



RACGP

Royal Australian College of General Practitioners

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*RACGP submission to the Royal
Commission into Violence, Abuse,
Neglect and Exploitation of People
with Disability*

*Issues paper: Healthcare for people
with cognitive disability*

April 2020

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1. Introduction

The Royal Australian College of General Practitioners (RACGP) welcomes the opportunity to provide a submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Royal Commission) issues paper on healthcare for people with cognitive disability.

The RACGP is Australia's largest professional general practice organisation, representing over 41,000 members working in or toward a career in general practice.

The RACGP is responsible for:

- defining the nature and scope of the discipline
- setting the standards and curricula for training
- maintaining the standards for quality general practice
- supporting specialist general practitioners (GPs) in their pursuit of excellence in patient and community service.

The RACGP looks forward to contributing to further discussions around healthcare for people with cognitive disability. Should you have any questions or comments regarding the RACGP's submission, please contact Ms Michelle Gonsalvez, National Manager – Policy and Advocacy, on (03) 8699 0490 or at michelle.gonsalvez@racgp.org.au

Please be advised that in addition to this submission, the RACGP has provided detailed information on notice to the Royal Commission on all aspects of GP training in relation to cognitive disability. An overview of topics covered in the RACGP's response on notice is provided below in sections 1.1. to 1.3.

1.1. Specific Interests Networks

The RACGP recognises that many GPs develop an interest in specific areas of general practice throughout their career. It values these specific skills and experience through the endorsed groups of the RACGP's Faculty of Specific Interests.

The RACGP currently has 31 Specific Interests Networks, including a Disability Specific Interests Network.

The Disability Specific Interests Network was established in 2016 and currently has over 600 RACGP members, including students. Additional members can join at any time. The Network is chaired by Adjunct Associate Professor Robert Davis, Clinical Director of the Centre for Developmental Disability Health Victoria, Monash Health, Victoria.

The Network promotes an understanding of the needs of people living with disability to encourage discussion and development of appropriate resources for GPs. Members have an opportunity to share information and knowledge through meetings, educational events and email communications.

1.2. Roundtable on the Health of People with Intellectual Disability

The RACGP was a participant in the Roundtable on the Health of People with Intellectual Disability, convened by the Department of Health on 2 August 2019. The Roundtable was tasked with developing a National Roadmap to improve health services for people with intellectual disability.

As noted in the Department's [summary](#) of the discussion, recommendations from the Roundtable included:

- working with the Deans of Medical Schools on curriculum development to improve the education of doctors to better meet the health needs of people with intellectual disability
- promoting better uptake of the existing Medicare Benefits Schedule (MBS) health assessment items for people with intellectual disability
- establishing a network of centres of excellence on the health of people with intellectual disability, with at least one in each jurisdiction, building on existing centres.

The RACGP would support expanding access to the above mentioned centres to include consultations conducted via telehealth, as well as physical referrals.

The RACGP remains fully committed to this process and any ongoing consultation.

1.3. RACGP education, training and clinical resources

The RACGP has developed extensive training, clinical initiatives and resources for the management of abuse, neglect and violence of people with disability. These have been detailed in the above mentioned response provided on notice to the Royal Commission.

2. Recommendations

The recommendations below have been developed based on member feedback on access to healthcare for people with cognitive disability, and the reasons why this demographic may experience violence, abuse, neglect or exploitation.

Relevant background and rationale relating to these recommendations is outlined in sections 4–8 of this submission.

The RACGP encourages the Royal Commission to consider the issues raised in this submission and, in accordance with the views of our members, make recommendations aimed at:

- removing the financial barriers people with cognitive disability face when they attempt to access care, including:
 - increasing MBS rebates to reflect the real cost of providing ongoing comprehensive, patient-centred care to people with cognitive disability
 - promoting uptake of existing MBS health assessment items
 - considering how GPs can be reimbursed for time spent preparing reports and other relevant documentation to support National Disability Insurance Scheme (NDIS) applications
 - expanding the list of disability-related health supports funded by the NDIS to include some general practice supports not covered by Medicare
- providing education to disability workers, carers and health professionals to assist people with cognitive disability to make positive lifestyle changes and help all those involved in provision of care to this cohort – as well as people with cognitive disability themselves – identify potential and actual abuse
- providing clear, easy to understand health information to people with cognitive disability and improving their health literacy
- providing funding for advocacy services to assist people with cognitive disability to understand their healthcare options and navigate available supports
- strengthening the health and disability workforces by addressing staff shortages, particularly in rural and regional areas, and increasing remuneration for workers and carers
- fostering greater collaboration between the health and disability sectors to enable multidisciplinary, well-rounded care
- developing well-integrated GP referral pathways to better support people with cognitive disability in each state and territory
- increasing the role of GPs in NDIS planning to improve the administrative process and enable more holistic, integrated care
- establishing clear pathways to report instances of violence, abuse, neglect or exploitation and make complaints about services
- moving young people with disability out of residential aged care facilities to prevent social isolation and ensure they receive care targeted to their particular needs.

