



Response to the *Health care for people with cognitive disability: Issues paper*

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

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About PANDDA Inc

PANDDA Inc is the only Australian association representing the professional interests of nurses who work with and care for people with intellectual and developmental disability (IDD). Many of PANDDA's members work within disability-specific services; however, a growing number work in primary health roles, specialist assessment clinics, community health teams, private consultancy, and in academic/research institutes. PANDDA has published a series of position statements and practice standards for its members and also the wider public that are freely available for download from the PANDDA website: <http://www.pandda.net/index.html>

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Introduction

PANDDA Inc welcomes the opportunity to respond to the *Health care for people with cognitive disability: Issues paper* as part of the national consultation by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

The purpose of this submission is to express our concerns for the health and wellbeing of people with intellectual and developmental disability (IDD) from the perspective of professional nurses who work in the disability space and in response to questions as set out in the *Health care for people with cognitive disability: Issues paper*. Our approach is to express our concerns that are supported by the literature, together with offering a number of lived experience situations from a professional IDD nurse perspective. These are presented as *narratives*. A series of recommendations for the Commissioner is offered.

Question 1:

What do you think about the quality of health care for people with cognitive disability?

As a peak national body in the nursing care of people with IDD, PANDDA Inc is concerned that the safety and quality of health care of people with IDD is currently at risk, and potentially into the near future, for a number of reasons as discussed below. In the context of this Royal Commission into violence, abuse, neglect and exploitation of people with disability, our response is primarily related to neglect.

Despite the Australian government's commitment to reduce disability discrimination and disadvantage following the human rights based global push to improve the lives of people with disability at the beginning of the century, little progress has been made to date (Emerson et al., 2018). Indeed, Tonge, Torr and Trollor (2017) expressed concerns that there is apparent lack of government response in the healthcare sector compared to education, community-based programs, and accommodation. Institutional disability discrimination within health services is well-recognised across the globe (Disability Rights Commission, 2006; Mencap, 2007; Michael & Richardson, 2008) and is contrary to the UN Convention on the Rights of Persons with Disability (UNCRPD, 2006) and legislative guidelines of the Disability Discrimination Act (DDA) 1992. Equitable access to healthcare is a basic human right to which many Australians with IDD cannot realise.

Of greatest concern, is that although people with IDD are living longer due to advances in medical treatments and interventions, preventable deaths are twice as likely as the general population (Department of Justice and Attorney-General [DJA-G] QLD, 2016; Emerson et al., 2014; Trollor et al., 2017). Part of the problem is the lack of IDD health literacy of health professionals across all disciplines, affecting systems and service delivery, which is the focus of this response.

It is PANDDA's concern that despite the overwhelming and continuing evidence that people with IDD have poorer health outcomes due to inadequate services and IDD under-skilling of health professionals; equipping of services and health professionals is still lacking.

It should be noted that PANDDA Inc made a submission to the *Independent Review of Nurse Education* in 2019 with a number of recommendations, including the need for mandatory inclusion of IDD content in Bachelor of Nursing (BN) curricula, nationwide (Wilson, Howie & Atkins, 2019). In response, it was argued by the review committee that in order to include IDD content in an already overcrowded curriculum, other topics would need to be pulled out. On this point PANDDA disagrees with the committee, as it would be quite straightforward to mandate the inclusion of IDD-specific content across a range of units of study, such as IDD-specific case studies across the curriculum. In fact, the most recent iteration of the Nurses and Midwifery Board of Australia Standards for Practice (NMBA, 2016), mentions that nursing people with IDD will be one of the many challenges nurses face in their practice. In addition, it is our understanding that the Federal government is unsupportive of extending the BN study program from 3 to 4 years, which would allow for the more detailed inclusion of important topics such as nursing people with IDD (personal communication, Professor M. Williamson, Dean School of Nursing & Midwifery & Social Sciences, CQUniversity, October 12 2019).

PANDDA Inc acknowledges the great work carried out by various research teams and academic champions dedicated to the advancement of positive health outcomes for this marginalised population group in pockets throughout Australia. PANDDA Inc also acknowledges COAGs reform vision to improving the socialisation and independent living of people with disability through the introduction of the NDIS. However, more work needs to be done to improve health outcomes for people with IDD through further reform in national policy and practice aimed at overcoming barriers to equitable health care.

Question 2:

B. Can you tell us about any barriers that people with cognitive disability have experienced in accessing health care?

Our response is from a nursing perspective that seeks to address issues where nurses are involved. Our concerns are twofold: *Firstly*, the quality of nursing care within the disability sector is in peril as the number of IDD trained nurses diminish from the workforce. *Secondly*, the safety and quality of care outside the disability sector, that is, within acute care and primary care services is at risk due to the lack of IDD-specific training and education of generalist nursing staff.

First, understanding the complexities of healthcare needs for this diverse group serves to highlight the difficulties encountered.

As recognised in the Royal Commission's issues paper on health, IDD is often accompanied by co-morbidities (Cooper et al., 2015; Peterlin & Peterlin, 2016), and compared to the general population, people with IDD have higher rates of physical health problems (Beange et al., 1995), have early onset age-related conditions and are 2-3 times more likely to have mental health disorders (Tonge et al., 2017), are more frequent users of emergency departments and ambulatory care settings (Howlett et al., 2015) and experience longer hospital stays (Ailey et al., 2015). Australian research also highlights high rates of readmission to hospital suggesting issues exist during various stages of the hospital care and discharge processes (Iacono, Bigby, Douglas & Spong, 2020). Having regular contact with health care services suggests that health care providers and staff should be familiar with the diverse needs of this vulnerable population group. Unfortunately, both empirical and anecdotal evidence by PANDDA members suggests otherwise.

