

Submission to the Royal Commission into Violence, Abuse Neglect and Exploitation of People with Disability

*Issues paper: Health care for people with
cognitive disability*

February 2020

Background

The NSW Ageing and Disability Commission (ADC) commenced on 1 July 2019. The ADC is an independent statutory body, which is focused on protecting adults with disability and older adults from abuse, neglect and exploitation, and protecting and promoting their rights. Its roles include:

- Responding to allegations of abuse, neglect and exploitation of adults with disability (18 years and over) and older adults (65 years and over or, if Aboriginal and/or Torres Strait Islander, 50 years and over), including by providing advice, making referrals and conducting investigations.
- Following an investigation, taking further action that is necessary to protect the adult from abuse, neglect and exploitation.
- Raising awareness and educating the public about matters relating to the abuse, neglect and exploitation of adults with disability and older adults.
- Inquiring into and reporting on systemic issues relating to the protection and promotion of the rights, or the abuse, neglect and exploitation, of adults with disability and older adults.
- Meeting other obligations as outlined in the *Ageing and Disability Commissioner Act 2019* (the ADC Act).

The ADC also has a general oversight and coordination role in relation to the Official Community Visitor (OCV) scheme in NSW. Responsibility for administering the OCV scheme transferred from the NSW Ombudsman's office to the ADC in August 2019. OCVs are independent Ministerial appointees who visit:

- 1,764 accommodation services where an adult with disability or older adult is in the full-time care of the service provider
- 270 accommodation services where a child in care is in the full-time care of the service provider
- 17 assisted boarding houses.

Our submission has been informed by the OCVs who visit accommodation services and assisted boarding houses supporting people with disability, and the work of Visitors over many years in relation to the disability sector.

Issues relating to health care and access to necessary health services are frequently identified and raised by OCVs. For example, in 2018/19:

- Issues relating to the health care and/or personal care of residents accounted for 20% of all issues (950 issues) raised in OCV visit reports to disability supported accommodation services. This included concerns about residents' identified health, medical, dental, optical, auditory, nutritional, psychological and/or development needs not being addressed (265 issues).
- Issues relating to residents' health care and/or personal care accounted for 21% of all issues (14 issues) raised in OCV visit reports to assisted boarding houses. This included concerns about residents not being supported to access appropriate health and medical services and treatment as needed (10 issues).

This submission focuses on the issues that OCVs have seen and heard in their role in visiting people with disability in disability accommodation services and assisted boarding houses. Visitors note that their information is largely consistent with the information and findings in the NSW Ombudsman reports on the deaths of people with disability in residential care. However, while the OCV scheme and the reviewable deaths function focus on the same population, the death reviews have the benefit of hospital and other records, and a more in-depth examination of the interaction of residents with the health system. OCVs emphasise the importance of the Royal Commission referring to the NSW Ombudsman's reports for comprehensive information and analysis of the critical issues since December 2002, including the actions of NSW Health and other agencies in response to the Ombudsman's

recommendations, and numerous case studies detailing the experience of individual residents.¹

Access to timely and appropriate health services in the community

Overall, OCVs see variable practice in relation to the access of residents with cognitive disability to necessary health supports in the community, and the quality of the service they receive. Visitors noted positive practice in relation to some residents and services, including:

- GP home visits to provide a flexible response to the needs of some residents
- the involvement of specialists in combined strategies to facilitate a person-centred approach to the person's health issues.

However, OCVs identify a range of continuing (and, in many cases, longstanding) issues in relation to community-based health supports that adversely affect the health outcomes of people with disability in residential care.

Diagnostic overshadowing, delayed diagnoses and misdiagnoses

Visitors have advised that diagnostic overshadowing, and delayed or misdiagnosis continues to occur, adversely affecting the access of residents to timely and necessary treatment. For example, OCVs have noted in their visits:

- residents whose symptoms of recurrent urinary tract infections were overlooked due to diagnostic overshadowing – including increasing confusion being seen as part of their disability rather than having a treatable cause
- residents whose recurrent falls were ascribed to the progression of their disability and ageing, with delays in action to investigate the potential underlying cause
- residents for whom there appeared to be limited and/or delayed action taken in response to signs of weight loss, incontinence, or changes in their health or behaviour to investigate the cause.