3. The role of GPs in supporting people with disability

3.1. Continuity of care

GPs are most often a patient's first point of contact in the health system and provide ongoing care for their patients, including those with disability. GPs provide patient-centred, comprehensive, longitudinal care for patients to ensure they receive the necessary support outside of the practice.

Even when other health professionals are providing support to a person with disability, many people with disability often have other health issues which require care from GPs and their teams. Therefore, GPs are intrinsically involved in disability work and often have a strong and ongoing relationship with people who have a disability.

There is a current trend in general practice which has seen responsibility for primary healthcare of individuals transition from single to multiple practitioners. Familiarity may be important for both the patient and the GP when working with a person with cognitive disability, as the patient may be more comfortable seeing a doctor they know and trust.

3.2. Supporting patients to access the NDIS

GPs play an important role in assisting their patients to access the NDIS. When a person is applying to become an NDIS participant, they (or a National Disability Insurance Agency [NDIA] representative) will ask a GP to provide evidence of disability and functional impact. The GP may provide this evidence by completing the supporting evidence section of the NDIS Access Request Form, but will most commonly provide copies of relevant assessments or reports outlining the extent of the functional impact of a disability. This can be particularly helpful for patients and families who do not feel confident articulating the impact of a disability themselves.

If a patient's NDIS request is denied, they have the right to appeal the decision. Their GP may play a role in supporting them to do so, including alerting them to the possibility of appeal. If the original decision is upheld, the GP will often try to provide or find appropriate support services for them.

4. Healthcare for people with cognitive disability

Around 18% of Australians have some form of disability. One in five people with disability (21.5%) have mental or behavioural disability (of which 6.3% have intellectual and developmental disability).¹ Using standard measures of mortality and morbidity, there is a stark disparity between health outcomes for people with cognitive disability and those of the general population.

4.1. Understanding the health needs of people with cognitive disability

Research conducted in Australia and internationally shows that the life expectancy of people with cognitive disability is 10–20 years less than the general population.² Adults with a disability aged between 20 and 29 are between 5.9 and 7.4 times more likely to die than their non-disabled peers.^{3 4}

Mortality depends on the underlying cause of the disability, with conditions such as Down syndrome, Rett syndrome, cerebral palsy, Prader-Willi syndrome and Williams syndrome presenting with differing underlying health problems.⁵ The most common causes of death in people with cognitive disability are cardiovascular disease, respiratory illness, cancer and neurological diseases, with respiratory illness and neurological diseases being more unusual causes of death among the general population.^{4 5 6 7 8}

People with cognitive disability often have unrecognised medical problems,^{9 10} however regular systematic review by primary care doctors is effective in identifying these.^{11 12}

Doctors with a special interest in the health of people with intellectual disability, recognising the shortfalls in the healthcare of this demographic, published a consensus document on health targets for people with intellectual disability under the auspices of the World Health Organization.¹³ This was recognised by the federal government and underpinned the introduction of Medicare items for annual health assessments of people with intellectual disability.

4.2. Barriers which affect the quality of healthcare for people with cognitive disability

In order to address this disparity, healthcare must completely fulfil the particular health needs of different cohorts, including people with cognitive disability. RACGP members have identified a number of issues and factors that impact on the quality of healthcare for people with cognitive disability, including:

