

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

December 2021



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GLOSSARY

Australian Bureau of Statistics (ABS) – Australia's national statistical agency providing trusted official statistics on a wide range of economic, social, population and environmental matters.

Australian Commission on Safety and Quality in Health Care (ACSQHC) – The Commission is a corporate Commonwealth entity. Its purpose is to contribute to better health outcomes and experiences for all patients and consumers, and improved value and sustainability in the health system by leading and coordinating national improvements in the safety and quality of health care. Within this overarching purpose the Commission aims to ensure people are kept safe when they receive health care and that they receive the health care they should.

Australian Health Practitioner Regulation Agency (Ahpra) – The national organisation responsible for implementing the National Registration and Accreditation Scheme (the National Scheme) across Australia.

Australian Institute of Health and Welfare (AIHW) – an independent statutory Australian Government agency producing authoritative and accessible information and statistics to inform and support better policy and service delivery decisions, leading to better health and wellbeing for all Australians.

Clinical Commissioning Groups (CCG) – established as part of the Health and Social Care Act in 2012 and replaced Primary Care Trusts on 1 April 2013. CCGs are groups of general practices (GPs) which come together in each area to commission the best services for their patients and population.

Comprehensive Health Assessment Program (CHAP) – a two-part questionnaire designed to prompt a comprehensive health assessment for adults with intellectual disability, the tool is designed to help minimise the barriers to healthcare for people with intellectual disability by prompting health care and screening.

Diagnostic Overshadowing - when assessing an individual with multiple disabilities, this is the failure to discern the presence of one disability because its features are attributed to another, primary disability. In particular, the term refers to the failure to recognise a mental disorder in a person with intellectual disability because characteristics of that mental disorder are erroneously attributed to the intellectual disability.

Disability Care Provider (DCP) – an individual or organisation delivering a support or a product to a participant of the National Disability Insurance Scheme.

Disability Medical Assessment (DMA) – This assessment helps decide if people meet the medical rules for Disability Support Pension. A Government-contracted Doctor conducts the assessment and can be a Medical Practitioner or a Clinical Psychologist.

Disability Support Pensions (DSP) – Financial help if you have a permanent physical, intellectual or psychiatric condition that stops you from working.

Department of Social Services (DSS) – Australian Government department which aims to improve the wellbeing of individuals and families in Australian communities.

General Anaesthetic (GA) – an anaesthetic that affects the whole body and usually causes a loss of consciousness.

Government Contracted Doctor (GCD) – Contracted through the Australian Department of Human Services to conduct Disability Medical Assessments to assist in determining a person's medical eligibility for Disability Support Pensions. A GCD must be a registered and licensed medical practitioner, or where the DMA relates to a mental health condition, the DMA may be a registered clinical psychologist. GCD must have full registration with the Australia Health Practitioner Regulation Agency.

Intellectual Disabilities (ID) – disability characterized by significant limitations in both intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills. This disability originates before the age of 22.

Jobseeker Allowance (formally Newstart) – Financial help if you're between 22 and Age Pension age and looking for work. It's also for when you're sick or injured and can't do your usual work or study for a short time.

Kimberley Indigenous Cognitive Assessment (KICA) – A tool used to assess dementia in older Aboriginal people living in rural and remote settings. A collaboration between Dementia Australia NT, University of Western Australia and National Ageing Research Institute, written by Gail Marsh, Marilyn Inglis, Kate Smith and Dina LoGiudice. The KICA has been modified for use with Aboriginal people in regional and urban settings.

Key Performance Indicators (KPI) – a quantifiable measure used to evaluate the success of an organization, employee, etc. in meeting objectives for performance.

Local Health District (LHD) – established as statutory corporations under the Health Services Act 1997. They are responsible for managing public hospitals and health institutions and for providing health services to defined geographical areas of the State. ... promote.

Medicare Benefits Schedule (MBS) – a list of fees for medical services set by the Government for eligible hospital treatment as a private patient.

Medical Research Future Fund (MRFF) – The Medical Research Future Fund (MRFF) is a \$20 billion long-term investment supporting Australian health and medical research. The MRFF aims to transform health and medical research and innovation to improve lives, build the economy and contribute to health system sustainability.

Multidisciplinary Teams (MDT) – a group of health care workers who are members of different disciplines (professions e.g., Psychiatrists, Social Workers, etc.), each providing specific services to the patient, working together to deliver comprehensive patient care.