It is worth noting that in a range of cases, the overshadowing is by disability accommodation staff, who tend to be the gatekeepers for the resident's access to GPs and other health services. OCVs have noted the significant role that disability support workers play in supporting residents to access necessary health services and manage their health concerns – including their critical role in providing accurate and comprehensive information to health practitioners about the person, their medical history and presenting issues.

One of the common areas of diagnostic overshadowing noted by Visitors relates to mental health. OCVs have advised that they continue to regularly come across situations in which disability accommodation staff have been unable to obtain mental health support for residents due to mental health services deeming that the issues are 'behaviour' that is related to the person's cognitive disability rather than symptoms of mental illness. This barrier to access to mental health services is well-known and has previously been the subject of targeted work in NSW, including the development of a Memorandum of Understanding between (then) Ageing, Disability and Home Care (ADHC) and NSW Health in the provision of services to people with an intellectual disability and mental illness.² While Visitors welcomed this work, they note that:

- they have not seen this agreement translate into notable improvements on the ground for people with disability in residential care
- there appears to be a continuing lack of understanding on the part of both health and disability services about dual diagnoses of cognitive disability and mental illness.

¹ See <https://www.ombo.nsw.gov.au/news-and-publications/publications/annual-reports/reviewable-deaths>

² See <https://www.health.nsw.gov.au/mentalhealth/resources/Pages/mouandguidelines-disability.aspx>

The need for improved training and knowledge of health professionals in relation to people with cognitive disability

OCVs consistently hear from disability accommodation providers that there are few health professionals who have expertise in relation to people with cognitive disability, and that this experience and knowledge can make a significant difference to the person and their health outcomes. Services report that when families or providers find a 'disability friendly' practitioner, word quickly spreads and the health professional becomes inundated, with the result that many people with cognitive disability see the same limited pool of practitioners, can face long waiting lists, and can have to travel considerable distances to access the relevant health professional or service.

Recently, Visitors have seen small but positive signs that a new cohort of practitioners with knowledge and experience with people with cognitive disability is coming through. In this regard, some OCVs have noted the emergence of psychiatrists who have started to replace the previous longstanding psychiatrist who had seen large numbers of people with cognitive disability and mental health concerns. OCVs have heard positive feedback from staff in relation to the new practitioners.

Health assessment and screening

OCVs have advised that, while they see the Comprehensive Health Assessment Program (CHAP) tool on the files of residents in supported accommodation, they tend to see:

- a cursory response by GPs to the questions about the residents' health concerns (ticks and no details)
- very little or no information in the recommendations section, making it difficult for disability support staff to understand the person's key health issues and the steps they need to take to assist them.

Visitors particularly raised concerns about continuing to see CHAP tools in the files of female residents in which the GP has written 'N/A' in relation to women's health screening, including breast screening. In some cases, this appears to be linked to perceptions that a female resident will not be able to tolerate difficult or uncomfortable screening tests, such as a mammogram. However, OCVs noted that in these cases they do not tend to see evidence that alternative options have been considered or canvassed with the resident, such as ultrasound.

Positively, OCVs noted that they do see evidence of GPs undertaking Chronic Disease Management Plans with some residents, with associated referrals to community-based allied health practitioners (including dietitians and psychologists) for a certain number of funded visits.

Support in hospital

OCVs do not visit residents in hospital, and typically do not have access to hospital records. However, their visits to disability supported accommodation services and assisted boarding houses – including their review of the service records and discussions with residents and staff – have highlighted a range of issues relating to the support of people with cognitive disability in hospital.

In particular, OCVs identify longstanding and continuing concerns about the adequacy and quality of support that is provided by health staff to meet the needs of residents during hospitalisation – especially residents with communication difficulties and/or behaviour support needs. Visitors note that some disability accommodation providers continue to provide support staff to assist certain residents in hospital to reduce the risk of an adverse outcome associated with, for example, choking on food or fluids that do not meet their safe swallowing requirements.