- **greater prevalence of comorbidities among people with cognitive disability** than the general population. Their health needs are complex, and they may not have the communication skills or health literacy to communicate their needs. They may also be reliant on family members and carers to observe and communicate on their behalf
- **a lack of health information that is appropriate and/or accessible** for people with cognitive disability, often because this cohort is excluded from clinical trials and/or preventive and public health interventions, including health promotion activities
- **cost constraints** which can delay people with disability seeing a health professional, particularly if they rely on the Disability Support Pension or other forms of welfare
- **limited access to specialist health services** – this is particularly the case for people who are living outside of capital cities, however can also occur in suburban areas. It may be difficult for people with disability to travel long distances for appointments
- **low remuneration for disability carers and workers**
- **staff shortages**, meaning carers and workers are often overworked and have reduced capacity to adequately respond to people's needs. This not only affects the health of the people they are caring for, but also the health of the carers and workers themselves and their ability to provide support
- **prolonged wait times for the NDIS**, both in terms of assessments and responding to crisis situations. For people with cognitive disability, the system is very complex to navigate, and they may be relying on multiple people to guide them through the process
- **eligibility criteria for the NDIS** – people who acquire a disability after they turn 65 are not eligible for the scheme. As a result, they will likely receive considerably less support than people aged under 65. It is important that age is not a discriminating factor in regard to the level of disability support that people are able to access.

4.2.1. Staff training, expertise and capacity

The level of training undertaken and expertise of healthcare professionals in relation to care of people with cognitive disability varies between countries.

The Netherlands has a specific cohort of physicians who have received undergraduate and postgraduate training in the healthcare of people with cognitive disability. This professional group is supported through funding from insurance through the *Exceptional Medical Expenses Insurance Act (AWBZ)* introduced in 2006 and the *Social Support Insurance Act (WMO)* introduced in 2007.¹⁴

In the United Kingdom (UK) there is a 'Learning Disability' (the term used in the UK for cognitive disability) chapter within the Royal College of Psychiatrists. The chapter comprises psychiatrists who are trained in both the mental and physical healthcare of people with cognitive disability. In both the UK and Netherlands funding is provided to support nursing and allied health professionals working in multidisciplinary 'Learning Disability' teams.

The level of support for healthcare for people with cognitive disability varies across the United States of America (USA). There are a number of well-resourced university-based centres providing a focus on healthcare, research and undergraduate teaching in relation to people with cognitive disability.

By comparison, Australia has small centres in a few states with limited clinical availability providing specialised health supports for people with cognitive disability. These are staffed by a small number of physicians, many of whom are close to retirement. Compounding this has been the slow decline in government funding over time.

Case study: Services for people with cognitive disability in South Australia

In South Australia there are very few services that specifically cater to people with cognitive disability. There is one publicly funded clinic – the Centre for Disability Health – with local governance provided by the Aged Care, Rehabilitation and Palliative Care Division (ACRPC) of the Northern Adelaide Local Health Network. This service currently has no psychiatrist, a part-time neurologist and a 0.2 FTE GP, as well as some allied health professionals, and is involved in short-term complex care. One of the major barriers to redesigning this health service is attracting appropriately skilled staff.

Apart from the Centre for Disability Health and a general practice that provides care to around 200 patients with disability, there are no other specialised general practice services available to people with cognitive disability in South Australia.

4.3. Barriers that people with cognitive disability experience accessing healthcare

RACGP members report that the barriers experienced by people with cognitive disability in accessing healthcare are complex and multi-factorial. Most people with a cognitive disability have a lower socio-economic status than the rest of the population and face financial hardship. Accessing health services is challenging, with most patients needing to use bulk billing services or public health services which often result in lengthy wait times.

Further information regarding specific barriers is provided below.

4.3.1. Communication issues

It generally takes much longer than usual to adequately assess and manage patients with cognitive disability as their medical issues are more complex, often associated with communication problems and require extra time to communicate with carers.

Our members report that people with cognitive disability who have significant communication difficulties will often respond to a symptom that needs attention, such as pain, with a change in their behaviour. They are dependent on those supporting them to recognise they have a problem and to take the patient to see a medical practitioner.

Seeing a doctor in a standard GP clinic can, in itself, be a barrier to a person who struggles with change and new experiences. The person may become distressed, struggle to sit in the waiting area, refuse to sit on the examination couch or vocalise so loudly it is uncomfortable for other patients in the practice.

In assessing a patient with cognitive disability the GP will need to adjust for the individual's limited communication abilities, be reliant on secondary information from the carer, and accept limitations in their ability to examine the patient and capacity to perform appropriate tests. The GP will also need to be aware of the particular health implications and risks associated with the underlying cause of the person's disability.