My Health Record – An online summary of your key health information which can be viewed securely online, from anywhere, at any time by the individual or medical practitioner.

National Disability Insurance Agency (NDIA) – The independent statutory agency created by the Australian Government in 2013 to implement the National Disability Insurance Scheme (NDIS).

National Disability Insurance Scheme (NDIS) – run by the National Disability Insurance Agency, the scheme funds reasonable and necessary supports and services that relate to a person's disability to help them achieve their goals. 'Reasonable' means the support is most appropriately funded or provided through the NDIS. And 'necessary' means something a person needs that is related to their disability.

National Health and Medical Research Council (NHMRC) – a statutory authority within the Australian Government which develops evidence-based health advice and translates research findings into evidence-based clinical practice guidelines for the Australian community, health professionals and governments. The Council provides advice on ethical practice in health and the conduct of health and medical research.

National Health Service (NHS) UK – the umbrella term for the government-funded medical and healthcare services everyone living in the UK can use without being asked to pay the full cost of the service.

National Standards for Disability Services (NSDS) – first produced in 1993 they were developed to help to promote and drive a nationally consistent approach to improving the quality of services. They focus on rights and outcomes for people with disability. There are six National Standards that apply to disability service providers – Rights, Participation and Inclusion, Individual Outcomes, Feedback and Complaints, Service Access and Service Management.

National Training Packages system – Australian Department of Education, Skills and Employment National Careers Institute training packages are a key feature of Australia's national vocational education and training (VET) system. Training package qualifications are occupational skills standards against which training delivery and assessment of competency can take place. They are developed through a process of national consultation with industry.

Pharmaceutical Benefits Scheme (PBS) – an Australian Government program that subsidises medicines to make them more affordable. The PBS is governed by the National Health Act 1953.

Primary Health Networks (PHN) – An administrative health region established to deliver access to primary care services for patients, as well as co-ordinate with local hospitals in order to improve the overall operational efficiency of the network.

People With Disability (PWD) – The International Classification of Functioning, Disability and Health, known more commonly as ICF, conceptualises a person's level of functioning in terms of body functions and structures, activities, and participation, as a dynamic interaction between their health condition(s) and environmental and/or personal factors. Disability is an umbrella term for impairments of body function or structure, activity limitations or participation restrictions.

Regional Australia Institute (RAI) – Founded in 2021, the Regional Australia Institute (RAI) is a think tank devoted to issues concerning regional Australia. The organisation gathers and analyses the information on regions and makes it readily accessible to people around the country.

Royal Australasian College of Medical Administrators (RACMA) – a specialist medical college which provides education, training, knowledge, and advice in medical management. Recognised by the Australian and New Zealand Medical Councils, it delivers programs to medical managers and other medical practitioners who are training for or occupying Specialist Leadership or Administration positions.

Royal Australasian College of Physicians (RACP) – a specialist medical college which connects, trains and represents 28,000 medical specialists and trainee specialists from 33 different specialties, across Australia and Aotearoa New Zealand.

Executive Summary

The Royal Australasian College of Medical Administrators (RACMA) has taken a broad view of violence, abuse, neglect, and exploitation for people with disability. We believe a systemic failure to bridge the gap between what a person with disability needs, and what is available to them, should also be viewed as violence, abuse, neglect, and exploitation, through omission as much as direct acts of commission (i.e., one person abuses or attacks another person physically).

Our College Members believe the people who are most vulnerable are those with catastrophic physical disabilities and those with cognitive disability arising from:

- developmental delay
- traumatic brain injury
- mental illness
- age-related decline of the mind.

Accordingly, RACMA's Submission Paper will focus on these cohorts.

People with cognitive impairments, activity limitations and employment incapacities need other people to assist and support them with physical care, decision-making and self-advocacy in living their lives. Provision of this life-learning and personal physical support for active participation, requires specific individual attention to ensure that optimal healthcare for people with disability is positive. However, RACMA suggests the major issue will be that support of this nature is very costly.

Having regard for the many lived experiences already outlined and acknowledged in the Royal Commission into Violence, Abuse, Neglect and Exploitation of People With Disability Interim Report (Commonwealth, 2020)¹, this paper addresses systemic issues, which RACMA believes are of high importance to people with disability, especially cognitive disability. This paper provides feedback and makes suggestions about the provision, support, and governance of care in health and disability systems and supported accommodation.