Identifying and meeting support needs in hospital

OCVs identify positive practices on the part of a range of disability accommodation providers in having hospital support plans (or equivalent) on the resident's file, to enable the provision of brief but important information to hospital staff about the person's support needs. However, Visitors have advised that, while the hospital support plan is designed to provide a prompt for hospital and disability staff to discuss at an early point the resident's support needs, how they can best be met in hospital, and the roles and responsibilities of the hospital and the disability service,³ this does not appear to be reflected in practice. In this regard, OCVs hear from disability accommodation staff that the necessary discussions do not routinely occur; hospital staff do not always seek or listen to information from disability support staff despite their knowledge of the resident; and there are significant risks to the resident as a result.

Disability accommodation providers have indicated to Visitors that the high risks faced by people with cognitive disability and swallowing difficulties in hospital from aspiration and choking are a prime factor in their decisions to provide support staff during the resident's admission, particularly at mealtimes. Providers have indicated prior experience of residents receiving food and fluids in hospital that do not meet their mealtime requirements, or being unable to consume their meal due to a lack of physical support to do so.

OCVs have advised that the access of people with disability to behaviour support in hospital is also raised by disability accommodation providers. The principles agreed by the Council of Australian Governments (COAG) to determine the responsibilities of the NDIS and other service systems identify that any funding in a person's NDIS package 'would continue for supports for people with complex communication needs or challenging behaviours while accessing health services, including hospitals and in-patient facilities'.⁴ However, disability accommodation providers have indicated to OCVs that this does not adequately cover the extent of the individual support required by some residents in a hospital setting. Overall, Visitors hear from disability accommodation providers that health services are not well equipped to meet the behaviour support needs of some residents, and support is not well coordinated between hospital and disability services, adversely affecting the patient with disability. Visitors noted examples of residents with cognitive disability and complex behaviour needs who are able to be supported without restrictive practices at home, who have had experiences of physical restraint in hospital.

Transfer of care from hospital to home

OCVs have noted repeated issues associated with the transfer of care of residents of supported accommodation services from hospital back to their home. In this regard, OCVs advise that:

- Despite guidance in NSW Health policy,⁵ there is a continuing misconception among hospital staff that disability accommodation settings are medical models that staffed by nurses and other health practitioners. As a result, there are instances of hospital staff seeking to discharge individuals with significant changes in their health and support needs (for example, following the insertion of an enteral nutrition tube or other surgery), without adequate assessment of whether the person's changed health needs can be safely met at home.
- They see evidence of poor coordination between hospitals and disability services in relation to discharge planning, including inadequate guidance for disability support staff about the actions

³ See NSW Health and Ageing, Disability and Home Care (ADHC) Joint Guideline: https://www1.health.nsw.gov.au/pds/ActivePDSDocuments/GL2013_001.pdf

⁴ COAG Principles to Determine the Responsibilities of the NDIS and Other Service Systems: <https://www.coag.gov.au/sites/default/files/communique/NDIS-Principles-to-Determine-Responsibilities-NDIS-and-Other-Service.pdf>

⁵ See, for example, NSW Health policy directive on *Responding to Needs of People with Disability during Hospitalisation*, https://www1.health.nsw.gov.au/pds/ActivePDSDocuments/PD2017_001.pdf

they need to take to meet the person's health needs post-hospital (including, for example, wound management, and changed swallowing requirements). While in some cases disability accommodation providers have successfully delayed the person's discharge from hospital pending assessment and appropriate coordination of care, in other cases residents have been discharged and returned to hospital again shortly afterwards.

An OCV provided the example of a man with cerebral palsy who was susceptible to respiratory infections. He was hospitalised for treatment of pneumonia and was discharged by the hospital at 2am. Information held by the service indicated that the hospital incorrectly believed that there were nurses at his residence providing full-time care. The service informed the OCV that it had submitted a complaint to the hospital.

The following case study from the *OCV Annual Report 2017-18* outlines a similar experience.⁶

Case study – OCV Annual Report 2017-18

Five residents with disabilities live in a house that an OCV visits. They enjoy living together and have a good relationship with staff.

One of the residents, Mallick, has ongoing challenges with his health, often contracting infections and requiring time in hospital. Despite his health challenges, he is happy living in the house and often tells the OCV about his activities and adventures when she visits.

