the delivery of services to people with disability in NSW, including:

- receiving and resolving complaints about disability services, and assisting people with disability to make complaints
- reviewing the pattern and causes of complaints about disability services, and making recommendations to improve how services handle and resolve complaints
- monitoring and reviewing the delivery of disability services, and making recommendations for improvement
- inquiring into matters affecting people with disability and disability services, and reviewing the situation of people with disability in residential care
- reviewing the causes and patterns of the deaths of people with disability in residential care, and making recommendations to reduce preventable deaths
- overseeing and coordinating the Official Community Visitor scheme, and
- promoting access to advocacy support for people with disability to ensure adequate participation in decision making about the services they receive.

Since 3 December 2014, our office has also had responsibility for the disability reportable incidents scheme, comprising the mandatory reporting and oversight of the handling of serious incidents involving people with disability in supported group accommodation.

All of our functions apply to the NDIS sites in NSW.

Reforming the National Disability Advocacy Program

The rollout of the NDIS signals a significant change in the way disability supports are accessed by, and the models of support available for, people with disability. Advocacy services have vital roles to play in the changing disability landscape – in relation to the NDIS, and more broadly. We support the intended reform of the National Disability Advocacy Program (NDAP) to ensure that advocacy services are best placed and well supported to assist people with disability to meaningfully exercise choice and control in their lives, and better able to respond to their individual needs.

We agree with the vision for a reformed NDAP that is proposed in the discussion paper, including that it should:

- provide accessible and independent advocacy support to people with disability irrespective of their age, disability type, cultural background, and place of residence
- contribute to the evidence base, with a data collection system that enables identification and reporting of systemic issues
- integrate and complement services provided under the NDIS, by states/territories, and mainstream organisations, and
- have a consistent and equitable funding model.

Models of advocacy

In our experience, individual and systemic advocacy supports play a critical role in relation to people with disability, their families, and other supporters. Advocacy supports are fundamental to enabling people with disability to maximise choice and control over their supports, gain and maintain independence, and achieve genuine social and economic inclusion. Among other things, advocates play a crucial role in:

- supporting people with disability to make their own decisions
- providing key information to people with disability and their supporters, at the time that they need it, in ways that work for them
- supporting people with disability and their supporters to navigate specialist disability support and mainstream service systems including the health care system and legal system
- identifying and reporting potential abuse or exploitation of people with disability
- helping and empowering people with disability to speak up about abuse, neglect or exploitation, and
- providing timely assistance to resolve emerging issues with support providers, and urgent help at times of crisis.

Our office has consistently seen the benefit of individual advocacy for people with disability, particularly for people who do not have informal support networks, or where the person and their informal networks need support to make decisions, or to raise and resolve concerns locally and at an early point. Advocates have been effective in bringing serious individual and systemic matters to our attention on behalf of people with disability. In particular, advocates have played a key role in alerting us to individuals with disability at substantial risk due to:

- abuse, neglect and exploitation – including physical, sexual and financial abuse; misuse of restrictive practices; and failure to act on serious health issues
- poor quality or inadequate disability or health support, and
- significant isolation from the community and supporters.

It is important to recognise that, without the involvement of advocates (and other independent persons such as Official Community Visitors) many of these matters would not have been brought to our attention. It is also worth noting that the need for individual and systemic advocacy for people with disability extends beyond specialist disability supports. Advocates have alerted us to significant individual and systemic issues relating to mainstream services such as health, education and justice.

We consider that, to the maximum extent possible, all types of advocacy supports should be accessible to people with disability, irrespective of an individual's geographic location. We agree with the position voiced in the discussion paper, and consistent with the UN Convention on the Rights of Persons with Disabilities, that the focus should be on the human rights of the person with disability and their individual needs, and not on what model of advocacy is available in their local area.

We support the Disability Council of NSW's submission regarding the importance of building capacity for user-led organisations to provide advocacy supports (such as self-advocacy and peer-led advocacy), and agree that this provides a way to improve access to fit-for-purpose advocacy regardless of location.

Improving access to advocacy supports

As part of the National Disability Advocacy Program, concerted work is needed to improve the availability of, and facilitate access to, advocacy support around Australia, including regional and remote areas. On a separate but related note, it is imperative that there is adequate provision of culturally appropriate advocacy support.

To improve broader access to advocacy supports – including for people with disability from Aboriginal and Torres Strait Islander communities, culturally and linguistically diverse communities, rural and remote areas, and/or those who are socially isolated – it is critical that there is a focus on an outreach approach. It is important that advocacy services are sufficiently resourced to enable proactive steps to be taken to reach and support people with disability who may require advocacy assistance, and are not solely reliant on referrals or requests for support.

Improving the advocacy evidence base and coordination on systemic issues

We support the work DSS is undertaking, in collaboration with advocacy agencies, on an improved data collection system. There is a need for clarity and national consistency in how the quality and outcomes of advocacy support are measured and reported.

It is important that the data that is collected by advocacy services is collated and publicly reported, with associated analysis of the quantitative and qualitative data to identify gaps and current and emerging systemic issues to inform the work of relevant agencies, including the oversight bodies established as part of the NDIS Quality and Safeguarding framework, the NDIA, and state and territory agencies.