As noted in the Interim Report of the Commission there are often ongoing clinical and healthcare issues associated with disability. Clinical governance is a concept deeply understood by health leaders yet appears to be poorly implemented in the disability sector. Clinical governance has been defined as the set of relationships and responsibilities established by a governing body, executive, clinicians, patients, consumers and other stakeholders to ensure good clinical outcomes.²

This paper also incorporates real life personal accounts and experiences from people with disability (all names have been de-identified for privacy and ethical reasons) in order to demonstrate the systemic issues which, contribute to violence, abuse, neglect and exploitation.

¹ Hon. R Sackville AO QC, Hon. R G Atkinson AO, Dr R L Galbally AC, Mr A J McEwin AM, Ms B Bennett PSM, Ms A J Mason OAM, Hon. J F Ryan AM, 'Royal Commission into Violence, Abuse, Neglect and Exploitation of People With Disability Interim Report', October 2020, viewed February-August 2021.

<https://disability.royalcommission.gov.au/system/files/2020-10/Interim%20Report.pdf>

² Australian Commission on Safety and Quality in Healthcare, Our Work - Clinical Governance, 2019, viewed February-August 2021, <https://www.safetyandquality.gov.au/our-work/clinical-governance>

Recommendations

The following recommendations summarise the critical messages of this paper to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People With Disability:

1. National Disability Insurance Scheme (NDIS) and Disability Support Pensions (DSP)

- i. The NDIS supports the development of a regional/ locally based directory of disability services, such as through the national Primary Health Networks (PHN).
- ii. The NDIS develops a clinical unit to assist disability support providers in considering the needs of clients, and to act as clinically informed advocates for the client.
- iii. The NDIS allocates crisis and respite funding for people with disability in their care packages.
- iv. Informal and family carers are given access to NDIS funding for their training and other needs.
- v. All NDIS care plans should include funding for a healthcare assessment and these healthcare plans should be included as part of the overall NDIS care plan framework.
- vi. Where indicated by a completed Comprehensive Health Assessment Program (CHAP) tool [the program which accredits home and community-based healthcare organisations that make high-quality care a strategic business priority], people with disability have access to NDIS funding for clinical case management for the follow-up and management of their identified healthcare needs.
- vii. The NDIS care plans should indicate if people with disability require and are approved for a healthcare plan, with justification for approval/disapproval.
- viii. That the current age cut off threshold of 65 years is reviewed and must include access to the NDIS for older Australians, who are ventilator dependent.
- ix. Applicants intending to claim for DSP, are placed on an interim DSP allowance and are exempt from the reporting/certificates/job seeking and New Start Allowance requirements, whilst waiting for their Job Capacity assessment with Services Australia.

2. Governance

- i. The Aged Care Quality Standards that are now in effect³, should be considered and contextualised for the Disability sector. RACMA recommends the following be included:
 - an annual attestation in relation to the structures, systems, and processes in place to deliver safe and high-quality care
 - a care governance committee, chaired by a non-executive member with appropriate experience in care provision
 - a system of regular feedback from, and engagement with, people receiving aged care, their representatives, and staff
 - a complaints system, with effective risk management practices covering care risks, financial and other enterprise risks
 - a documented 'credentialling' system.
- ii. A review is undertaken of the credentialing, accountability and competencies of Allied Health staff and Disability Support workers, including any training required for assigned responsibilities.

³ Australian Government Aged Care Quality and Safety Commission 'Quality Standards', November 2021, viewed February-August 2021, <https://www.agedcarequality.gov.au/providers/standards>

- iii. The disability sector develops a clinical governance framework, which is supported by a system of continuous improvement strategies, to ensure reliability, safety and quality of clinical care and the care environment. This framework should:
 - address issues of leadership, culture, and workforce (clinical and non-clinical), patient safety systems and clinical performance
 - outline how responsibilities and accountabilities for the quality of care are shared, including how risks will be mitigated through continuous improvement strategies
 - foster an environment of excellence in care for consumers.

