Submission No 347

INQUIRY INTO IMPLEMENTATION OF THE NATIONAL DISABILITY INSURANCE SCHEME AND THE PROVISION OF DISABILITY SERVICES IN NEW SOUTH WALES

Organisation: NSW Ombudsman

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Submission to the NSW Legislative Council Inquiry into the implementation of the NDIS and the provision of disability services in NSW

September 2018

Background

The work that has informed our submission

Our submission is informed by our extensive work in relation to people with disability and disability services over the past 16 years, and our consultations with the disability sector. Under the *Community Services (Complaints, Reviews and Monitoring) Act 1993* (CS CRAMA), the responsibilities of our office include a range of functions targeted at improving the delivery of services to people with disability, 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
- providing oversight and coordination of the Official Community Visitor (OCV) scheme.

Since 3 December 2014, the Ombudsman's office has operated the disability reportable incidents scheme, under Part 3C of the NSW *Ombudsman Act 1974*. The scheme comprises the reporting and oversight of the handling of serious incidents – including abuse and neglect – involving people with disability in supported group accommodation.

Since July 2016, our office has had a standing inquiry into allegations of abuse and neglect of adults with disability in the community, such as the family home.

Changes to safeguarding arrangements in relation to the NDIS in NSW

On 1 July 2018, the NDIS Quality and Safeguards Commission started in NSW and SA, and many of our functions relating to the oversight of services and supports for people with disability moved to the NDIS Commission. In particular, it is worth noting that:

- the NDIS Commission has primary responsibility for handling complaints and receiving notifications of reportable incidents involving NDIS providers
- the Ombudsman's office continues to finalise its existing matters involving NDIS providers
- we continue to have jurisdiction over services operated, funded or licensed by the Department of Family and Community Services (FACS) – including FACS-operated disability accommodation, and assisted boarding houses
- there is no change in relation to the work of the Ombudsman's office in coordinating the OCV scheme, our operation of the 'child related' reportable conduct scheme, or our standing inquiry into the abuse and neglect of adults with disability in community settings
- we are working with the NDIS Commission (and other complaint handling bodies) to ensure there is 'no wrong door' for making a complaint, and
- we continue to review the deaths of people with disability in residential care through a joint approach with the NDIS Commission, whereby the Commission examines the actions of registered NDIS providers, and our office examines the intersection with NSW service systems (such as health, justice and other services).

Ahead of the start of the NDIS Commission, the NSW Minister for Disability Services and the Commonwealth Minister for Social Services extended an existing arrangement to continue the NSW Ombudsman's jurisdiction over NDIS providers until 1 July 2019. The arrangement provides for the definition of 'service provider' under CS CRAMA to continue to include 'a person or organisation who provides supports to a NSW NDIS participant where that person or organisation is authorised or funded as part of a participant's plan'. The arrangement enables the Ombudsman's office to complete matters that are already in train, and to continue important functions for the next year; such as the operation of the OCV scheme in relation to disability providers, our standing inquiry into the abuse, neglect and exploitation of vulnerable adults, and our reviews of the deaths of people with disability.

We are working with the NDIS Commission on robust operational arrangements to ensure that we minimise any duplication of effort in relation to any individual matter.

Enabling choice and control

Potentially the most significant reform presented by the NDIS is the shift to people with disability exercising maximum choice and control over the supports they need. However, it is important to recognise that the NDIS is still relatively new, and it will take time for substantial changes to occur that will give effect to participants having genuine choice and control.

In our experience, considerable work is required to realise this opportunity. In this regard, we note that:

- some plans have been developed without any involvement of, or contact with, the participant
- it does not appear that decision-making supports are routinely considered as part of the planning process
- in a number of matters, providers have sought and taken direction solely from the participant's family or spouse – including in circumstances where the participant has decision-making capacity; there are concerns about potential abuse or neglect of the participant by the involved family/spouse; and/or the wishes of the family/spouse are at odds with the goals in the participant's plan.

Strengthening decision-making supports

From our involvement in matters, we believe that there is scope to ensure that decision-making support is provided or at least offered to participants to maximise their ability to make (or at a minimum, inform) decisions and exercise their rights, will and preferences. In this regard, we note that, in many cases, decision-making *capacity* will be heavily dependent on the quality and adequacy of the decision-making *support*. In our view, the need for decision-making supports should be considered and identified at an early point in the planning process, and built in as a key part of relevant participant's plans.

More broadly, it is vital that there is a strong and well-considered framework for the provision of timely, accessible and ongoing decision-making support for participants and other people with disability. NDIS plan development and review – with skilled planners – are important mechanisms for facilitating access to decision-making support. However, there also needs to be adequate scope to enable other individuals who may be in contact with the person – such as Local Area Coordinators, Community Visitors, advocates, and NSW government agencies and community services – to prompt access to decision-making support for those who may not have been previously identified as requiring this type of assistance.

On a related note, we support the recommendations of the NSW Law Reform Commission (NSWLRC) from its recent review of the *Guardianship Act 1987*, relating to the development of a new framework for assisted decision-making in NSW – including:

- provision for supported decision-making arrangements as part of a suite of different assisted decision-making options
- provision for decision-making supporters to assist the person in communicating their decisions to others, and advocating for the implementation of the decision where necessary
- roles for a NSW Public Advocate in facilitating the development of support agreements; mediating disputes about assisted decision-making; administering and/or promoting decision-making assistance services and facilities; and setting guidelines for supporters and representatives.

However, it is important to recognise that the role of a Public Advocate should complement, not duplicate or replace, the role of community advocacy. There is a vital continuing role for community advocates who work with and support people with disability and other individuals who require decision-making and advocacy assistance, and who advocate for broader, systemic issues across a range of life domains. Our office has seen the benefit of individual advocacy for people with disability, particularly for people without an informal support network, or where the person and their informal supports need assistance to raise and resolve concerns locally and at an early point.