Barriers to accessing quality health care for this vulnerable group and strategies for improving health outcomes where there is potential for nurses to make a difference are concerned with: knowledge deficits; diversity and complexity of health care needs; ambiguity of the role of carers; poor health literacy; and systems failure, which are now discussed in more detail.

Knowledge deficits

It is our concern that there is a general lack of confidence, knowledge and skills across all health disciplines in meeting the health care needs of people with IDD, and this is appropriately acknowledged in the issues paper. A lack of 'disability confidence' leads to poor practice and workforce gaps in this important area of health service delivery that results in **neglect** (Heslop et al., 2014).

A number of factors contribute to this situation, namely, lack of education and training in IDD care and poor staff attitudes towards people with IDD, often as a result of knowledge deficit (Iacono et al., 2014; Noronha & Pawlyn, 2019; Tua, Neville & Scott, 2017). Michael & Richardson (2008) reported that staff who lacked training in IDD tend to stereotype and devalue the person's worth. In fact, the AIHW (2017a) reports that 1 in 5 people with disability experience discrimination by health staff. Poor attitudes by health professionals include stigmatisation (Noronha & Pawlyn, 2019), implicit bias (Fitzgerald & Hurst, 2017), diagnostic overshadowing (Manohar et al., 2016), and poor communication (Lewis, Gaffney & Wilson, 2017) that negatively impact the quality of care.

From a nursing perspective, lack of disability confidence is unsurprising, since there is little IDD content in nursing curricula in Australia (Trollor et al., 2016). The reason for this lies in the past. Historically, IDD nursing content was taught within the Mental Health nursing curriculum. However, following recommendations by the *Royal Commission of Inquiry into the Callan Park Mental Hospital* in 1961, a 3-year hospital based Mental Retardation Nursing program (re-named Developmental Disability Nursing in 1980) was developed separately to Mental Health nursing in recognition of the need for a more social rather than medical model of care. The first graduates of the IDD program emerged as registered nurses in IDD in 1969.

However, when nursing transitioned to higher education in the late 1980's, these specialty programs dissolved with the expectation that mental health and IDD content be incorporated into the generic undergraduate nursing program. Indeed, some PANDDA Inc members were responsible for developing extensive IDD exit competencies at that time. Unfortunately, over time IDD content has gradually been eroded from the curriculum. It seems ironic that another Royal Commission, some 60 years later is examining similar issues, albeit some small gains in the meantime; bringing the investigation full circle.

Of gravest concern in all of this, is that nurses who were trained in Mental Health and/or IDD nursing before the 1980's are now retiring from the workforce, leaving a deficit in IDD knowledge and skills. In 2018, PANDDA conducted a national survey of nurses who work in IDD care and found that the average age of IDD nurses was 53.2 years; however, only 50% reported having IDD-specific qualifications (Wilson et al., 2020). As only half the IDD workforce have IDD specific knowledge and skills and the other half seemly lack understanding of the complexities of IDD care, quality nursing care of people with IDD is in a precarious situation.

In the current climate, nurses who lack IDD education feel overwhelmed, underprepared, lack understanding of the role of family and caregivers and struggle to overcome communication difficulties (Lewis et al., 2017). Part of the problem is the poor health literacy of nurses concerning the diversity and complexity of health care needs for this vulnerable population group.

Diversity and complexity of health care needs

People with IDD have varying levels of intellectual functioning and understanding, a range of associated physical conditions and communication difficulties, all of which require an array of services and multidisciplinary assistance across a variety of contexts to maintain good health across a lifetime.

Varying intellectual functioning. People with *mild* IDD may function independently with minimal support and guidance; whereas people with *profound* IDD will need 24/7

supported care within institutional facilities. The higher the needs, the greater the risk of adverse health outcomes. In addition, personality and the level of social supports influence capability, confidence and coping abilities (Centre for Developmental Disability Health [CDDH], 2016).

Varying physical disabilities and conditions. IDD is often associated with genetic disorders, the most common being Down syndrome (Vissers, Gilissen & Veltman, 2015). Genetic conditions can affect other organs and/or metabolic processes; therefore, it is important for nurses to be aware of likely co-existing conditions so that an appropriate diagnosis is not missed.

Being cognisant of associated disabilities such as autism, cerebral palsy, sensory impairments, and social and communication disabilities serves to better address health care needs (CDDH, 2016). Approximately 27% of people with autism and 45% of people with cerebral palsy also have IDD (AIHW, 2017b; Reid et al., 2018). It is important for nurses to understand that unusual behaviour associated with autism such as flapping, spinning, or repetitive behaviour may be a normal response to a change in routine so that preventative measures can be initiated (Ministry of Health, New Zealand, 2017). Similarly, allowing more time for someone with cerebral palsy when communicating or attending to physiological needs, is respectful of the person's disability affecting muscle coordination.

Furthermore, IDD is associated with higher rates of chronic conditions such as epilepsy, gastro-oesophageal reflux, dysphagia, diabetes, obesity, being underweight and poor oral health (Wilson et al., 2019; Wilson & Charnock, 2017), requiring a range of nursing skills to address individual needs.

Varying communication needs. Communication with people with IDD is complex. Factors affecting communication difficulties can originate from the disability itself, the staff and/or the caregiver.