3. Standards

- i. Consideration is given through the Council of Australian Governments (COAG) or its equivalent for the development of a nationally agreed set of standards for human services sectors in disability, aged care, and health.
- ii. A review is undertaken by the NDIS Quality and Safeguards Commission of the National Standards for Disability Services (NSDS), using the Standards for Aged Care and Health as comparisons, to assess whether the quality and safety of care would be enhanced by the inclusion of additional standards.
- iii. The National Safety and Quality Health Service Standards developed by the Australian Commission on Safety and Quality in Health Care (ACSQHC) be amended to specifically require engagement with consumers living with disability, including the engagement with people with disability in clinical governance of healthcare providers.
- iv. The ACSQHC National Safety and Quality Health Service Standards be reviewed regularly for their inclusion of clinical and corporate governance standards that support person-centred care for people with cognitive disabilities.
- v. The standards governing medical consultation rooms be reviewed to ensure there is always disability access.

4. Quality of care

- i. Providers of accommodation for people with cognitive disabilities, be required to meet the standards for evaluation of care from both the ACSQHC and the NDIS Quality and Safeguards Commission.
- ii. Providers of accommodation are required to make their 'quality' indicator reports easily available to stakeholders.
- iii. Reforms from successive law reform commissions concerning people with diminished responsibility be enacted with diversionary programs for people with cognitive disabilities in all states.

5. Complaints

- i. The standards for accreditation of organisations, specifically the ACQSHC and NDIS provider organisations, require regular audit monitoring of complaints and how people with disability are being cared.
- ii. The Disability Ombudsman (or equivalent for each jurisdiction) be required to report on complaints of bullying, harassment, abuse, neglect and violence and the changes implemented following their investigations.

6. Better healthcare

- i. The accreditation of organisations (disability or health) providing long-term rehabilitation and/or long-term habitation care for people with cognitive disabilities include a requirement for health checks by primary care nurses and/or doctors on an annual basis. If psychotropic medications are prescribed, health checks should be on a quarterly basis.
- ii. The cost of clinical case management be met through the NDIS. Alternatively, more grants are made available for nurse specialists/case managers in selected general

practices via PHNs, as is with the current arrangement for funding diabetes case managers.

- iii. Funding be provided to establish multi-disciplinary specialist clinics in at least one tertiary centre of each jurisdiction. These units would serve as a tertiary referral centre, and an important focus of teaching, training, and research.
 - iv. State-based funding plans for healthcare for people with disability should continue to include:
 - general policy commitments
 - hospital and health service capacity regulations
 - specific Local Health District (LHD) level service development and identification of critical mass special units for people with long-term cognitive disabilities, from all causes (e.g., state-wide spinal services, district-wide paediatric-adult service transition teams, forensic units for people with cognitive disabilities, intellectual disability research institutes).
 - v. NDIS Disability Care Providers (DCPs) are linked with PHNs and LHDs (or equivalent in the relevant jurisdiction) and that disability care providers work collaboratively with PHNs to provide integrated and comprehensive directories of locally available services.
 - vi. Where DCPs are caring for people with disability, who also have health issues, all DCPs should have some staff who are appropriately clinically trained and regulated by a regulator such as the Australian Health Practitioner Regulation Agency (Ahpra) or equivalent, supervising the care.
 - vii. The Medicare Benefits Schedule (MBS) be reviewed to assess whether changes or the addition of new item numbers might assist in addressing the health inequality experienced by many people with disability.
 - viii. A formal health assessment resulting in a healthcare plan is made mandatory for people with disability funded under NDIS (unless the people with disability or guardian opts out).
 - ix. All NDIS plans for people with disability with complex care needs, should include provision for health assessments which are done by a multi-disciplinary team, including medical, nursing, and other allied health professionals.
 - x. Healthcare plans should indicate who has responsibility for implementation of the healthcare plan (people with disability, carer, guardian, or GP) and who has responsibility for demonstrating compliance with the plan (this may be the provider).
 - xi. Consideration by the Commonwealth health funding authorities, to investigate how GP surgeries and specialists' rooms may be supported to provide better access and care for people with disability. Examples include a specific disability appointment booking system with additional staff (perhaps intermittently) to assist people with disability and identify who is presenting for medical examination.
 - xii. Health system targets agreeing to bridge the expected health inequality gap, are included in the relevant funding agreements between the Commonwealth and jurisdictional governments.