On a recent hospital stay, the hospital discharged Mallick in the early hours of a winter's morning, after phoning the overnight staff member to come and collect him. The staff member was concerned about the early morning discharge, noting that the house was insufficiently staffed for her to leave the residents unattended to pick Mallick up, and the extreme cold weather that may exacerbate Mallick's already fragile condition. The staff member contacted the on-call manager for support. However, in the meantime Mallick was discharged from hospital, despite service requests for him to remain a few more hours to help support a smooth transition back home.

Mallick was subsequently readmitted to hospital 16 hours later with a respiratory infection. The service spoke to the OCV about several instances where the local hospital had discharged Mallick earlier than the service believed was necessary. The service said that they felt they could not complain. The OCV raised the issue as a complaint to the Ombudsman's office. The complaints officer wrote to NSW Health about Mallick's pattern of discharge from hospital, often early and without consideration for his circumstances.

As an outcome of the complaint and following contact with NSW Health, the service provider developed a protocol with the local hospital to better support Mallick during hospitalisation and on transfer of care back home.

On a follow up visit, the OCV read that Mallick had several further admissions to hospital since her last visit and the care provided by the hospital had been much more tailored to his needs. The service had also engaged a registered nurse to be available on-call should Mallick require early intervention, helping to limit his time spent in hospital.

The OCV, in collaboration with the NSW Ombudsman's office, NSW Health, and the service provider, was able to get a positive outcome to support Mallick to remain healthy and well.

⁶ *OCV Annual Report 2017-18*, p29: https://www.ombo.nsw.gov.au/data/assets/pdf_file/0005/66569/OCV-Annual-Report-2017-18.pdf

Care coordination between health and disability services

A strong theme raised by OCVs concerns the importance of cooperative and effective working relationships between disability accommodation services and health services, and the difference this makes to residents' access to, and support from, health services. Visitors flagged relationship building and formalising roles and responsibilities between the two sectors as an important area for improvement. OCVs indicated that they have seen positive work by some disability accommodation services to develop and sustain working arrangements with their local hospital, to the benefit of residents. However, Visitors noted that this is not common, and it relies on proactive and persistent disability providers that are able to navigate the health system and engage the right health service representatives. NSW Health policy advises Local Health Districts (LHDs) to develop and establish agreements and protocols with local disability support providers;⁷ however, in the experience of OCVs, this is typically not reflected in practice.

More broadly, OCVs noted that some of the work between health and disability services to support people with cognitive disability in their contact with health services appears to be one-sided, with a lot of the work being undertaken by disability support staff. Visitors advised that disability support workers seem to be in the position of having to advocate for residents' needs in health services and push for reasonable adjustments to be made, rather than this work being led by health practitioners and other staff. OCVs hear from disability support staff about their reluctance to raise issues with health staff, and the difficulty of seeking to escalate matters within the health service or make a complaint.

Visitors noted that they had previously seen good links between health services and disability accommodation providers when (then) ADHC had a Clinical Governance team in one region. The Clinical Governance staff helped to facilitate communication between health services and ADHC accommodation staff, provided training to group home staff to support post-hospital discharge care, and escalated matters with LHD representatives when required. OCVs note that the recent extension by NSW Health of Intellectual Disability Health Teams (or other specialist roles) across LHDs may provide opportunities to improve care coordination between health and disability services; however, it is not clear the extent to which this will be the case.

OCVs advised that issues relating to care coordination between health and disability services also apply to community-based health services. There are a range of residents of disability accommodation services and assisted boarding houses who have complex and chronic health concerns, and who require a coordinated and collaborative approach between health and disability supports (with the person at the centre). Visitors particularly noted the considerable health risks faced by some residents associated with lifestyle factors, including obesity, insufficient exercise and poor diet. While OCVs have seen some positive work between providers and health services to support residents to address these issues that feature in preventable deaths, they note that this is not common.