Many systemic disability advocacy agencies, such as the NSW Council for Intellectual Disability, are skilled at identifying the systemic issues being raised by, or otherwise affecting, people with disability, and bringing those issues to the attention of key agencies in a constructive and considered way to inform policy and practice decisions. Coordination on systemic issues in NSW has been assisted, at least in part, by the establishment of the Disability Network Forum (DNF), a network of advocacy, peak, and information services, which is coordinated by the NSW Council of Social Service (NCOSS). The creation of the DNF has provided a mechanism for easier liaison and consultation by government, and enabled a range of advocacy and other services to feed in information and advice in relation to critical issues and policy.

The interface with the NDIS and addressing conflict of interest

We note that the COAG Disability Reform Council has agreed that decision supports, safeguard supports, and capacity-building for participants will be funded as part of the NDIS; and that systemic advocacy and legal review and representation will be funded outside of the NDIS.

In relation to the interface with the NDIS, we welcome the recognition in the discussion paper that people with disability will continue to require access to advocacy outside of the NDIS. There is a need to ensure that independent advocacy support is available and accessible for people with disability who are applying for the NDIS (and navigating the application process); people with disability who have been found ineligible for the NDIS; and those who have been deemed eligible for early intervention support only. We also see advocacy support playing a proactive role in reaching people with disability who

have an unmet need for services, and require support to initiate contact with the NDIS. Independent advocacy is also needed for people with disability in respect to mainstream services (and their obligations under the UN Convention and the National Disability Strategy).

We are aware that many advocacy services currently provide substantial support to people with disability and their families/other supporters to understand the NDIS and to navigate the eligibility and access process. There is a need to ensure that advocacy services are appropriately resourced to continue this work (including addressing unmet need) throughout the transition period, until the full-roll out of the NDIS and finalisation of the ongoing funding and support arrangements.

There is potential for conflicts of interest in organisations providing both NDAP funded advocacy services and NDIS funded supports (such as decision-making supports). We note the decision of the COAG Disability Reform Council that any such services would need to demonstrate effective mechanisms to avoid potential conflict of interest and duplication of funding. To support this action, it is important that there is sufficient clarity regarding what comprises advocacy supports under the NDAP, and what comprises decision supports, safeguard supports, and capacity building under the NDIS.

These dual funding arrangements also present issues for the management of complaints about the advocacy organisations. It is likely that NDIS participants seeking to complain about the conduct of an advocacy organisation that is providing both advocacy and decision-making support would have separate complaint agencies to approach – DSS (or other funding body) in relation to the NDAP funded supports, and the independent National Disability Commissioner (or other oversight body) in relation to the NDIS funded supports. To the greatest extent possible, there should be a ‘no wrong door’ approach in relation to receiving and handling complaints by people with disability, and transfer or referral mechanisms between complaint handling bodies to minimise duplication and confusion for participants. However, consideration should be given at the outset as to how to mitigate potential confusion and problems that may arise for participants as a result of the dual funding arrangements.

Understanding and improving access to justice

Since 3 December 2014, our office has had responsibility for the first, and only, legislated scheme in Australia for the reporting and independent oversight of serious incidents – including abuse and neglect – involving people with disability who live in supported accommodation (under Part 3C of the *Ombudsman Act 1974*).

Through this scheme, and our work over the past 16 years in relation to the employment-related child protection ‘reportable conduct’ scheme, we have a sound understanding of some of the barriers that prevent people with disability from accessing justice, and the importance of legal advocacy support for people with disability who are victims, witnesses, or alleged offenders.

There are many reasons why people with disability (as well as their families and other supporters) may not report abuse and/or neglect, or otherwise gain access to justice, including:

- limited communication
- a fear of speaking up
- a fear of not being believed

- reliance on paid staff for daily and ongoing support
- lack of awareness of their rights
- poor understanding of what abuse and/or neglect is and how to report it
- a belief that people with disability make unreliable witnesses
- prior experience of seeing poor outcomes for other people with disability who have reported abuse or neglect, and
- prior experience of police not charging alleged perpetrators.

Advocacy services play a key role in assisting people with disability to overcome many of the above barriers, in order to gain access to justice. Legal advocacy services, including the Intellectual Disability Rights Service (IDRS) in NSW, provide critical assistance in supporting people with intellectual disability who are victims, witnesses, or alleged offenders of abuse in their contact with police and the broader criminal justice system, including courts.

However, in our experience, few people with disability who are involved in situations of abuse and/or neglect are linked to advocacy support, and services such as IDRS are limited in their hours and location of operation, and are focused on people with a particular type of disability. There is a need for expanded legal supports of the type provided by IDRS, including legal advice, coordination of volunteers to provide independent support, and individual and systemic advocacy to improve access to justice and outcomes for people with disability.

In relation to systemic advocacy, we note that the NSW Council for Intellectual Disability has a long history of providing effective advocacy on the issue of appropriate access to justice for people with intellectual disability, including work to prevent and reduce the inappropriate contact of alleged offenders with intellectual disability with the criminal justice system. The advocacy of NSW CID and IDRS, in addition to other advocacy organisations, has informed our current work to develop:

- guidance for disability support staff on the initial and early response to abuse and neglect in disability services, and
- a joint protocol to reduce the contact of people with disability in supported accommodation with the criminal justice system.

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