Empowering people with disability to speak up

Substantial ongoing work is required to help participants and other people with disability to develop the necessary skills to meaningfully exercise choice and control over their supports and services, and become savvy consumers. In the transition to the NDIS in NSW, FACS funded a range of projects that were aimed at building capacity in people with disability to understand and exercise their rights in the context of the NDIS landscape.

In 2015, as part of this suite of initiatives, FACS funded our office to undertake a project to promote the rights of people with disability ahead of the full rollout of the NDIS in NSW. The Rights Project for People with Disability focused on three main areas:

- helping people with disability to understand and exercise their rights in the transition to the NDIS
- promoting accessible complaint systems and practices among NSW Government agencies and disability service providers
- strengthening systems to prevent, identify, and respond to the abuse, neglect and exploitation of people with disability.

A key aspect of the project included the development and delivery of a 'Speak Up' training workshop, designed to encourage people with disability to speak up when they would like a change in their lives or when something is not right, and to develop the skills to do so. During the course of the project, we delivered 116 workshops to almost 1500 people with disability and support staff. Most of the people who participated were people with intellectual disability who lived in supported accommodation, such as group homes or large residential centres. We contracted people with intellectual disability who are well-known self-advocates to co-deliver the workshops with us.

However, it is a major disservice to people with disability to provide information about how to exercise their rights without ensuring that appropriate supports are in place to help them to do so, and to ensure that services are adequately prepared and equipped to respond. We have undertaken, and continue to undertake, significant work with providers and mainstream agencies in relation to improving complaint systems and practices; and

identifying and effectively responding to the abuse and neglect of people with disability. In relation to the latter, there is an important need for a comprehensive and sophisticated approach across government and community to recognising and appropriately responding to signs of abuse, neglect and exploitation of adults with disability (and vulnerable adults more broadly). The recommendations of the NSWLRC for the establishment of a NSW Public Advocate provide a useful mechanism for seeking to address these issues. (We further discuss this later in this submission).

People with complex support needs

There are a range of factors that currently adversely affect the ability of people with disability to have genuine choice and control over their services and supports, including thin markets in some locations and for certain types of supports. However, some of the greatest challenges are experienced by people with disability who have complex support needs – particularly complex behaviour needs and/or complex health needs. In our experience, people with complex support needs are at high risk of:

- having providers cease supports, including accommodation
- remaining in inappropriate settings – such as hospital or prison – due to a lack of alternative agreed options, and funding disputes
- not having their needs met and experiencing significant adverse consequences due to a lack of providers who are able and willing to provide supports.

The NDIS support coordinator role is critical – particularly for people with complex support needs. We have emphasised the need for greater investment in these roles and building of capacity to ensure that there are skilled support coordinators with the appropriate expertise. However, we are aware that there is a broader need for knowledge and skill development in the NDIA in relation to people with complex support needs – to ensure that their needs are comprehensively understood and appropriately reflected in their NDIS plans, and to minimise unnecessary risks associated with having to wait for reviews of plans or reviews of decisions.

In the main, people with complex support needs do not currently have choice and control over their supports – it is providers who continue to have the weight and power. While this issue pre-dates the NDIS, the key difference is that the NSW Government previously stepped in to either provide the services (as 'provider of last resort') or to contract a non-government provider who was able and prepared to deliver supports. In the course of the past year, several traditional providers of these supports have told us that they are increasingly not taking clients who are 'high risk', because the risks and costs to their organisation outweigh the benefit. In this regard, they have told us that the NDIS funding for some clients with complex support needs is inadequate across a range of support areas; the expectations by families and others about what can be delivered are too high; and the risk of negative or reactionary media coverage is too great.

We recognise that the NDIA is undertaking work to put in place arrangements to better support and 'maintain critical supports' for NDIS participants with complex support needs involved in the justice system. Information to our office identifies that this is crucial, and that there are a range of issues that need to be addressed as a matter of priority. The report by the Council for Intellectual Disability (CID) on its 2017 roundtable on meeting complex behaviour support needs in the NDIS, *A pathway through complexity*, provides a useful overview of some of the key issues, including but not limited to, those involved in the justice system. Our office attended and contributed to the discussions, and we support the report.[1]

[1] Council for Intellectual Disability, 2017, *A pathway through complexity: report from the NSW roundtable on meeting complex behaviour support needs in the NDIS*.

Transfer of government-operated specialist disability services

NSW Ombudsman project on the transfer of Ageing, Disability and Home Care (ADHC) accommodation services for people with complex support needs

In the context of the NSW Government's transfer of ADHC's specialist disability services to non-government providers, the Ombudsman's office (with funding from FACS) has been undertaking a project since 1 July 2017 to look at the transfer process for people with disability in ADHC accommodation who have complex support needs.

The aim of the project is to identify, at an early point, any significant issues that may affect clients, and provide oversight and advice to address these issues during the transfer process. To assist with the project, we established a reference group, comprising representatives from FACS, the Department of Premier and Cabinet (DPC), Health, Justice, the Intellectual Disability Rights Service (IDRS), CID, People with Disability Australia (PWDA), and the Public Guardian.

The project involves a selection of ADHC residences accommodating people with disability and complex support needs, and includes:

- visiting the residences prior to transfer to review records and to talk with staff and clients
- obtaining input from guardians, families and other supporters, and OCVs
- raising with FACS ahead of transfer any identified issues relating to individual clients and the broader transfer process, and tracking the actions that are taken in relation to these issues
- discussing the transfer process with the involved NGOs, and visiting the residences post-transfer.

Some of the consistent issues that we have identified concern the importance of:

- enabling early and continued contact between the relevant NGO and clients/families and staff
- minimising the impact of transfer on the operations of the residences that are being transferred, particularly in relation to the provision of supports to clients
- ensuring that client-related documentation is accurate and complete ahead of transfer
- ensuring that there are strong and effective links to accessible, appropriate and responsive health and other clinical supports for clients ahead of transfer.

The project was initially scheduled to be completed at the end of June 2018. However, as the transfer of some of the selected accommodation services is not yet completed, the project has been extended until the end of September 2018. We will issue a report on the project this year.