At least 60% of the IDD population have severe communication disability (AIHW, 2008). Communication difficulties arise due to either *expressive* (difficulty expressing concerns, symptoms, feelings) or *receptive* (difficulty understanding abstract concepts and complex language) communication barriers (CDDH, 2016). Difficulty expressing concerns, symptoms and history affects health care professional ability to correctly assess, plan and implement care (CDDH, 2016). Whereas impaired receptive communication means that information is not being understood, affecting the ability to make decisions and healthy lifestyle choices (CDDH, 2016). Most people with IDD will often communicate through behaviours, which varies with the given situation.

For example, pain can present as *behavioural change* which is often unrecognised by nurses resulting in inadequate pain assessment and under-response to pain (Findlay,

Williams & Scior, 2014). Another example is that most people with IDD embrace routine. If faced with change, such as an unfamiliar hospital environment, anxiety levels can increase that may be expressed in behavioural change. Including a tour of the ward environment during the pre-admission period and being first on the theatre list helps to reduce anxiety prior to surgery. Similarly, a person with Autism spectrum disorder (ASD) may be better placed in a single hospital room away from the stimulation of lights, noise and the busy ward environment. Of greatest concern is when communication presents as *challenging behaviours*, which are disruptive to services and routine. Challenging behaviour is defined as, 'Behaviour of such intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion' (Royal College of Psychiatrists, 2007). It is important that nurses understand the psychology behind challenging behaviours in order to reduce risk to all. It is also important that nurses are aware of the different communication methods and tools used to facilitate communication interactions. For example, some people with IDD are non-verbal and may communicate by sign language, eye-gazing or make use of assistive devices. Assistive devices can be as simple as communication boards, or more complex in the form of computerised or robotic technology requiring advanced knowledge and skills. Awareness of individual communication needs is respectful of the person as a whole. Communication breakdown also occurs when staff are indifferent.

For example, people with IDD report being excluded from conversations as health professionals prefer to engage in conversation with carers instead (Chinn, 2017). Nurses may not engage in conversation with the patient if they perceive them to be lacking in capacity to understand as a result of stereotyping (Lewis et al., 2016). Devaluing the patient in this way affects self-esteem and confidence in engaging in own health care with associated consequences (Chinn, 2017). Talking down to the patient as though they were a child or yelling is also demeaning. Communicating may take extra time compared to those who can freely communicate their needs. According to Hemsley, Balandin and Worrall (2012), nurses who perceive that communication takes too long, together with workload demands, tend to avoid direct contact with the patient. In addition, some nurses leave patients with IDD until last during routine cares because of the perceived extra time taken for successful communication encounters (Hemsley et al., 2012). Failing to take time is considered **neglect** and increases the risk of adverse health outcomes (Jaques et al., 2018). Indeed, families emphasise the need to avoid hurrying and taking time to get to know the person due to differing individual needs, which includes talking to families who know the person best.

Including families and carers is central to promoting positive nurse-patient relationships as caregivers have extensive knowledge of the person's history, personality and behavioural responses. Indeed, family presence is often 24/7 as vigilance is important

to minimise fear, anxiety, and ensure adequate care and safety (Hemsley et al., 2012). Lack of acknowledgement of carer input is strongly associated with unavoidable deaths (Heslop et al., 2014). On the other hand, over-reliance on carer knowledge can also lead to inaccurate information exchange if carers misinterpret or miss signs and symptoms of physical or mental health problems (Chinn, 2017). In addition, if carers find topics awkward to talk about, such as breast screening and cervical cancer screening, the person with IDD may miss out on important screening programs (Swaine et al., 2014).

Communication is a fundamental human right requiring nurses to develop knowledge and understanding of varying IDD communication needs. Poor communication is mitigated through nurses having a better understanding of: behaviour as way of communication; the preferred method of communication; the need to include people with IDD in conversations; allowing more time; the risks and benefits of caregiver involvement, and getting to know the patient, all of which are strategies to improve health outcomes.

Ambiguity of the role of caregivers

There is ambiguity of nurses' expectations of caregivers. During hospitalisation, nurses often rely on paid and unpaid carers as a way of managing their feelings of under-preparedness during communication encounters (Lewis et al., 2017). There may be heavy reliance on caregivers to provide direct support, such as personal hygiene, which may then become unwelcome if the carer interferes with hospital routine (Hemsley et al., 2011). Nurses must be cognisant of their professional obligations to provide direct care in accordance with the professional nursing codes and standards for practice (Nursing and Midwifery Board of Australia [NMBA], 2016). Carer advocacy is also confusing when seen as interference rather than enhancing the person's hospital experience (Hemsley et al., 2011). Adding to the confusion is the differences between paid and unpaid carers. Paid carer knowledge of the person may vary according to the length of time in the carer role, whereas, unpaid carers are usually family members who will have lifelong knowledge of the person's background (Hemsley et al., 2011). Paid carers are also less likely to stay long hours due to the conflict of job role and tend to visit as a friend, rather than as a worker (Hemsley et al., 2011). Misunderstandings have also occurred around caregiver involvement in consent to treatment (Sowney & Barr, 2007). Hemsley et al. (2011) maintain that there is a general lack of policy and guidelines about the role of carers in hospital, which contravenes safety and legal obligations. Clearer guidelines and policy on the role of carers is needed to improve confidence for nurses when engaging with carers during nurse-patient interactions.