4.3.2. Limited access to skilled patient advocates

All individuals have a right to self-determination regardless of whether they have a disability and should be allowed the opportunity to define what their own wellbeing means to them.

Members report that having a patient advocate or a trained 'service navigator' who understands the needs, wants and priorities of the individual is often necessary. However, access to these advocates may be limited, particularly in rural and regional communities.

4.3.3. Poor health awareness

Our members note that patients with mild cognitive disability who may be relatively mobile and living independently in the community are less likely to be aware of health lifestyle factors such as the importance of a good diet, regular exercise, the need for safe sex, and the risks posed by cigarettes, alcohol and other drugs. They miss out on important health

education and health promotion messages. They will often not recognise the need for regular health checks by GPs and dentists and tend to present later in the disease process. It is often important that they have an advocate or a person that knows them well to encourage and support healthy behaviours.

4.3.4. *Financial barriers*

Members note that the current Medicare system is inflexible and does not appreciate the complexity of care patients with cognitive disability require. There is a financial disincentive to provide long or prolonged consultations and, as such, GPs may be less inclined to take on large numbers of patients with disability.

Many people with cognitive disability reside in supported residential accommodation and the use of medication charts is commonplace. This demographic is also subject to a higher burden of chronic disease – as such, polypharmacy is widespread and patients require frequent repeat prescriptions. As Medicare does not remunerate time not spent face-to-face with a patient, it can place financial strain on a GP to write repeat prescriptions and update medication charts without seeing a patient for a consultation.

Furthermore, no payments are available under the General Practitioner Aged Care Access Incentive to support GPs who provide care to people with disability in supported residential accommodation, as these payments are restricted to government-funded residential aged care facilities.

4.3.5. *Lack of multidisciplinary care*

Members note that while patients with complex conditions such as cerebral palsy see a range of specialists and allied health professionals working in multidisciplinary teams within paediatric services, this access almost entirely disappears when they become adults. The GP is left to assume responsibility for this care, often with very little handover of information and extremely limited hospital-based specialist support.

4.3.6. *Mental health problems*

People with cognitive disability also have a high prevalence of mental health problems, however there is a lack of experienced psychiatrists and mental health workers to assess and manage these issues. Diagnostic criteria for mental health issues have been developed based on experience with a population without a cognitive disability. Research by the Royal College of Psychiatrists in the UK has shown that these criteria miss the diagnosis of two in three patients with cognitive disability compared with a psychiatrist trained in the area and diagnostic criteria specifically designed for people with cognitive disability, such as the *Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/Mental Retardation (DC/LD)*.¹⁵

4.4. Improving access to healthcare for people with cognitive disability

4.4.1. *Multidisciplinary healthcare*

The needs of adult patients with complex health needs in the community are often unmet. This means people live with chronic ill-health and untreated health conditions, which restrict their independence and ability to participate in and contribute to their communities.

Effective and comprehensive healthcare, delivered through collaborative and multidisciplinary GP-led teams, has the potential to not only improve quality of life for people with cognitive disability, but also lead to greater financial efficiencies and better use of limited resources.

4.4.2. *Changes to the MBS*

Appropriate changes should be made to the MBS to make the system more responsive to the needs of people with cognitive disability.

The RACGP recommends that Medicare rebates for GP consultations be increased to reflect the real cost of providing ongoing comprehensive, patient-centred care to people with cognitive disability.

The RACGP also supports the recommendation from the Roundtable on the Health of People with Intellectual Disability that MBS health assessment items be better promoted to encourage greater uptake. People with intellectual disability are one of the target groups eligible for an annual health assessment, however only a very small percentage of this cohort actually receive these assessments. This may be due to a lack of awareness among GPs that they can claim these item numbers.

4.4.3. Education

Members note that education and training should be provided to disability workers, carers and other health professionals to assist the people they care for to make positive lifestyle changes, and help all those involved in provision of care to this cohort – as well as people with cognitive disability themselves – identify potential and actual abuse.

Education should also be provided to people with cognitive disability around abuse, violence and what is appropriate/inappropriate behaviour (and how to report it). There should also be a focus on empowering people with disability to make their own health decisions (general health, specific health conditions and preventive health).

4.4.4. Service navigation

Members have suggested that people with cognitive disability should have access to a service that can assist them to navigate available supports. This should include connecting people with affordable services, defining what wellbeing means for the person and supporting their right to self-determination. Funding for the provision of this service should be directed to those most in need of advocacy and linkages to supports within the community.