Other key issues

Actions to assist people with cognitive disability to overcome their resistance to treatment

OCV have advised that they see many people with cognitive disability in residential care who are resistant to medical treatment – including people who:

- are prescribed anti-anxiety medication to facilitate medical examinations or tests
- refuse to attend medical appointments
- pull off oxygen masks, pull out intravenous drips, and actively attempt to climb out of bed in hospital.

⁷ NSW Health policy directive on *Responding to Needs of People with Disability during Hospitalisation*, https://www1.health.nsw.gov.au/pds/ActivePDSDocuments/PD2017_001.pdf, section 4.2.

However, aside from the prescription and use of PRN anti-anxiety medication ahead of specific medical examinations and tests, Visitors typically do not see evidence of actions being taken – by disability accommodation providers or health practitioners – to assist the relevant residents to overcome their aversion and enable them to access necessary treatment. In this regard, OCVs advise that, while service progress notes and communication books will identify these issues – such as staff recording that a procedure needed to be rescheduled due to the person’s resistance – the problem won’t be included in the person’s behaviour support plan. The opportunity to develop and implement behaviour support strategies that specifically target the person’s resistance to medical assessment and treatment is lost.

The problem becomes particularly stark when treatment limitation decisions are made in relation to the person with cognitive disability, on the basis that they are likely to resist the treatment (for example chemotherapy) and/or become distressed. OCVs have heard from disability support staff and managers about actions they have taken to advocate with hospital staff on behalf of the person with disability to access treatment, at times against the views of the person’s family. However, Visitors still do not see evidence of action being taken at the front end to help the person to overcome their resistance, minimise their distress, and improve their health outcomes.

OCVs note that there are useful resources that are available to assist disability and health services to work with people with cognitive disability to make it easier for them to understand health procedures (such as blood tests) and reduce anxiety and resistance.⁸ However, Visitors generally do not see these resources in disability accommodation, or recognition or awareness by staff of the existence of this guidance.

Involvement of people with cognitive disability in decisions about their own health care

In the experience of OCVs, people with cognitive disability in residential care are not always adequately involved in, or supported to make, their own health care decisions. At times, OCVs have identified a poor understanding on the part of disability and health providers about consent requirements and options for supporting the person with cognitive disability to be able to maximise their ability to make informed health care decisions.

NDIS and access to health care

OCVs note that many of the problems relating to the access of people with cognitive disability to health care pre-date the NDIS. However, they have identified particular issues that are linked to the scheme, including:

- there is limited NDIS funding for transport, and some disability accommodation providers have advised OCVs that transporting a person to their medical appointments can mean reducing the funding that is available for other supports, such as community access
- the funding for behaviour and communication support is insufficient to cover the provision of disability support staff to assist a participant with complex behaviour and/or communication needs while they are in hospital
- there does not appear to be adequate funding for staff training, which can present health risks to some residents
- there continues to be a lack of understanding and clarity as to what the NDIS funds in terms of health care

⁸ For example, see ‘Say Less, Show More’ visual resources, including ‘I need to have a blood test’, ‘I am going to hospital’, ‘I need to have an x-ray or ultrasound’, and ‘I am going to have an operation’: <https://www.aci.health.nsw.gov.au/resources/intellectual-disability/childrens-services/say-less-show-more>; and NSW CID Easy Read information guides for people with intellectual disability in relation to health care, including ‘Going to hospital for surgery’: <https://cid.org.au/resource-category/health/>.

- the move away from disability accommodation providers being responsible for most supports for residents has presented some opportunities, but has also resulted in some accommodation support providers advising OCVs that they do not have responsibility for some health-related supports ('we're just the SIL provider'), and pushing it over to the support coordinator – at times, identifying who has responsibility for providing the support can be difficult.

OCVs have advised that the changes to the NDIS to enable the funding of speech pathology assessments and the development of mealtime management plans has had a positive impact. Visitors indicated that they have seen greater involvement of student speech pathologists in disability accommodation services, with the positive flow-on benefits of more timely assessments and plans for residents, and greater understanding by the allied health practitioners of both people with cognitive disability and supported accommodation settings.

Visitors emphasised the need for more education and training for disability support staff in supporting people with cognitive disability to access health care. They advised that it is common for a Team Leader role to work across multiple houses, and staff now access information and updates through online training rather than team meetings. OCVs have noted that this is leading to staff feeling isolated and lacking knowledge and confidence to adequately respond to health care needs.