Poor health literacy

The World Health Organization (WHO, 2016, para. 1), defines health literacy as, "...the ability of individuals to gain access to, understand and use information in ways which

promote and maintain good health for themselves, their families and their communities". Low health literacy levels increase the risk of serious illness; the need for emergency care and hospitalisation; medication mismanagement; missing out on important vaccinations; and ultimately poorer health outcomes (ACSQHC, 2018).

People with IDD have poor health literacy due to reduced ability to access, process and act on information offered; failure of health professionals to deliver necessary information in an accessible manner; and systems failures (Chinn, 2017; Scott & Havercamp, 2016). Given that people with IDD have higher rates of health conditions associated with mortality, such as epilepsy, obesity, respiratory disorders, gastro-oesophageal reflux disease, and mental health problems (Trollor et al., 2017), good health literacy has a strong place here and an opportunity for nurses to play a key role.

However, it has been demonstrated that poor attitudes by health care staff may contribute to deficits in health literacy. For example, health professionals may withhold information from the person with IDD because of perceived inability to comprehend information which is considered **neglect** (Queensland Health, 2017). Furthermore, if poorly treated by staff, people with IDD are less likely to return for follow-up care or avoid accessing services altogether, resulting in missed opportunities for health information exchange (Moscoso-Porras, 2018).

Consideration must also be given to position in life. Many people with IDD belong to the lower socio-economic group and struggle financially because of barriers to gaining employment along with the financial costs associated with their disability (Judicial Commission of NSW, 2019). Therefore, costs of health care, costs of travel to health care services, and cost of medications impact on compliance to treatment. The AIHW (2017a) reports that 1 in 5 people with disability delayed or did not see a GP because of cost. Nurses have the potential to bridge the gap here by liaising between the client and services.

Systems failure

Systemic issues such as lack of support in accessing health care and ineffective coordination between disability and health services contribute to morbidity and mortality (DJA-G QLD, 2016). Allocation of funding to disability services and health services in Australia is separate, which has the potential to create gaps in services (Hemsley et al., 2011). Poor uptake of screening and preventative programs, including dental health (McIlfatrick et al., 2011), suggest that healthcare systems are failing to address these unmet needs. Institutional discrimination leads to poor policy and practice in the absence of IDD education and training and if allowed to continue, government health departments are effectively, guilty of **neglect** (While & Clarke, 2010). Specific areas of concern are during admission and discharge processes; when

transitioning from paediatric to adult services; or from adult to geriatric services; as well as in primary care.

Admission barriers. People with IDD often present to emergency departments without paperwork or unaccompanied by a caregiver, and together with receptive and expressive communication difficulties can hinder the history-taking process with the potential for serious adverse outcomes (Lewis et al., 2016). In the presence of poor staff attitudes, this situation can be disastrous.

Narrative: A person with IDD and cerebral palsy who was non-verbal and tended to respiratory aspiration, was rushed to the emergency department with respiratory difficulties. The ED nurse's first question was, "Does he have a not for resuscitation (NFR) order?" The nurse made the assumption that the patient had poor quality of life, not understanding that he enjoyed life to the full in the supported accommodation with supports in place. This nurse did not allow for the person's individual personality and full enjoyment of life. (Virginia, RN, PhD (candidate), NSW inner regional hospital).

Discharge barriers. Health professionals may not know how to navigate disability services when transitioning from acute care services especially with more complex cases, which leads to gaps in ongoing care (CDDH, 2016). The provision of discharge information is confusing for health care staff when unsure of who had authority, given the need for confidentiality (Webber, Bowers & Bigby, 2010). Health professionals may also rely on carers to arrange health reviews and regular check-ups and therefore follow-up care goes unchecked (CDDH, 2016).

Further confusion arises when health professionals assume staff in residential care will manage ongoing medical treatment despite not being trained in post procedural care. Webber et al. (2010) report that patients are often discharged early with the assumption that home care was better, and if met by refusal were often referred to aged care. Whereas support staff assume that health care staff are cognisant in IDD support care, which, in the presence of poor attitudes, can lead to worse outcomes.

Problems also arise when family are no longer providing care and support, for example, when parents die, causing long delays in discharge if there is no place to go.

Narrative: An Australian Aboriginal patient with IDD and challenging behavioural problems was unable to be discharged for 12 months following an acute care admission because family and community could no longer care for him and no suitable accommodation was available. In the meantime, the behaviour was disruptive in the ward, affecting staff morale and compromising patient care (Virginia, RN, PhD (candidate), remote Northern Territory).

Transition from paediatric to adult health services. The paediatrician is central to patient care during childhood encounters with the health care system, which is different in the adult system where the patient will encounter a multitude of specialists (Bloom et al., 2012). There is no clear pathway for transition from paediatric care to adult care and is a stressful time for children with special health care needs and their families (Bloom et al., 2012).

Transition from adult to geriatric services. There is no clear pathway for transitioning from adult to geriatric services, as the ageing of people with IDD is a more recent phenomenon. There are three broad service system options that are evolving. Age-integrated models where the person with IDD “ages in place” and the service system adapts to these changing needs. Specialist service models are where a disability service creates a segregated IDD-specific ageing service in response to the changing needs of many of their clients. The final model are generic service models where people with IDD transition into local aged care facilities.

Primary care. Routine health checks are essential to maintain good health and identify preventable problems in a timely way (DJA-G QLD, 2016). However, uptake of recommended annual health assessments such as the Comprehensive Health Assessment Program (CHAP) supported by Medicare is ad hoc (Lennox et al., 2013). Again, there is potential for practice nurses and IDD nurses to play a role here to improve uptake.