5. NDIS-specific issues

5.1. Problems that people with cognitive disability have experienced with the NDIS

5.1.1. Health/disability interface

Our members report that the transition from state-based disability service provision to the NDIS has disrupted connections between the health and disability sectors. Although limited in scope, these connections provided the opportunity to problem solve when existing supports could not cope with emergency and complex presentations.

Historically, there has been a tendency for the health and disability sectors to limit and restrict service output to their area of responsibility. This has been further accentuated by the shift from state-based to Commonwealth-based service delivery in the disability sector. It is important that this new service delivery environment strengthens and formalises links between health and disability services.

There was previously greater flexibility to access support from other sectors when receiving funding primarily through one sector (eg health or disability). Member feedback indicates that new lines of communication need to be developed to prioritise capacity for ongoing cooperation between the health and disability sectors.

In the past people without family support were assisted when accessing GP or specialist health services by case managers who knew them well. This improved their attendance at appointments and helped with communication between the doctor and patient, particularly supporting the implementation of treatment and management of their disability. Members suggest that clarity is required from the NDIA around who is responsible for this role and how this will be monitored and evaluated over time.

5.1.2. Some people with disability are unable to participate in planning discussions

RACGP members have noted that patients with cognitive difficulties may need active support to be involved in planning discussions.

A participant's ability to advocate often determines what is included in their plan. Members report that some family members or carers of people with a cognitive disability are able to advocate on their behalf and therefore can assist in securing appropriate funding. Greater involvement of external patient advocates and family members/carers in patient consultations and NDIS planning discussions would enable more rounded care. However, it should be noted that not all participants have access to a skilled advocate with the knowledge and awareness to speak on their behalf.

5.1.3. Choosing supports

Ensuring that NDIS funds are well spent requires a good understanding of available supports. However, people with disability and/or their carers face significant imbalances in power and information, compared to service providers competing for clients and associated funding.

NDIS participants and their carers face challenges in fully understanding available services and their appropriateness. Our members note that services now exist in a competitive commercial marketplace and are promoted to varying degrees, with some being overpriced and underservicing participants. Current standards of practice within the NDIS are not well defined.

The process of comparing and choosing services is time-consuming, confusing and taxing on individuals and their carers, as well as GPs and patient advocates.

5.1.4. GPs are often not involved in planning conversations

The RACGP provided a [submission](#) to the Joint Standing Committee on the National Disability Insurance Scheme inquiry into NDIS planning in September 2019. This submission outlined the RACGP's concerns in relation to the lack of involvement of GPs in the planning process.

5.1.5. Lack of funding for NDIS assessments

The Department of Health has confirmed that patients are eligible to access MBS rebates for consultations with their GP when the GP is assisting them to apply for the NDIS (eg assisting with an Access Request). However, MBS rules for GP consultations stipulate that they can only be billed if the patient is present in the consultation room.

Our members have advised that the NDIA requests extensive reports supplying a patient's medical history, letters from other non-GP specialists, discharge summaries and more. The NDIA may request this information separately from or subsequent to an Access Request. Where similar reports are prepared for other insurers (who might request the information in the same way the NDIA does), a GP will charge the insurer for the time and effort involved.

A GP is unlikely to request that a patient attend a consultation for paperwork the GP can complete in the patient's absence, particularly if the patient's disability prevents them from easily accessing the practice. In such cases, because the patient is not present while the request is completed, MBS rebates are not available and there is no other existing facility for the NDIA to reimburse the GP for their time and expertise completing such requests.

Without support from the MBS, a financially vulnerable patient seeking access to the NDIS may be unable to afford their GP's fee for this service.

The RACGP recommends that consideration be given to how GPs can be reimbursed for time spent preparing reports and other relevant documentation to support NDIS applications. This includes circumstances where their patient is not physically present in the consultation room.

5.1.6. Access to the NDIS for people with psychosocial disability

As noted above, people with cognitive disability often also experience mental health problems. People living with psychosocial disability have experienced significant challenges with accessing the NDIS. There are some major philosophical malalignments between the NDIS, framed around the 'permanency' of disability, and psychosocial disability, which has a recovery focus due to its fluctuating impact on the wellbeing of the individual.