The importance of reasonable adjustments to meet the needs of the person with cognitive disability

OCVs emphasised the difference in experience and health outcomes for residents who had benefitted from reasonable adjustments being made to enable their effective access to health services and treatment. Examples include:

- health providers visiting the person at home to reduce anxiety
- provision of information in Easy English or pictures
- minimising waiting times
- providing extended consultation times

More broadly, Visitors noted the importance of a person-centred approach – clearly identifying the support needs of the individual with cognitive disability and taking active steps to meet those needs to maximise their access to health services and necessary treatment. Importantly, many of the elements that help people with cognitive disability to access – and feel safe when accessing – health care, are consistent with a person-centred approach, including:

- being familiar with the health care provider
- being supported by people/ disability support staff who know the person well
- being supported to understand what is happening (examination/assessment, tests, treatment) in a way that works best for them, including a planned approach where possible
- having their support needs clearly identified and collaborative work undertaken to meet those needs in the health setting.

Increasing awareness and ensuring implementation of existing good practice resources and guidance

There is a wealth of resources, training modules, fact sheets and other guidance that is aimed at improving the health care of people with cognitive disability, including their access to, and support from, health services. This has particularly been the case since the development of NSW Health's Service Framework to Improve the Health Care of People with Intellectual Disability, and the associated roll out of the Agency for Clinical Innovation (ACI) Intellectual Disability Network and pilot of intellectual disability health teams. Key examples include (but are not limited to):

- NSW ACI ID Network's *Building capability in NSW health services for people with intellectual disability: the Essentials*.⁹ The Essentials includes 10 guiding principles of quality health services for people with intellectual disability, a self-assessment tool for health services, and links to useful resources, such as the 'Top 5 toolkit' and the 'Admission2Discharge Together Folder for People with a Disability'.
- NSW Council for Intellectual Disability's Easy Read information guides for people with intellectual disability on health care – including 'Going to hospital for surgery', 'Me and my doctor' and 'After visiting the doctor'.¹⁰
- Health Education and Training Institute (HETI) has 10 educational resources related to disability, including 'Let's Talk Disability' and 'Community and Inclusion'.
- The Department of Developmental Disability Neuropsychiatry's (3DN) resources,¹¹ including 'Accessible Mental Health Services for People with an Intellectual Disability: A Guide for Providers', and a range of e-learning modules on intellectual disability mental health, communication, consent, and assessment and management of mental disorders in intellectual disability.
- Family Planning NSW's factsheets for people with intellectual disability on sexual and other health, including 'Being a Healthy Woman' and 'All About Sex'.¹²

Despite the availability of resources and guidance, OCVs note that awareness of this information across disability services is low. While OCVs do not visit health services, the experience of residents in contact with health services suggests that awareness and implementation of the available guidance in these services is also limited. There would be benefit in focusing on strategies for raising awareness and ensuring the implementation and application of the existing guidance.

Overall main points

The work of OCVs in their visits to people with cognitive disability living in disability supported accommodation and assisted boarding houses has emphasised the need for action to:

- ensure early and collaborative work to identify the person's support needs and the best ways to meet them in a health setting, including through the use of reasonable adjustments
- identify people with cognitive disability who are averse or resistant to medical examinations and treatment, and take early and consistent action to help them to minimise their resistance – including through targeted positive behaviour support strategies and a person-centred approach to support
- better coordinate support for people with cognitive disability between health and disability providers
- focus on increasing awareness and ensuring implementation of existing good practice resources and guidance that are aimed at improving access to, and the quality of, health care for people with cognitive disability.

⁹ See <https://www.aci.health.nsw.gov.au/resources/intellectual-disability/id-essentials/home> and https://www.aci.health.nsw.gov.au/data/assets/pdf_file/0005/372524/ACI16008_ID_The-Essentials_D5.pdf

¹⁰ See <https://cid.org.au/resource-category/health/>

¹¹ See <https://3dn.unsw.edu.au/content/education-resources>

¹² See <https://www.fpnsw.org.au/factsheets/individuals/disability>