Narrative: As a parent of a child with IDD (as well as a registered nurse, I attempted to have a CHAP assessment for my daughter in 2018; however, the GP (inner regional Queensland) was unaware of CHAP program and although did try to initiate the process, the process appeared convoluted and consequently my daughter has still not had a CHAP assessment. (Virginia, RN, PhD (candidate), QLD inner regional district).

In summary, there is potential to overcome many barriers to equitable health care across the continuum where nurses can be involved. Building capacity through work-ready graduates who have a solid understanding of the diverse health care needs of this cohort will address deficits in care by improving confidence and attitudes toward people with IDD and their families.

Question 3:

B. Can you tell us about any problems that people with cognitive disability have had with the NDIS and accessing health care?

Problems for discussion include quality of nurse-related care at risk, attitudes by disability service staff, and confusion regarding ownership of post-discharge care due to uncertainty of funding allocation.

It is the concern of PANDDA that given the confusion about funding for health-related services together with the lack of presence of nurses in the NDIS, people with IDD may not be receiving the appropriate health care services in the community putting them at risk of adverse health events. The NDIS has been reluctant to fund health-related nursing services, claiming that this is the responsibility of State health departments. Although this stance has been slightly relaxed in 2019 with the inclusion of nursing within the core supports funding category, there are still perceived gaps in health care that would benefit from further nursing interventions, for example, blood glucose monitoring for people with diabetes and profound IDD, and monitoring/management of anti-epileptic medications for people with severe epilepsy.

In the national survey of IDD nurses, Wilson et al. (2020) found that nursing roles were primarily concerned with direct assessment and care of people with IDD, supervision of support workers, and education of others. Nursing regulation requires that any decisions made regarding nurse-related practice must be assessed and evaluated by registered nurses and this includes supervision of care given by EN's, AINs and untrained staff (Queensland Nurses and Midwives' Union [QNMU], 2017). For example, untrained and unsupervised carers who administer medicines but who do not have the necessary pharmacology knowledge put clients at risk. Another example is the poor health literacy of caregivers. One of the leading causes of avoidable deaths for people with IDD is aspiration pneumonia (Trollor et al, 2017). The authors found that there was increased risk to patients with IDD as they may not easily report symptoms and that caregivers may not have the skills to identify the problem.

In addition, by upskilling untrained staff, peak national nursing bodies (including PANDDA Inc) are concerned for the potential to erode the quality of nursing care. In a submission to the Productivity Commission, the Queensland Nursing and Midwifery Union (QNMU, 2017) recommended that NDIS funded nursing services and support should only be delivered by qualified nurses in order to deliver quality and cost-effective outcomes. The QNMU (2017) also recommended that the NDIS be fully funded for such nursing services. Such concerns relate to the professional nursing boundaries being crossed by untrained carers performing nurse-specific tasks, putting clients' safety at risk, and this is echoed by the DJA-G QLD (2016).

Another concern is the stigmatisation by care providers (support staff, social workers, therapists and direct-care staff), which can affect the quality of support and this is more distinct when associated with higher levels of care (Pelleboer-Gunnink, 2019). IDD nurse involvement by liaising services and advocating for the client has the potential to ameliorate poor attitudes.

Narrative: Hospital administration and clinicians often advise that post-operative care is a NDIS responsibility, for example, post-operative assessment and treatment following

a surgical procedure such as a hip replacement, insertion of spinal rods, physiotherapy /rehabilitation following procedures or Occupational Therapy assessment and rehabilitation following a stroke. Conversely, an NDIS Planner (September 2019) stated that physiotherapy for a child with autism and Avoidant Restrictive Food Intake Disorder (ARFID) is a health responsibility due to the acute nature of the osteopenia and therefore could not be funded from the NDIS funding. This condition was directly related to the disability and therefore the responsibility of the NDIS. (Denise, PANDDA committee member, NSW).

Narrative: Most hospitals require a support worker/parent to stay with the person during assessments and admission for the duration. This is not always possible if the person with IDD does not have a family member available. NDIS does not currently fund carer supports during admission. (Denise, PANDDA committee member, NSW).

Question 4:

A. What do you think should be done to fix the problems people with cognitive disability have in getting health care?

A number of evidenced-based good practice examples are listed below. Also included are suggestions by PANDDA members who work in the disability space. Recommendations are also offered at the end of this document.

Good practice examples

- UK. Good practice database. Public Health England, Reasonable Adjustments Database, <https://www.improvinghealthandlives.org.uk/adjustments/> (DJA_G QLD, 2016).
- UK. Role of the learning disability nurse (LDN) in the community as well as a liaison person within acute care services.
- Queensland. Role of Nurse Navigators (Disability specialist nurses). URL: <https://www.health.qld.gov.au/sunshinecoast/html/services/nurse-nav>
- NSW. Role of clinical nurse consultant (CNCs) – provides guidance to disability services staff and acts as intermediary with health services and the client (DJA_G QLD, 2016).
- Reasonable adjustments can be as simple as: allowing more time, identifying IDD on admission documents, providing accessible information, including people with IDD in conversations, looking for non-verbal cues, respecting caregiver knowledge of the person, familiarising patients to the hospital environment during pre-admission, placing them first on the waiting list, and providing necessary supports and services in the process.