Transfer of other government-operated specialist disability services

Health supports

In our June 2015 report to Parliament on the deaths of people with disability in residential care, we noted the range of health-related services that were block-funded by FACS, and highlighted the critical role these services play in supporting the health needs of this population. These services included multidisciplinary allied health services and Practice Leader positions; nurse and dietitian positions in dysphagia clinics; specialist nurse positions in each District; outreach psychiatry clinics, and others. We emphasised that, in

light of the withdrawal of FACS from the provision and funding of specialist disability services, NSW and the Commonwealth needed to discuss and reach agreement on the future arrangements for these services as a matter of priority.

Since that time, NSW Health has assumed responsibility for some of the formerly FACS-funded services, including the Comprehensive Health Assessment Program. In its most recent budget, the NSW Government announced two years of funding for initiatives to be led by NSW Health to address identified service gaps arising from the immaturity in the NDIS and unresolved boundary and interface issues between the NDIS and mainstream services – including the formerly FACS-funded health-related services of the dysphagia service, an autism regional assessment service, and supports for people with co-morbid intellectual and psychosocial disability. In addition, the budget committed additional recurrent funding of $4.7 million per annum to enhance and extend the three existing intellectual disability health teams, to add three new specialised teams and nine new specialised intellectual disability nurse or allied health positions.

Criminal justice expertise

FACS currently provides support to people with disability in the Community Justice Program (CJP) and the Integrated Services Program (ISP), and provides specialist clinical and other assistance to both FACS staff and NGOs in delivering those programs. FACS holds significant expertise on supporting this population with complex support needs, and also performs key functions in relation to assessing and managing risks, and client matching and placement management, to reduce further contact with the criminal justice system.

It is evident that the ongoing provision of specialist clinical support is vitally important to successfully mitigating critical risks for the clients and the community, and enhancing their wellbeing. Arrangements for the transfer of FACS' CJP and ISP services to the non-government sector will need to ensure the continuity of this support.

Workforce issues

The challenges for providers and participants in sourcing and retaining high quality and sufficient staff to meet existing and future demand are well known. The use of casual staff and labour hire staff is common, and this pre-dates the NDIS.

From our work, there is a need to ensure that there are targeted strategies to retain and attract support staff with certain skills, including staff skilled in working with people with particularly complex support needs (such as those in contact with the criminal justice system). Concerns have been raised about the loss of skilled staff in the transfer of ADHC specialist disability services to the non-government sector, in addition to the natural attrition of longstanding staff of retirement age.

It is also important that the skills and quality of staff meet the needs of individuals with disability, and an individual's choice of staff is not unduly compromised by the introduction of qualification requirements. We have consistently heard from people with disability that qualifications are not critical for them; rather, it is about whether the person is good to work with, positively engages with them, and will support them in the way that they want and need. We note that qualifications are no guarantee of quality, and it is important that values-based recruitment is coupled with thorough induction processes and training. In our experience, the exception is first aid qualifications. Our work in reviewing the deaths of people with disability in residential care has consistently highlighted the importance of staff having current first aid qualifications, and regular refresher training.

Challenges facing disability providers and their sustainability

We are conscious of a range of issues affecting providers and their sustainability, including delays in accessing funds, inadequately funded NDIS plans and delays in obtaining plan reviews, and difficulties identifying and contacting the right people in the NDIA. However, we note that it is still early days for the NDIS; the significant issues are recognised by the NDIA and other regulators; and the NDIA has a significant schedule of work activity that is aimed at addressing the issues.

The commencement of the NDIS Commission and its market oversight functions (together with related work by the NDIA) should provide greater opportunity to explore and address significant issues affecting the sustainability of NDIS providers, and related availability of supports for participants. It will be important to identify and address thin markets at an early point; and to implement strategies, such as the use of incentives, to promote the development of supports in key areas, including for participants with complex support needs.

The safeguarding and quality assurance arrangements under the NDIS Commission are critical. However, we note that the arrangements introduce significantly increased reporting requirements for registered NDIS providers compared with what was in place before 1 July 2018. Among other things, registered providers are required to notify the NDIS Commission of a substantially expanded range of 'reportable incidents' in a much shorter timeframe, and have reporting obligations associated with the use of restrictive practices. It is reasonable to expect that registered providers may experience difficulty in meeting the costs of regulatory compliance. In our view, there would be merit in the NDIS Commission and the NDIA giving specific consideration to the administrative costs involved in providers both meeting their reporting obligations, and taking effective action to address risks – such as investigative action in response to allegations.

It is important that arguments relating to providers' sustainability are appropriately interrogated, and are not unduly used as the basis for ending supports to participants. In this regard, we note that in a range of complaints we have handled about the cessation of supports by registered providers, the providers have argued that the action was needed due to, at least in part, the impact on their 'sustainability' and 'viability'. For example, the service's funding will not sustain the amount of contact that a particular family wants. However, in a number of these matters it has not been evident that the provider had taken all reasonable steps to resolve the issues (and the related viability concerns) before making a decision to end supports. As a result of an increased number of complaints, in June 2018 we released good practice guidance on *Minimising conflict, maximising support: Families, NDIS participants and NDIS service providers working effectively together*. The guidance is to help providers to understand the ways in which they can prevent, manage and resolve conflict, and support effective communication with families, to minimise any adverse impact on clients.

Provision of supports for NSW citizens with disability

It is imperative that the transition to the NDIS in NSW is used as a catalyst to ensure that mainstream services provide accessible and appropriate supports to people with disability, to enable maximum participation and engagement in the community on an equal basis with other citizens. Substantial and sustained action is required across all government agencies and other mainstream services to give effect to the UN Convention on the Rights of Persons with Disabilities and the National Disability Strategy.

We recognise that the *Disability Inclusion Act 2014* introduced enhanced requirements relating to whole-of-government disability inclusion planning, including the development of

a State Disability Inclusion Plan and individual agency Disability Inclusion Action Plans. However, while this provided an important legislative base, it has not resulted in the fundamental and widespread changes that are needed to make critical and lasting gains in the outcomes for, and the genuine community inclusion of, people with disability in NSW.