The following measures below should be funded to improve healthcare for people with disability:

 - Funds should be made available for long-term care planning and case management for people with disability. This is based on evidence it promotes compliance with treatment regimens and supports individuals to take ownership of their care responsibility.
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- Good case management should have a regular periodic follow up by a trained, multi-disciplinary team, such as those commonly used to coordinate the long-term management of people with chronic conditions (e.g., diabetes, heart failure, respiratory failure). This may prevent deterioration of an existing disability.
- The Comprehensive Care Standards (National Safety and Quality Health Service Standards) should include a requirement that specific harms, such as restrictive practices, are identified. This is especially so for those people with disability with cognitive impairment and unpredictable behaviours, to minimise any harm (known risks) within the health system of vulnerable cohorts of people with disability. [The National Safety and Quality Health Service Standards detail a Comprehensive Care Standard that is a co-ordinated delivery of the total healthcare required or requested by a patient. This care needs to be aligned with the people with disability (PWD) expressed goals of care and healthcare needs. It should consider the effects of the patient's health issues, their life and wellbeing and is 'clinically appropriate'.]
- A comprehensive health assessment tool, such as CHAP or similar, should be routinely used in all health assessments of people with disability. These tools have been shown by research to make a substantial difference to health, well-being, and longevity.
- Medicare benefits/remuneration for healthcare for people with disability should be reviewed. This includes considering whether the time-based MBS remuneration provides an economic disincentive for some general medical practitioners, i.e., GPs, to allocate the necessary time to address comprehensively, the healthcare needs of people with disability, especially those people with major communication issues. [Managing the complex care needs of individuals with disability may be very time consuming. Medical practitioners indicate they are not satisfactorily remunerated under the current Medicare arrangements. Thus, the time-based Commonwealth Medical Benefits Schedule (MBS) remuneration (through the Medicare scheme) may provide an economic disincentive for some General Medical Practitioners (i.e., GPs) to allocate the necessary time to address comprehensively, the healthcare needs of PWD. This being more so for those people with major communication issues.]
- Funding for the completion of necessary paperwork for DSP applications should be provided. [The completion of complex paperwork or undertaking a major file review requires long appointments and is an issue with GP's and medical specialists, who maintain that they are not adequately funded by the MBS. Most applicants cannot afford a private fee arrangement.]

7. Electronic health record

- i. Ensure, with informed consent, all NDIS-funded people with disability and their care providers, are given access to (and use) an integrated electronic health record such as My Health Record. This will provide a central system for practitioners to record appropriate clinical information.
- ii. Provide funding for each people with disability who receive support for their health needs for the entering of their details into the Commonwealth's My Health Record.
- iii. Ensure CHAP tool or equivalent is made available through the My Health Record system.

8. Research

- i. Establish a 'disability research and innovation fund' through an annual allocation equal to 1.8% of the total Commonwealth Government expenditure on disability.
- ii. Request the National Health and Medical Research Council (NHMRC) to report annually the types and amounts of research funded on issues for people with disabilities, including highlighting disability research that also addresses indigenous health issues.
- iii. Expand the NHMRC national priorities for research, which currently only specifically focus on dementia and mental health, to include (common) causes of disability.
- iv. Request the NHMRC consider the development of a national research agenda into the prevention of disability, especially intellectual disability and track the agreed goals to monitor progress to ensure good intentions are not eroded.
- v. Request the Medical Research Future Fund (MRFF) consider the proportion of its funds that are and should be directed to disability research.
- vi. Include through the NHMRC, the application of social determinants of health and health equity approaches⁴ in public health research into disability.
- vii. Request the NHMRC and other research funding bodies, to explore the relationship between cognitive, affective, and behavioural dimensions of stigma to identify interventions that will reduce stigma.⁵
- viii. Allocate research funds to a wide range of disability issues including:
 - the causes of disability in regional Australia
 - ways of reducing the incidence of disability, especially disability resulting from road trauma
 - the socioeconomics of disability
 - prevention and treatment of age-related disability health conditions
 - innovation in the delivery of disability services, including through co-funding arrangements with industry providers and through workforce-related research and technology.

9. Data

Improve the quality of disability data outcomes by:

- i. having consistent definitions of disability across data sources
- ii. ensuring that all mainstream data sources adopt the concept of a disability flag to identify people with disability
- iii. addressing the fragmented, dispersed, and incomplete data, regarding services used by people with disability (specialist and mainstream)
- iv. improving reliability reports on specific population groups within the broader disability population
- v. making available relevant data collected, not collated or otherwise, available for statistical purposes
- vi. integrating data across settings and life area domains to examine pathways and outcomes for people with disability
- vii. generating data for the health and life outcomes for the Australian population living with disability.