PANDDA Inc member suggestions

- Incorporate clinical placement in a multi-disciplinary disability team as part of the overall placement options for all health professionals (this was offered by ADHC in the past). Hands-on experience under supervision offers a realistic approach to working with people with IDD and improves attitudes (Lewis et al., 2017).
- Dedicated school clinics for general health screening of children and young people with IDD and school nurses to be educated in, and offer support for, the management of complex behaviours.
- Offer regular ongoing educational programs and webinars for professional development opportunities provided through local Primary Health Care Networks that target Practice Nurse Managers.
- One stop shop clinics that have sedation facilities if required for people with anxiety or challenging behaviours to assist with care and a more thorough assessments.

There are a number of useful tools available that can assist a smoother transition during admission to hospital including the *One-page profile*, *Top Five* form, hospital passports, and personalised disability profiles.

[One-page profile](#) offers a quick reference for health care staff on 3 important areas concerning the individual: 'What people appreciate about me', 'What is important to me', and 'How to support me'. Hospital staff complete the form with the help of the patient and family. The concept was developed by Helen Sanderson in the UK and is used in a few places in Australia. However, greater uptake is required.

[Top Five form](#) originated in NSW in relation to dementia patients but has been adapted for use with ID also. The family and patient complete the form at home and take it with them on admission to hospital. This form relates more to behaviour issues and informs staff of the 5 top tips and management strategies to aid communication and support for patients with cognitive impairment.

[Hospital passports](#) offer individualised information specific to the patient. Templates are available, although UK orientated.

B. How could the NDIS and health systems work better for people with cognitive disability?

A number of suggestions by PANDDA members are listed as follows:

- Equal recognition of the role of nurses and Allied Health in the delivery of therapeutic interventions.

- Health pathways for funding under NDIS for people with IDD to assist with the management of complex health issues and better facilitate community participation.
- Expand the recently introduced health outreach clinics (in NSW) to rural and remote areas, as well as nationwide.
- The provision of community health teams across Australia to include IDD-specialised nurses to support people with IDD who have complex health needs.
- Provide training and resources to NDIS Planners and Support Coordinators re health care needs. Prioritise health care needs during the NDIS planning process. Many families do not even think about health care needs as a person gets older.
- Government funded health promotion campaigns to PREVENT health issues. For example, sexual health/relationships training, oral health, healthy lifestyles education programs, and better access to cancer screening programs.
- Greater recognition of nursing interventions and access for highly skilled nurses within the Capacity Building frameworks of the NDIS
- The provision of Medicare provider numbers to highly skilled nurses who can support people with IDD living in the community who also have chronic health conditions.

Question 5:

Why do people with cognitive disability experience violence, abuse, neglect or exploitation in health care? What are the causes?

A number of suggestions are listed as follows:

- People with IDD are not valued.
- Lack of health staff understanding leads to stereotyping and associated prejudices.
- Poor attitudes by health care staff leads to poor uptake of preventative educational and screening programs, and poor follow-up on health checks.
- If staff perceive communication takes too long or is too challenging, they will leave the patient until last and/or may not provide health information in which to make informed decisions on own health care.
- The busy health care environment and demands on workloads adds stress to health care workers who may become impatient when interacting with someone who is perceived to take up more time.
- Untrained staff report being scared of some people with IDD, which affects the ability to complete positive patient-staff communication interactions.
- If health care staff do not understand that behaviour is a way of communication, health care needs will not be met.

- If health care services and staff are unaware of the legal requirement to make reasonable adjustments, then there is failure to meet legislative requirements.
- Due to cognitive deficits, people with ID are more vulnerable and open to violence, abuse, neglect and exploitation by unscrupulous people wanting to take advantage.
- Poor experiences with health care services leads to fear of subsequent encounters and reluctance to seek services.

Question 6:

A. Is the violence, abuse, neglect or exploitation that people with cognitive disability experience, different in doctor's or GP's surgeries, medical centres, hospitals, specialists or consultants?

Our experience suggests that poor treatment of people with IDD occurs in all centres.

- Health facilities just do not have the capacity to care for people with IDD on an equal basis as people without IDD.
- People with IDD require longer appointments, have greater health issues, and can be perceived as a challenge to untrained staff.
- Reasonable adjustments are required across all health care contexts, although may not necessarily be fully understood in order to implement appropriate strategies. For example, pre-empting anxiety behaviour.

B. Is the violence, abuse, neglect or exploitation that people with cognitive disability experience, different in public, private or not-for-profit health care?

As people with IDD belong to the lower socio-economic group and most are on disability pensions, private health insurance is not an option. Therefore, private practice is less accommodating. Timely access to dental care is also affected.

Question 7:

A. Are experiences of violence, abuse, neglect or exploitation in health care different for particular groups of people with cognitive disability?

The following groups are at greater risk (although not limited to):

- People with severe and profound IDD.
- People with IDD and challenging behaviours.
- People with dual diagnosis of IDD and mental health.
- People with IDD who have ageing carers (usually parents) or whose parents have died.
- People with IDD who live in supported residential homes.

- People with IDD who live alone.
- People with IDD who present to healthcare services (particularly emergency departments) without an accompanying support person.
- People with IDD who transition from paediatric services to adult services.
- Young people with IDD living in aged care facilities.
- Girls and women with IDD are at greater risk of sexual abuse.
- People with IDD who identify as belonging to the LGBTQI group.
- People with IDD who have had contact with the criminal justice system.
- People with IDD who are homeless.
- People with IDD who are illicit drug users.

B. Are experiences of violence, abuse, neglect or exploitation in health care different for First Nations and culturally and linguistically diverse people with cognitive disability?