It will be important to ensure that the review of the Disability Inclusion Act results in a renewed focus on the National Disability Strategy and the introduction of clear governance arrangements and independent oversight of implementation. We appreciate that the Disability Council is part of the existing governance arrangements, and we believe that the Council is a vital element for ensuring that people with disability are directly involved. However, we note that the Disability Council sits within FACS. In our view, the importance of the disability reforms and the work that is required by mainstream services warrant the additional rigor of independent oversight and scrutiny.

Regardless of which independent body provides the oversight, Part 3B of the Ombudsman Act provides a useful example of how such a role could be formalised in legislation. Part 3B provides the Ombudsman's office with the role of monitoring and assessing Aboriginal programs (specifically, the NSW Government's OCHRE program), and outlines specific provisions relating to the provision of information by public authorities that have functions under OCHRE, and reporting on any matter concerning OCHRE.

Adequacy of current regulations and oversight mechanisms

We support the NDIS Quality and Safeguarding Framework, and welcomed the start of the NDIS Quality and Safeguards Commission in NSW on 1 July 2018. Over an extended period of time, we provided significant input to the development of the Framework, and the establishment of the NDIS Commission and the intended operation of its functions. This included detailed guidance in relation to reportable incidents and complaints, sharing information and knowledge about our data holdings and systems, and providing detailed information on staffing numbers, roles and grades to inform the set-up of the NDIS Commission.

In addition, in November 2017, we established a joint project team with the Department of Social Services to support the effective transition to the NDIS Commission, which included:

- providing advice and feedback to inform the legislation and Rules, including in relation to complaints, behaviour support, reportable incidents, information sharing, the NDIS Code of Conduct, and the practice standards
- developing guidelines and related resources for NDIS providers about their obligations, including in relation to reportable incidents, complaints, and procedural fairness
- preparing complaint handling guidelines for the NDIS Commission, in partnership with the Victorian Office of the Disability Services Commissioner
- customising existing Ombudsman products for its use
- providing feedback on the proposed communication with people with disability and their families about the NDIS Commission and its functions.

Arrangements to enable continued oversight in relation to the deaths of people with disability in residential care in NSW

We also liaised with the NDIS Quality and Safeguards Commissioner, the Complaints Commissioner, and the Registrar in relation to a number of transitional issues prior to the Commission assuming its functions. In particular, we held discussions about the jurisdiction of our respective agencies in relation to the deaths of people with disability in residential care. The arrangement between the NSW and Commonwealth Ministers (see page 3) will

ensure that the deaths of these individuals continue to be examined, with an ongoing focus on preventing or reducing avoidable deaths. The arrangements and joint approach between our office and the NDIS Commission in relation to the deaths of people with disability in residential care will enable both:

- examination by the NDIS Commission of the actions of registered NDIS providers
- examination by the NSW Ombudsman of the intersection with, and actions of, NSW service systems (such as health, justice, and other services).

We consider that the arrangements in NSW during 2018-19 may also provide a template for other jurisdictions to consider, and potentially lead to a national approach to reviewing the deaths of people with disability and to identifying strategies for reducing preventable deaths.

Existing gaps

Overall, the regulatory framework for NDIS participants and providers in NSW have been enhanced. We note that, among other things, it is a national approach; the scope of the reportable incidents scheme is much broader; the functions of the NDIS Commission provide an integrated regulatory approach; and there will be a worker screening system.

However, there is a small number of important safeguards that are not currently part of the framework that will require consideration by the NSW Government during the course of this year, in collaboration with the Commonwealth and other State and Territory Governments through national governance forums.

The Official Community Visitor (OCV) scheme

The Ombudsman's office coordinates and oversights the OCV scheme in NSW. OCVs are independent ministerial appointees who visit people in full-time residential care – comprising people with disability in supported accommodation, children and young people in residential out-of-home care, and people living in assisted boarding houses. A key focus of the scheme is on identifying and raising any issues affecting residents, and promoting their rights. For many people in residential care, the OCV scheme provides a vital safeguard, including that, at times, OCVs are the only independent parties in contact with the resident and looking at what is happening for them.

However, at present the NDIS Quality and Safeguarding Framework does not include a community visitor scheme. A multilateral review of existing community visitor schemes in relation to people with disability is expected to be conducted in 2018, which will examine the intersection of the schemes with the NDIS. The outcomes of the review will inform the future operation of the NSW OCV scheme in relation to people with disability.

We support the review of community visitor schemes to examine the intersection with the NDIS. In our view, a community visitor scheme should be part of the national framework – the annual reports of the NSW OCV scheme provide evidence of the value of the scheme, and the outcomes it achieves for highly vulnerable residents. However, at a minimum, there are opportunities to ensure that the OCV scheme is well-aligned with the NDIS and the national safeguarding framework.

We also note that the NSW Government has shown ongoing support for the OCV scheme, including increased funding in the last two financial years to accommodate an increased number of residences.

Deaths of people with disability in residential care

At this stage, the joint arrangements between the Ombudsman's office and the NDIS Commission in relation to the deaths of people with disability in residential care are only in place until 1 July 2019.

Strengthening oversight and protections for people with disability in NSW

As noted earlier, there is a need for improved governance and oversight arrangements in relation to the actions of NSW mainstream agencies to give genuine effect to the UN Convention and the National Disability Strategy. In addition, our work has emphasised the need for strengthened regulatory arrangements and oversight in relation to the following key areas affecting people with disability, and vulnerable adults, in NSW.

Safeguards to address the alleged abuse, neglect and exploitation of vulnerable adults

Since July 2016, our office has had a standing inquiry into allegations of abuse and neglect of adults with disability in the community, such as the family home. The Ombudsman's office started receiving concerns about adults with disability in community settings in August 2015, in the wake of the commencement of the Disability Reportable Incidents scheme and the progressive withdrawal of FACS providing specialist disability services.

We commenced the standing inquiry in recognition of the seriousness of the matters being reported, and in the absence of any other agency with the powers to investigate allegations that do not reach a criminal threshold. Further, in many of these matters, there has been a need for an agency to play a lead role to ensure that the information held by various agencies is considered holistically and to arrange for a coordinated interagency response to address the critical issues.