As a result, many people living with psychosocial disability have been unable to engage with the assessment process for the NDIS (eg finding it confusing and distressing), chosen not to participate, or received assessments and plans that do not meet their medium to longer term needs.

5.2. Improving the NDIS for people with cognitive disability

5.2.1. Strengthening the role of GPs

GPs play a pivotal role in multidisciplinary care teams and are key contacts for people with cognitive disability. They are best placed to help patients navigate the health system by building trusted relationships.

It is important that GPs are adequately supported to fulfil this role by:

- providing them with clear guidance on the requirements for supporting evidence for patients applying for the NDIS or the Disability Support Pension
- increasing remuneration for GPs to enable them to provide a wider breadth of services to patients (eg preventive health checks and the development of individual health plans)
- increasing funding for research into improving the health of people with cognitive disability and how to strengthen interactions between this cohort and the primary care system
- improving communication between GPs and the NDIS – including providing GPs with a copy of a patient's NDIS plan (with patient consent) to allow them to keep a complete record of their patients' health and social journey and support continuity of care
- implementing more efficient and reliable disability assessment tools for GPs to assess and support people across the spectrum of disability, as [previously highlighted](#) by the RACGP
- recognising the time spent by GPs preparing reports and completing other documentation to support NDIS applications, including consideration of how GPs can be reimbursed when a patient is not physically present in the consultation room
- developing well-integrated GP referral pathways to better support people with cognitive disability in each state and territory
- providing education and training for GPs on services available through the NDIS.

Implementation of the RACGP's [recommendations](#) by increasing the involvement of GPs in the NDIS planning process would:

- speed up the planning process by ensuring planners are provided with comprehensive information about the functional impact of a person's disability
- reduce patient stress as the patient is more supported to advocate for their support needs
- allow for more equitable distribution of limited NDIS funds, with realistic expectations prior to the formulation of a plan as to how much therapy a participant requires per given year
- ensure the GP can maintain referrals and improve the flow of communication between the participant's care team
- reduce costs by minimising the volume of enquiries being submitted to the NDIA
- potentially reduce requests for plan reviews due to establishing a clear expectation for care, ongoing continuity of care and a clear pathway for review when indicated.

5.2.2. Improving NDIS-GP engagement

While the NDIA has provided useful information about ways the NDIS and health professionals can work together to achieve the best outcomes for participants, members report that most of the material for GPs has been largely online or presented at conferences. It therefore tends to be accessed by those who already have an interest in this area.

Member feedback indicates that there is a need to target medical students in the undergraduate curriculum and GPs in their practice with brief educational activities. It would also help if there was a liaison officer within the NDIS available to GPs when an issue arises regarding a participant's plan.

5.2.3. Improving dialogue between the health and disability sectors

As the NDIA is a national body, there are new and emerging opportunities to work constructively with professional bodies within the health sector. This includes the medical, allied health and nursing professions. Existing training and professional development in disability could be reinforced and further developed both at an undergraduate and postgraduate level. Similarly, promotion of research to inform best practice could improve quality of care.

Building collaborative partnerships between the health and disability sectors will enable people with disability to achieve and maintain optimal health and function, and therefore live better, more inclusive lives.

5.2.4. Funding for health supports

The NDIS only provides funding for a limited range of disability-related health supports, [as announced by the NDIA in October 2019](#). This does not, however, extend to general practice supports. RACGP members have suggested that the NDIA could provide some funding for general practice supports outside of Medicare rebates, including for non-face-to-face consultations or travel time for home visits.

5.2.5. Strengthening the disability workforce

More disability support workers are needed to meet growing demand, particularly in rural and regional areas. Workers require access to care and support themselves to prevent burnout due to the stresses of working with patients with complex needs.

It is also critical to ensure that staffing levels for the NDIS are adequate to improve assessment and response times and prioritise crisis management.

6. Violence, abuse, neglect and exploitation in healthcare

6.1. Examples

Examples of violence, abuse, neglect or exploitation that can occur in healthcare settings include:

- lack of awareness of and/or interest in patient needs
- 'pigeon-holing' patients with disability and ignoring the diverse and unique health and social needs of individuals
- infantilising patients with disability and/or ignoring their rights to autonomy and self-determination
- failure to administer medications within appropriate timeframes
- missed medication doses in supervised care environments
- failure to adequately prevent falls
- use of physical, chemical or mechanical restraint
- use of psychotropic medications to manage challenging behaviours rather than addressing the underlying cause.