It should be noted that this paper does not include any detailed response concerning Australia's First Nations peoples or people from CALD backgrounds, as it is assumed that advocates in this area will be submitting their own responses to the Royal Commission. Peak national bodies representing these groups will have an insider view on the issues faced and therefore, will offer a more appropriate response.

C. How does a person's gender, age, or cultural or sexual identity impact on people with cognitive disability getting health care?

The following groups are associated with greater risk:

- The incidence of IDD is greater in males.
- Females with IDD and sexual health. Women and girls with IDD are at greater risk of sexual abuse than females without IDD (Australian Human Rights Commission [AHRC], 2014). Current services are mostly concerned with support following an adverse event. More resources are needed for preventative educational programs.
- Males with IDD and sexual health. The sexuality of men and boys with IDD has been historically neglected within a female-dominated service system, meaning that sexual health needs are either totally overlooked or negatively problematised (Wilson, Parmenter, Stancliffe, Shuttleworth & Parker, 2010).
- Ageing parents with own age-related health issues impacts on ability to continue being the main carer.
- Health care follow up decreases following transition from the Paediatric services if there are chronic issues. If no outstanding health needs are present, there is little follow up once a child leaves generic early childhood services.

- Aboriginal and Torres Strait Islander peoples with IDD are four times likely to experience discrimination due their heritage than their non-Aboriginal counterparts with IDD. Access to disability services in remote communities is an issue.
- People from CALD backgrounds. Although data is lacking in Australia, other countries have reported lower uptake of disability services, language barriers, lack of knowledge of cultural beliefs and values, racism in service provision, together with poor knowledge of IDD (Doody & Doody, 2012).

Question 8:

A. What could prevent people with disability experiencing violence, abuse, neglect or exploitation in health care?

Suggestions are as follows:

- Educating health care professionals across all disciplines. However, nurses represent the largest group in the health care workforce and work closely with people with IDD, their families and caregivers. Therefore, educating nurses in IDD care would have a strong impact.
- Systems approach: capacity building at a local level that was research funded. Programs that worked should be introduced at a national level.
- Federally funded dedicated nurse-led teams in areas of greatest need.
- Improved admission and discharge procedures. Consider adopting nation-wide approach using hospital passport system, similar to the UK that has demonstrated success with this approach.
- Develop a comprehensive and accountable discharge planning process that is well planned prior to discharge with follow up from hospital to ensure services are in place.

Narrative. A young 11-year-old with Prader Willi syndrome whose mother had personality disorder and chronic medical issues of her own had surgery to insert a spinal rod. The child was discharged with no discharge plan evident, no follow up physiotherapy organised and no link to local ADHC team. This highlights the issue of Community Services being reluctant to challenge inadequate care of person with IDD. (Denise, PANDDA committee member, NSW).

B. What would make a person with cognitive disability feel safe when getting health care?

Suggestions are as follows:

- Reasonable adjustments: Allowing more time, both individually when interacting with the patient, as well as factored into staffing workloads. Staff awareness of likely anxiety and behavioural responses when interacting with health care services so that preventative strategies can be implemented.
- Respect: Being respected by allowing own decision-making in the provision of care. Health care staff should assume competency and self-advocacy for the person with IDD before deferring to a caregiver.
- Including caregivers in communication interactions.
- Allowing caregivers access and support 24/7 if needed.
- Respecting caregiver knowledge.
- Listening to caregivers.
- Presence of a person who understands, such as a Nurse Practitioner as a Case Manager similar to the Case Management role within the Ageing Disability and Homecare (ADHC) Multidisciplinary teams to provide Case Management and monitoring when required for people with chronic health care needs.

Can you give us any examples?

The Paul Ridd Foundation (<http://paulriddfoundation.org>), based in in Wales (UK), has championed the use of several strategies that include: the mandatory use of a 7-Step Care Bundle for people with IDD, education about how to make reasonable adjustments, and an IDD champions programme in acute care settings. Moreover, the Wales government has implemented and funded an IDD liaison nursing strategy across the country where all acute settings have an ID liaison nurse to improve care and outcomes.

Question 9:

A. What would stop a person with cognitive disability reporting violence, abuse, neglect or exploitation in health care?

The following suggestions are offered:

- Not knowing their rights.
- Not knowing how to make a complaint due to cognitive deficit associated with the disability.
- Not having an advocate, or the advocate lack of confidence in making a complaint.
- Fear of retribution or further abuse.
- Not being validated when a complaint is lodged. For example, according to the Judicial Commission of NSW (2019), judicial officers and juries may have preconceived ideas about people with IDD and assume incompetence,

unreliability and lack of credibility when giving evidence. Such prejudicial views already exist within health care services, potentially impacting on a person's ability to raise a complaint.

- If proceedings reached a court of Law, people with IDD would be disadvantaged by communication barriers associated with the complexity and abstract nature of legal language, and speed or length of proceedings (Judicial Commission of NSW, 2019). The situation is made worse if the person with IDD is Indigenous, of ethnic or migrant background, is female, a child or young person, belongs to the LGBTIQ group, or practices a particular religion (Judicial Commission of NSW, 2019). In addition, evidence may be discredited due to behavioural and communication issues associated with IDD (Judicial Commission of NSW, 2019).
- Additional issues when making a complaint are: people with IDD are more prone to suggestibility; they may be eager to please an authoritative figure and therefore offer desired answers rather than correct answers; many may be prone to cued behaviour; and poor understanding of concepts and questions asked as well as implications of answers given (AHRC, 2019).
- A person with IDD may have inadequate literacy skills to be able to read and understand a written statement (AHRC, 2019).