We are notified of these matters via an arrangement with the National Disability Abuse and Neglect Hotline, and contact from disability and mainstream services (such as day program providers, Centrelink, health services), neighbours, and extended family members.

Between 1 July 2016 and 30 June 2018, the Ombudsman's office received 207 reports of alleged abuse and/or neglect of adults with disability living in community settings. It is important to recognise that:

- the vast majority of these matters (160; 77%) relate to the conduct of the person's family and other informal supports, and members of the community – they do not relate to the conduct of service providers,[2] and
- the Ombudsman's office has received the 207 matters of concerns about individuals despite not actively promoting this role and work. As a result, and based on the Ombudsman's experience with the Disability Reportable Incidents scheme, the number of matters reported to date does not represent the prevalence of incidences of this kind across the community.

The concerns tend to include financial abuse, neglect, ill-treatment, emotional/ psychological abuse, physical abuse, and suspected sexual abuse.

The Ombudsman's response to these matters typically involves undertaking inquiries with agencies that are currently (or have recently been) involved with the person; checking available intelligence on relevant parties (including police and child protection databases);

[2] In the 47 matters that did relate to the actions of service providers, the issues primarily related to no, inadequate or inappropriate response to concerns. In the main, these were issues that we identified in the course of responding to the concerns that had been raised about the health, welfare and safety of the adult with disability.

bringing agencies together to facilitate the exchange of relevant information, discuss the existing risks, and agree on necessary actions; and monitoring the implementation of the agreed actions.[3]

In November 2016, we held a public forum on *Addressing the abuse, neglect and exploitation of people with disability*. The forum was attended by over 500 people with disability and their supporters, service providers, government agencies and others. Forum participants noted the critical need for an effective framework to respond to this particular issue for those who are vulnerable and living in the community. In response, we gave a commitment to do what we could to advocate for a more robust framework for this particularly vulnerable cohort.

Our handling of the many matters that have been raised with us relating to the alleged abuse and neglect of adults with disability in community settings has highlighted that providing an effective interagency response to this issue can be relatively straightforward – provided that the agency taking the lead role has access to the right information, adequate powers, and the cooperation and support of key government and non-government stakeholders. In 2016/17, we provided a briefing paper to DPC and FACS on our work as part of the standing inquiry, and proposed the establishment of a NSW Public Advocate. We emphasised the important need for a Public Advocate (or equivalent) to investigate allegations of abuse, neglect and exploitation of vulnerable adults – including adults with disability and older people – and to take the lead in facilitating and coordinating the response to safeguard individuals. We noted that establishing a Public Advocate is consistent with recommendations from NSW and national inquiries into elder abuse, and our March 2016 submission to the NSWLRC review of the Guardianship Act.

Against this background, we support the recent recommendations of the NSWLRC relating to the establishment of an independent statutory position of the Public Advocate to (among other things) investigate – of its own motion or in response to a complaint – cases of potential abuse, neglect and exploitation. Importantly, the NSWLRC recommendations appropriately recognise the need for the Public Advocate to be able to intervene in court or NSW Civil and Administrative Tribunal (NCAT) proceedings in certain cases, and to have powers to:

- apply for and execute a search warrant if needed
- require people and organisations to provide documents, answer questions and attend compulsory conferences
- refer allegations to equivalent agencies in other jurisdictions
- exchange information with relevant bodies (including NCAT, our office, the NDIS Commission, the NDIA and relevant NGOs)
- have read-only access to the police and child protection databases.

In addition to upholding the rights of people with disability to live free from abuse and have effective access to justice, our work has underscored the importance of addressing these issues in order for people with disability – and the state of NSW – to fully realise the benefit of the NDIS. In this regard, we note that a range of the matters we have handled have involved:

- adults with disability with significant needs who have been largely hidden from the community, with no access to disability supports

[3] The Ombudsman's actions in relation to these matters have been via a standing inquiry into the abuse and neglect of people with disability in community settings, under s11(1)(e) of the *Community Services (Complaints, Reviews and Monitoring) Act 1993*.

- NDIS participants whose family members have blocked their access to necessary disability and health supports
- family members who have used the allocated transport funds under the NDIS, despite the participant never leaving the house.

Information sharing

We have consistently argued that there needs to be provisions for agencies to be able to exchange information that relates to the promotion of the safety of people with disability. We do not believe it is consistent with the rights of people with disability who are adults to be affected by a broad information exchange provision (such as that under Chapter 16A of the *Children and Young Persons (Care and Protection) Act 1998*. However, from our extensive experience and discussions with the disability sector, we are nevertheless convinced that it is essential that agencies dealing with allegations of abuse or neglect have the ability to exchange information consistent with their legislative obligations and existing common law duty of care responsibilities. In our view, there is a need for a legislative provision to enable agencies that have responsibilities relating to the safety of vulnerable adults to be able to provide and receive information that promotes the safety of vulnerable adults.

However, while the NSWLRC recommendations in relation to the Public Advocate include powers for the proposed agency to exchange information with relevant bodies (including relevant NGOs), this requires the Public Advocate to be at the centre of any information exchange. To enable an effective response to alleged abuse, neglect and exploitation of vulnerable adults, it is vital that prescribed agencies are able to provide and receive information to promote and improve the safety of the alleged victim.

Screening of workers

We look forward to the introduction of the NDIS worker screening system on 1 July 2019, and recognise the critical gaps that are intended to be filled by the nationally consistent screening system. We have provided input to the development of the NDIS screening system, based on our experience with the reportable conduct scheme and the Working With Children Check system in NSW, and the major gaps we have identified in relation to adults with disability through our operation of the Disability Reportable Incidents scheme.

An area of concern to us relates to the arrangements for unregistered providers. In particular, while 'self-managing' NDIS participants *may* request that workers have an NDIS Worker Screening Check, it is not compulsory. We have emphasised the need for this aspect of the system to be evaluated. Therefore, we support the inclusion in the Intergovernmental Agreement on Nationally Consistent Worker Screening for the NDIS, of a commitment to monitor and review the effectiveness of the arrangements in relation to unregistered providers (supported by the NDIS Commission's examination of its regulatory intelligence).