6.2. Reasons why violence, abuse, neglect or exploitation may occur

There are a number of reasons why people with cognitive disability may experience violence, abuse, neglect or exploitation in healthcare, including:

- difficulty communicating their needs due to:
 - cognitive impairment
 - a lack of appropriate advocacy support services or personnel, as well as health education (eg general health information, what is or is not acceptable, what to expect in a consultation)
- a reliance on others (such as carers) to observe if they are unwell or need access to care. This can make them vulnerable, particularly if there is high staff turnover in hospitals or care facilities, as continuity of care is key in observing signs of abuse and behaviour changes over time. A regular GP can help to identify signs of abuse and take appropriate action

- a lack of conversation around sexual health and what is or isn't appropriate, which can leave people with cognitive disability vulnerable.

Members report a number of variable factors that can contribute to violence, abuse, neglect or exploitation of people with cognitive disability, including:

- the complexity of their disability
- the financial cost of managing their condition
- their organisational ability
- the education received by a healthcare worker who sees a patient with cognitive disability and their capacity to spend sufficient time with the patient to provide adequate care. Appointments that are rushed or are with healthcare workers who have not received education in assessing a patient with cognitive disability are more likely to result in violence, abuse, neglect or exploitation.

People with cognitive disability often come into contact with health services in a crisis situation when they are in discomfort or distress. They can be frightened, confused and/or extremely anxious and may express this distress by attempting to escape or protect themselves from those trying to assess and help them. This can be interpreted as uncooperative or aggressive behaviour and may lead to the use of physical, mechanical or chemical restraint.

Overwhelming anxiety in health settings may have been a learnt behaviour from childhood in which a young person with disability was restrained for a procedure. This person may then reach adulthood and continue to expect or experience restraint and pain, which are associated with confusion and fear. They understandably believe that the health professional approaching them is going to hurt them. Having positive experiences in both childhood and adulthood can help counter these negative experiences and reduce anxiety and fear.

Research has shown that people with cognitive disability are vulnerable to sexual abuse throughout their lives. There is no reason to believe this form of abuse is more or less prevalent in the health setting. As a person can have limited capacity to understand if they have been abused, it is important that an advocate or support person be present when they are being examined or treated.

6.3. Responding to challenging behaviours

The more severe the cognitive disability, especially when there are challenging behaviours or communication barriers, the more likely a person will be inappropriately assessed and managed. Members report that challenging behaviours can result in inadequate physical examination and difficulties completing investigations such as blood tests and scans. This can also lead to inappropriate prescribing of psychotropic medications to mask the behavioural change rather than address its underlying cause.

Presentations to doctors or emergency departments are often dismissed as being 'disability-related' and may not be properly investigated.

6.4. Staffing issues

Staff in health services who are not experienced or trained in dealing with challenging behaviours can themselves become anxious and overly restrictive in their approach to the patient. At times there are situations that require urgent attention and restraint is the only option to protect the person concerned and others in their vicinity. This may also arise when staffing levels are inadequate.

If a patient is unable to describe their symptoms or how they are feeling, this may lead to an over-reliance on the opinions of support workers (who often have not worked with the patient for very long). Incorrect diagnoses are therefore more likely to occur, which can result in a management plan that does not address the real medical issues.

6.5. Tests and procedures

A key part of healthcare for the general community includes the need for regular blood tests and some physical procedures such as cervical cancer screening smears, dental examinations and x-rays. Some patients become so distressed by these tests and procedures that they can only tolerate them with sedation or a general anaesthetic.

There is extremely limited capacity within the health sector for a GP responsible for the healthcare of an individual to arrange these standard investigations, even when clinically indicated. As such, the standard of healthcare provided to the individual is often less than we expect for the general population.

6.6. Reporting violence, abuse, neglect or exploitation

Our members have suggested that violence, abuse, neglect or exploitation may not be reported because of:

- a poor understanding of and inability to recognise signs of violence, abuse, neglect or exploitation
- uncertainty around how to report abuse or requiring support to do so
- a lack of an alternative healthcare options in rural and regional areas
- domestic violence and a reluctance to exit an abusive relationship (eg because a person with cognitive disability feels that their condition will not be accepted by another partner)
- communication issues (eg inability to read or use a telephone), which can be further complicated if someone is reliant on a violent partner for assistance.