B. What would make it easier for a person with cognitive disability to complain about violence, abuse, neglect or exploitation in health care?

The following strategies are suggested:

- Dedicated disability advocacy teams within health care services.
- Brochures on *Patient Charter of Rights* in Easy English and multiple languages that are made available in every health care service.
- Making reasonable adjustments when making a complaint such as feeling validated, offering support so that the person does not feel overwhelmed, uncomfortable or fearful, clear explanations of complaint procedures, being treated with respect (Judicial Commission of NSW, 2019), and involving significant others (caregivers) where necessary to ensure information is understood.
- Reducing communication barriers by educating health care staff to: not talk down to the person with IDD as though they were a child; talk to the person themselves in the first instance, not the caregiver; determine communication preferences such as communication board or sign language; talk slowly, use simple language, use sentences with one concept at a time; use teach back technique to ensure information has been understood.

Question 10:

Have we missed anything? What else should we know?

PANDDA Inc recognises Developmental Disability Nursing as a specialty area. However, in Australia, there are no known approved programs of study for mental health, paediatric or disability nursing (NMBA, 2019). The UK is the only country in the world that officially recognises the specialty role of the Learning Disability Nurse (LDN) through pre-registration and post-registration programs. *Learning disability* is the preferred terminology for IDD in the UK. LDNs practice across a range of practice settings, liaising between services in collaboration with the multidisciplinary team, families, carers and community disability liaison teams, as well as provide education to staff. During hospital encounters, LDNs liaise between the treating team, hospital ward, patient and carers to promote a smooth hospital experience between admission and discharge, assisting to make decisions through their IDD expertise (DJA-G QLD, 2016).

There is strong evidence to support the LDN role across all four UK countries (Brown et al., 2012; Castles, Bailey, Gates & Sooben, 2014; Doody et al., 2018; Heslop et al., 2014) in improving the experiences of patient, caregivers and staff alike and ultimately, improve quality of life. In Australia, where specialist health practitioners exist, health outcomes for people with IDD are better (DJA-G QLD, 2016).

Conclusion

The national consultation by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability is a welcome and timely opportunity for people with disability, their families and carers, disability advocacy groups, and the disability sector in general to highlight the inequities faced by this marginalised group in society. This submission in response to the *Health care for people with cognitive disability: Issues paper* highlights the difficulties encountered that contribute to neglect of health care for people with IDD. PANDDA Inc offers a number of recommendations from a nursing perspective to improve the health outcomes of people with IDD when accessing health care services. Improvement in policy and organisational change, in particular, investment in IDD education and training for nurses is needed to improve equitable health care. Addressing these areas of concern seeks to optimise quality health care that ensures the basic human rights of people with IDD are upheld.

Recommendation 1:

The commissioner recommends a national approach to mandatory education and training in IDD specific content for all health care professionals to build capability and capacity in IDD care. Education and training to be included in both undergraduate and post-graduate education courses of all disciplines as well as ongoing through staff education programs to address gaps in lifelong learning. Content should include First

Nations peoples and CALD communities. Self-advocates, their families, and leading advocacy organisations to be involved in education content. Focus should be concerned with the concepts of valuing people with disability and reasonable adjustments as set out in the DDA 1992. This is supported by Department of Attorney-General QLD, (2016); Temple and Murdoch (2012); Trollor et al. (2017); and While & Clarke (2010).

Recommendation 2:

A nationwide approach to primary health care with dedicated IDD teams that coordinate services adopting a person-centred approach to facilitate health care needs of people with IDD across all contexts and levels of care. This is supported by Trollor et al. (2017). In addition to mandatory training for all staff, PANDDA Inc strongly believes there is a real need for the role of the specialty IDD nurse in Australia to work in collaboration with multiple services and disciplines.

Recommendation 3:

A national approach to how health outcomes, inequities and disadvantage of people with IDD are formally reported, recorded, monitored, and analysed. This recommendation is supported by Emerson et al. (2018), Trollor et al. (2017) and DJA-G QLD (2016).

Recommendation 4:

A national approach to policy regarding clear guidelines for the role of carers during encounters with health care services that serves to meet safety standards and legal obligations. Improved allocation of funding between health services and the disability sector to allow paid carers to support during hospitalisations when family are unable to attend. These recommendations are supported by Hemsley et al. (2011).

Recommendation 5:

The commissioner recommends that national annual health checks such as the evidenced-based CHAP program be mandatory for all people with IDD and that the process of engaging with CHAP program be made more accessible. This recommendation is supported by DJA-G QLD (2016) and Lennox et al. (2016). Similarly, a more inclusive approach to national preventative health measures.

Recommendation 6:

Capacity for improved coordinated care between primary care and secondary care services and between the disability and healthcare sectors. Mapping IDD specific service pathways such as admission and discharge processes should be implemented nationwide. This is supported by DJA-G QLD, (2016), and Trollor et al. (2017). One area for policy development identified in the *National Disability Strategy 2010-2020*

concerns improving the interface between health services and disability systems to optimise health and wellbeing (Commonwealth of Australia, 2011).

Recommendation 7:

All disability workers undergo mandatory IDD specific training with particular attention to respiratory, neurological and behavioural risk associated with IDD and should form part of accreditation for disability services. This is supported by DJA-G QLD, (2016), and Troller et al. (2017).

Recommendation 8.

The commissioner examines the UK model of IDD care, such as the use of IDD liaison nurses in acute care settings and IDD-skilled nurses employed within each community health team.

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