Protections for people with disability in supported accommodation

Many people with disability have lived in their supported accommodation for an extended period of time. However, they do not have tenancy rights and are highly vulnerable to losing their accommodation – particularly people with complex behaviour support needs. Complaints to our office have highlighted the need for greater protections for people with disability in supported accommodation to prevent unfair evictions. It is currently too easy for providers to cease provision of accommodation support to a participant.

We welcome the consultations the NSW Government has undertaken on the proposal to legislate resident rights and protections for people with disability renting in long term supported group accommodation. Among other things, our submission to the consultations suggested options for strengthening protections for residents with disability to minimise the

risk of unfair eviction. In particular, we indicated the need to include processes that involve a requirement on accommodation providers to notify a range of key parties of an intention to terminate an accommodation agreement (including the NDIA, support coordinator and NDIS Commission), to enable early action to be taken to resolve the situation.

Intersection between the NDIS and NSW mainstream and community services

We note that the terms of reference of the inquiry include 'incidents where inadequate disability supports result in greater strain on other community services, such as justice and health services'. Our work has identified a range of matters in which people with disability have remained in inappropriate accommodation settings – such as hospitals, mental health facilities, and prison – due to issues associated with access to, or the adequacy of, disability supports, such as:

- a lack of available and appropriate community-based accommodation and support options
- delays in the person being approved as an NDIS participant and obtaining an NDIS plan
- the previous disability provider refusing to accept the person back or continue to provide supports, and
- difficulties in health and other services obtaining relevant information from the NDIA and disability providers about available supports.

However, it is important to recognise that a) many of these issues pre-date the NDIS, and b) it is not always about inadequate disability supports.

The issue of people with disability continuing to reside in inappropriate accommodation after the point at which they clinically or legally need to be there is not new. In November 2012, we tabled a special report to Parliament on our inquiry into people with psychosocial disability who were residing in mental health facilities beyond the point at which they clinically needed to be there, and the multiple barriers that prevented them from leaving.[4] At the centre of the inquiry was the access of people with mental illness and psychosocial disability to disability services in NSW, and the need for (then) ADHC and Health to work more effectively together in providing support. Similarly, we have been involved in many cases in which individuals with disability had been left in general hospitals by disability providers who indicated they could no longer provide support. These matters existed well before the NDIS.

More broadly, we expect that the disability reforms associated with the NDIS *will* result in greater strain on community services, such as justice and health services – not necessarily because of inadequate disability supports, but because a critical part of the reforms involves appropriately repositioning responsibility for the provision of community supports to mainstream services. While we agree that the shifts are necessary, we also note that they present significant risks to people with disability in the short-term. It is imperative that there is a comprehensive approach to addressing the risks while mainstream services get up to capacity.

There are a range of issues affecting supports for people with disability that relate to the intersection between the NDIS and mainstream NSW service systems, such as the health and

[4] NSW Ombudsman 2012, *Denial of rights: the need to improve accommodation and support for people with psychiatric disability*, https://www.ombo.nsw.gov.au/__data/assets/pdf_file/0010/7489/SR_Denial_of_Rights_Mental_Health_Report_Web.pdf

justice systems. In the main, the more significant and protracted issues relate to disputes between the Commonwealth and NSW agencies and providers about whether the NDIA or mainstream service systems are responsible for funding particular supports. Notable current or recent examples relate to funding for:

- swallowing assessments and related written guidance for people with disability who have dysphagia
- housing modifications to better meet the behaviour needs of individuals and mitigate risks to them and others
- voluntary out-of-home care for children and young people with disability
- nursing support to administer insulin to individuals with disability and complex health needs who are unable to self-administer the medication.

There are intergovernmental committees and working groups that discuss and seek to negotiate a resolution to these issues, and we appreciate that multilateral negotiations can be complex and difficult to resolve quickly. However, we also note that it is individuals with disability and complex support needs who are typically at the centre of the impasse, who face significant risks.

We welcome the action taken by the NSW Government to establish an Integrated Service Response for people with intensive support needs to coordinate mainstream services and provide short-term support before their needs escalate. Given the significance of this work, it will be important to ensure that the service is evaluated and there is public reporting on the outcomes and key issues arising from its work. While there are internal government governance arrangements relating to this critical initiative, it is not evident that there is ongoing independent monitoring.

Justice

Joint Protocol to reduce the contact of people with disability in the criminal justice system in NSW

People with cognitive and/or mental health impairments are over-represented in the criminal justice system. Some of their contact with police is in relation to minor offences or in response to behaviour that would be best managed using trauma-informed and person-centred approaches to support.

To seek to reduce the unnecessary contact of people with disability in supported accommodation with the criminal justice system, in June 2017 the Ombudsman's office released a Joint Protocol for disability accommodation providers and police. Among other things, the protocol aims to:

- reduce the frequency of police involvement in responding to behaviour that would be better managed solely within the disability accommodation service
- improve relationships, communication and information sharing between local police and disability services
- ensure that appropriate responses are provided to people with disability living in supported accommodation who are victims.

We established a statewide steering committee to monitor the implementation of the protocol, comprising representatives of 27 agencies, including the NSW Police Force (NSWPF), FACS, non-government disability accommodation providers, the NDIA, and other key government and non-government agencies.

In addition, to support and monitor the implementation of the protocol, key actions by our office included holding a series of regional forums with police and disability providers; analysing data relating to contact with police; and developing training resources for support staff.

Regional forums with senior police and disability providers

At the time that we released the protocol, we surveyed disability accommodation providers and found that only 13% had an identified police officer as a contact in their local area. Against this background, in 2017-18 we held four regional forums with senior police and representatives of disability accommodation providers to assist the parties to develop relationships and improve communication. We held the forums in Dubbo (Western Region), Sydney (North West and Central Metropolitan Regions), Merewether (Northern Region), and Campbelltown (South West Metropolitan and Southern Regions). The forums were attended by 510 stakeholders, including 121 senior police, and 389 disability provider representatives.