It may be difficult to identify the appropriate channels to report suspected violence, abuse, neglect or exploitation. While reports to police may be obvious if a crime has clearly been committed, guidance on reporting where matters are less certain is needed.

7. Experiences of vulnerable groups

7.1. First Nations and culturally and linguistically diverse people

There is a lack of available research into cognitive disability and Aboriginal and Torres Strait Islander people, particularly with regard to their experiences of violence, abuse, neglect or exploitation in healthcare.

The proportion of Aboriginal and Torres Strait Islander Australians who accessed assistance from disability service providers in 2012 was twice that of the general population.¹⁶

According to the Australian Institute of Health and Welfare, Aboriginal and Torres Strait Islander Australians are 1.8 times more likely to have a disability, and two times more likely to use disability services provided under the National Disability Agreement, than non-Aboriginal and Torres Strait Islander people (2017-2018).¹⁷

For both Aboriginal and Torres Strait Islander people and cultural and linguistically diverse people with cognitive disability, it is important that their care is culturally appropriate.

7.2. Lesbian, gay, bisexual, transgender and intersex (LGBTI) people

LGBTI people with disability are more likely than non-LGBTI people with disability and LGBTI people without a disability to experience:

- higher rates of discrimination and reduced service access
- greater restrictions on freedom of sexual expression
- reduced social support and connections
- mental health problems, placing them at a heightened risk of self-harm due to the effects of discrimination, stigma and abuse.¹⁸

Stigma and prejudice against LGBTI people with disability are associated with an inability to include their specific situation and needs in sex and relationships education and resources, placing them at increased risk of sexually transmitted infections (STIs) and reducing their capacity to develop respectful, intimate relationships.¹⁸

There is also lack of professional training, resources and support for disability and allied health workers around working with LGBTI people with disability.¹⁸

8. Preventing instances of violence, abuse, neglect or exploitation in healthcare

Any preventive approach should focus on the environment and systems of care, rather than necessarily on behavioural management of individuals. A healthcare system that is focussed and responds to the care needs of people with disability as an operational norm will reduce instances of violence, abuse, neglect or exploitation.

The autonomy and independence of a person with a disability should always be respected, and they should be included in decisions about what they can or cannot do.¹⁹

The Netherlands, UK and USA have all trained and provided medical practitioners with specialised skills to support people with cognitive disability. Experience gained overseas has enabled better understanding of the roles of both health and disability professionals and facilitated a multidisciplinary approach to care.

As mentioned earlier, a group of around 600 RACGP members (medical practitioners and students) have identified an interest in disability. The specific interest of these practitioners suggests an opportunity for educating the GP workforce to provide more specialised care to people with cognitive disability.

8.1. Actions to prevent violence, abuse, neglect or exploitation in healthcare

RACGP members have identified a number of specific steps that can be taken, which are outlined in the table below.

Area	Recommendation
Educating people with cognitive disability	People with cognitive disability should be provided with appropriate education in order to empower them around their health and wellbeing, highlight what is and isn't appropriate and what to expect from a consultation.
Complaint mechanisms	People with cognitive disability are vulnerable to neglect as they often cannot advocate for themselves. Services need to be accountable for the quality of the service they provide. There should be clear pathways for patients or carers to make complaints and the services should be responsive to them. Where there is a concern about neglect outside health services, there needs to be a clear line of communication with the NDIS to rectify the situation.
Reporting	Those who raise concerns about violence, abuse, neglect or exploitation must be protected and supported. This will help to create a culture of communication and openness to discuss issues around practices that may be concerning.
Staffing	Carers and support workers must be adequately supported and remunerated, as the ability to identify abuse is reduced with higher staff turnover.
Educating carers and support workers	Continuing education should be provided to carers and support workers around the identification of violence, abuse, neglect or exploitation, which is especially important for people with cognitive disability who may be non-verbal and particularly vulnerable.
Educating the health workforce	Education should be provided to the health workforce during their tertiary studies on how to respond to the needs of people with cognitive/intellectual disabilities. There should be opportunities for all students to meet people with cognitive disability or complete placements in services that provide regular care to this cohort.
Young people in residential aged care facilities	Every effort should be made to move young people out of residential aged care facilities, which are generally not equipped to meet their care needs. These facilities are detrimental to the independence, mental health and wellbeing of young people

Area	Recommendation
	with disabilities and are socially isolating, limiting their ability to reach their full potential.

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