In addition to identifying key contacts in police commands and disability services, the forums have resulted in a range of agreed actions by the parties at a local level on how they will give effect to the protocol. To assist with the work, we have provided each police command with the details of all disability accommodation providers and residences in their area, including the contact details of the identified liaison officers. We are continuing to monitor progress in implementing the agreed actions.

Analysing data on incidents involving contact with police

To monitor the implementation of the protocol, we required disability accommodation providers to notify our office of any incidents in which police were called in response to the behaviour or conduct of a resident between 1 September 2017 and 30 June 2018. We received a positive response and support from disability providers and NSWPF in relation to this initiative.

We took a closer look at a sample of matters each month, including information in police databases, to examine the circumstances that led to police involvement, opportunities for prevention, the police response, and actions to minimise recurrence. We assessed that, in around one quarter of the selected sample of matters, it was not evident that police contact was warranted – including matters where police were contacted with the aim of sending a message to the client, the incident involved verbal threats only, and/or staff were contacting police to comply with the provider's operating procedures.

Our analysis of the notified incidents also identified a number of broader issues, including:

- the prevalence of contact with police for clients who are absent from the accommodation (either leaving without staff support, or not returning at the agreed time)
- the use of AVOs against clients to protect staff members, and subsequent breaches of the AVOs due to the involved staff continuing to work directly with the client
- staff calling police in response to lower-level behaviours between clients, without having a discussion with either client.

We are undertaking further analysis of the data, and will continue to publish the information in our Disability e-Newsletter, which is available on our website.

Increasing awareness and understanding of the Joint Protocol

We developed and released two animated video training resources for disability support workers and their managers. The short videos are designed to help staff to quickly

understand the protocol and their responsibilities. We released the videos in March 2018; by the end of June, they had received over 3,000 views on our YouTube channel.

To increase awareness and understanding of the protocol by police officers, and in addition to attendance at the regional forums, NSWPF developed and delivered a Six Minute Intensive Training Scenario (SMIT). Officers have also been using the Ombudsman's video training resources.

At present, whether the Joint Protocol will be taken up by the NDIS Commission remains unclear. However, the Ombudsman's office is continuing to monitor the actions of NSWPF to implement the protocol and the agreed action plans, and will have further discussions with the NDIS Commission in relation to the protocol and monitoring implementation by providers.

We have received positive feedback from disability accommodation providers regarding the efforts that have been made by a range of police commands to take the lead in implementing the protocol, including examples of strengthened relationships and better outcomes for residents with disability as a result of direct liaison between local police and disability providers. Providers have also advised us of the actions they have taken to improve their internal practices and systems to monitor implementation of the protocol across their services, and to educate staff and residents.

Improving investigative interviewing of people with cognitive disability

There are substantial barriers to people with disability engaging equitably with the justice system. Through our work, we have identified the need to enhance police expertise in interviewing people with disability who have communication support needs and cognitive disability, to maximise their ability to give evidence and gain effective access to justice.

Guidance on interviewing people with cognitive disability and communication difficulties

We have engaged Professor Penny Cooper to develop – in collaboration with our office – a guide and related training package for disability providers on obtaining 'best evidence' from people with cognitive impairment, particularly those who are the subject of, or witnesses to, alleged abuse. Professor Cooper devised and delivers the national training and procedural guidance for registered witness intermediaries in the UK and also trained the first cohort of intermediaries employed by the child witness intermediary pilot scheme in NSW. The main role of registered intermediaries is to assist two-way communication between children or vulnerable adults and professionals involved in the investigation and trial stages of a case (including police officers, lawyers, judges and magistrates).

A version of the guide and training package will also be tailored specifically for use by the NSWPF in their detective training course and their training to other police officers. The guide includes advice about removing interview barriers by making reasonable adjustments, interview planning and questioning techniques, the impact of trauma on communication, and the role of intermediaries.

Specialised skills within the NSWPF

There will continue to be cases that require specialist skills, particularly when they involve interviewing people with a cognitive impairment and/or communication difficulties. This need has been recognised by the Child Abuse and Sex Crimes Squad via a number of cases where they have either directly conducted interviews with vulnerable adults and/or provided expert advice to area commands. For example, in one case, charges were laid against an offender – including for aggravated break and enter, and two counts of aggravated sexual assault – after the area command engaged the Child Abuse Squad to interview the alleged victim, an adult with a cognitive impairment.

In contrast, we have reviewed cases where, despite the efforts of area commands to investigate allegations of abuse involving a person with cognitive impairment, evidentiary problems have arisen. For example, our work has shown that even in circumstances where police have shown initiative and have engaged workers from within the disability sector to help them in obtaining evidence, those engaged can sometimes lack the specialist expertise required to assist police without prejudicing the interview process. In other cases, we have observed police diligently attempting to gather evidence from alleged victims with cognitive impairment or communication difficulties, but the involved police have been unaware of the options available to them to assist with the interview process.

While we believe that it is critical to enhance the skill-set of police across commands, it is not reasonable to expect all police to acquire a high level of expertise in obtaining 'best evidence' from people with complex communication needs. In this regard, it would appear that providing area commands with direct access to, and advice from, specialist interviewers would provide another important option, particularly for those more challenging cases.

We also note that the specialist interviewing skills of officers within the Child Abuse and Sex Crimes Squad can be a valuable asset for commands to draw on. However, due to the Squad's existing heavy workload, their availability can be limited. In our view, consideration should be given to expanding the Squad's remit to include a specialist team of investigators tasked with providing investigative advice and assistance to area commands in conducting interviews with adults with cognitive impairment and/or communication difficulties. We recognise that this suggestion has resourcing implications. However, as we have highlighted in previous public reports, improved arrest rates, reduced delays and attrition rates, and improving the overall experience of child victims, illustrates that when police are given additional, targeted support and resources, very significant positive outcomes can be achieved.

Health

Our reports to Parliament on the deaths of people with disability in residential care have consistently highlighted the significant health challenges and risks faced by this population, and the considerable disadvantage and adversity they tend to experience in their contact with mainstream health services. In our June 2015 report, we pointed to substantial gaps we had found between what is required (by the UN Convention, the National Disability Strategy and policy directives) and what is experienced by people with disability. We indicated that action was required as a matter of priority to address the situation, and to close the gap and improve health outcomes for people with disability in NSW ahead of the transition to the NDIS. We noted that our work had underscored the considerable risks that exist for people with disability (in residential care and more broadly) if mainstream services are not ready at the point of transition to the NDIS and withdrawal of NSW Government-funded specialist disability supports.

Our August 2018 report has continued to identify the need for significant changes to make a fundamental difference to the health outcomes of not only people in residential care, but to people with disability generally. Our report provides multiple, powerful examples of the need for effective interagency work between health and NDIS disability providers, including individuals who did not receive the crucial support they needed to minimise their resistance to medical treatment, did not obtain timely and appropriate access to assessments and community-based support to identify and manage swallowing, falls, respiratory and obesity risks, and did not receive the assistance they required in hospital.

Dysphagia and the NDIS

In relation to the NDIS, our most recent report to Parliament on the deaths of people with disability in residential care draws attention to issues associated with the funding of

mealtime and dysphagia supports, and the associated risks faced by people with disability. The position of the NDIA is that swallowing assessments and the development of written guidance are the remit of the health system, as the actions are intended to prevent a health condition such as aspiration pneumonia. The NDIA has indicated that NDIS funding would generally be provided to ensure carers and staff are appropriate trained, and to provide assistance such as a support worker to help to implement the mealtime plan. Our reviews over the past 16 years have shown that dysphagia has significant and, often, fatal implications for the health of people with disability, and it is critical that they have timely access to skilled speech pathologists to obtain an accurate assessment and clear recommendations.

In our report, we noted that it is evident from our reviews of the deaths of people in disability services that:

- NDIS funding *has* been used by speech pathologists (and other allied health professionals) to undertake swallowing assessments and develop mealtime management plans for individuals.
- Most of the individuals with dysphagia who have died accessed speech pathology services from within the disability sector, not the health system.
- Although some people have received swallowing assessments in hospital, this has typically been in response to crisis situations after an episode of choking and/or aspirating. A small proportion of people have accessed dysphagia clinics, but these have also been part-funded by FACS.

Against this background, we are concerned about the increased risks faced by people with disability during the period in which they are only able to access funded speech pathology services (for swallowing assessment and written guidance) through the health system, but the health system is not yet sufficiently equipped to meet their needs and/or the demand. Our recommendations to NSW Health include that it should provide our office with details of current or proposed strategies to address these issues and meet demand in relation to people with disability.

We understand that NSW is working to address the issues in relation to health system and NDIS responsibilities, including dysphagia, through national governance arrangements. We have been advised that work is underway to address these issues, and is considered by NSW to be a matter of urgency.

Education

In August 2017, we tabled a special report to Parliament on our inquiry into behaviour management in government and non-government schools. In our report, we recognised that the change to the NDIS brings additional challenges for schools in undertaking interagency work, with a shift away from engaging a known government agency to potentially having a range of services engaged with the child with disability. However, it also provides opportunities to leverage off behaviour support under the NDIS, noting that good practice requires a comprehensive assessment and analysis of the meaning and function of behaviour in a whole-of-life context – including, for school-age children, home and school.

We noted that the shift to the NDIS means that there will need to be an alignment between the principles of choice and control that underpin NDIS funding and supports, and the strategies being developed by the school and other agencies to support the involved students and their families. Multi-agency work with students with disability and their families must not only have elements of strong interagency practice, it also needs to include a strong and effective partnership with the involved students and their families.

Recently, the Department of Education has commenced work to develop a new strategy for improving educational outcomes for students with disability and their families. The Department, in partnership with the Australian Centre for Social Innovation, has held a series of workshops with key stakeholders, and has also consulted separately with our office. We note that there are considerable challenges for the Department in settling what should be the priorities, strategies and desired outcomes in improving outcomes for students with disability, particularly against the background of a large number of proposals for reform in our report and recommendations in the September 2017 report from the Legislative Council inquiry into the provision of education to students with disability. It will be important for the Department to work, in an open and transparent manner, with independent experts and other key stakeholders on how best to respond to these critical challenges. In this regard, we subsequently proposed that the Secretary should establish a standing committee, including families, advocates and key agencies, to inform and assist in the monitoring of the work undertaken by the Department to address the issues raised in both inquiries.

Intersection between disability and mainstream services in relation to safeguarding vulnerable adults

Our handling of allegations relating to abuse, neglect and exploitation of adults with disability in community settings involve direct intersection with mainstream/community services and NDIS disability supports – but as discussed earlier, the issues are typically not about inadequate disability supports. The matters highlight the importance of a collaborative and coordinated approach, with a lead, independent agency.

In order to be effective, the proposed Public Advocate will need to have excellent business relationships with NDIS providers, the NDIA, the NDIS Commission, NSWPF, Health and a range of other stakeholders. To illustrate, it is the NDIS providers that in many cases see or strongly suspect the abuse and neglect taking place in the home. Therefore, it will be critical for them to report these cases to the proposed Public Advocate and, when required, be part of providing a well-calibrated multi-agency response.

Advocacy

It is important to recognise that community advocates play a critical role in relation to mainstream services in NSW – working alongside people with disability on an individual basis to raise and resolve issues about their contact with mainstream services, and identifying and raising systemic issues affecting people with disability in relation to those services. Notable examples include (but are not limited to) the work of key advocacy organisations in NSW in relation to:

- the treatment of people with disability in health and mental health services
- access to justice, including supports when in contact with police and/or the courts
- equitable access to local mainstream schools
- progress in providing accessible public transport
- appropriate access to domestic violence and homelessness services.

There is a vital ongoing need for accessible and effective advocacy services for people with disability in relation to mainstream and community services.

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