⁴A Kavanagh, 'Disability and public health research in Australia', in Wiley Online Library, June 2020, viewed February-August 2021, <https://onlinelibrary.wiley.com/doi/10.1111/1753-6405.13003>

⁵ H. A. Pelleboer-Gunnink, W. M. W. J. Van Oorsouw, J. Van Weeghel, 'Mainstream health professionals stigmatising attitudes towards people with intellectual disabilities: a systematic review' February 2017

viii. Improving existing data sources to better capture data about subgroups in the disability population. i.e., special, or vulnerable groups such as:

- First Nations peoples
- those who live in rural and remote Australia
- those who live in care settings
- the LGBTQI+ community
- culturally and linguistically diverse cohorts
- those who have suffered abuse, discrimination
- the homeless

10. Regional Australia

- i. Make available funds independent of hospital transfer funds to support travel by people with disability from regional areas to metropolitan centres for assessment or treatment.
- ii. Support the six policy tools outlined in the 2019 Regional Australia Institute (RAI) Report⁶ on disability, including exploring alternative ways of funding and providing disability services in regional Australia.
- iii. Increase funds for outreach clinics for disability support, especially by multidisciplinary teams (MDTs), with a view to ensuring a national network of support for regional Australians living with disability.

11. Education and training, and regulation compliance

- i. Ensure, through the Medical Board of Australia via the Australian Medical Council (AMC), all levels of medical training and education, including university clinician courses and Specialist Medical Colleges Continuing Professional Development programs, comprise:
 - an awareness of the needs of people with disability and the clinical skills essential to provide comprehensive and appropriate healthcare and outcomes for them
 - an awareness of diagnostic overshadowing, its frequency, and ways of reducing diagnostic errors, as well as the types of patients and conditions where this is more likely to occur, such as with patients with mental illness and disability, especially cognitive impairment, and behavioural disorders
 - 'experts-by-experience'
- ii. Clinical education of disability programs be incorporated into the National Training Packages system for care-worker training programs.
- iii. Request the relevant accreditation authorities to consider any changes to the knowledge, skills, and professional attributes of health professionals to address the care needs of people with disability, in line with 'Recommendation 82' of the Royal Commission into Aged Care Quality and Safety Final Report.⁷
- iv. Request the Commonwealth Government to provide funds for disability care teaching programs to be delivered by both the higher education and vocational education and training providers for all healthcare students. This is in line with 'Recommendation 83' of the Royal Commission into Aged Care Quality and Safety Final Report. Program

⁶ The Regional Australia Institute, 'Building the NDIS in Regional Australia: A Review of Key Policy Approaches,' p. 3, 2019, viewed February-August 2021, <http://www.regionalaustralia.org.au/home/wp-TRY>
http://www.regionalaustralia.org.au/home/building-the-ndis-for-regional-australia/content/uploads/2019/11/RAI_SIP-2019-2-1-1_Building_the_NDIS_in_Regional_Australia.pdf

⁷ Hon Gaetano (Tony) Pagone QC, Ms Lynelle Briggs AO, Royal Commission into Aged Care Quality and Safety, 'Final Report: Care, Dignity and Respect, volume 1, summary and recommendations', p. 262, 2021, viewed February-August 2021, <https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-volume-1.pdf>

- curriculum should include all areas of disability care and research, as well as clinical placements, where appropriate.
- v. Approve certain providers of disability care in particular regions to establish centres of research and training excellence for disability care in catchment areas and fund them accordingly for these activities.
 - vi. Ensure all staff working in the disability sector are appropriately regulated such as Personal Care Assistants (PCA's) behavioural therapists, care therapists and other disability carers when working with people with disability. [NDIS DCP's are categorised as 'General health service providers', who are not legally required to be registered under the national health practitioner regulation law. This is why they are known as non-registered providers. The many types of practitioners in this category include audiologists, naturopaths, dieticians, speech pathologists, homeopaths, counsellors, massage therapists, alternative therapists, and other providers of general health services. In Australia health professionals do require registration to practice. These are known as registered providers and are regulated under a national scheme by the Australian Health Practitioner Regulation Agency (Ahpra). Our concern are those providers who are not regulated and where violence, abuse, neglect, and exploitation occur to PWD as vulnerable people. RACMA insists that these non-registered providers be held accountable and must adhere to a code of conduct being a set of standards; and be appropriately trained in providing and healthcare or treatment of PWD.]
 - vii. Ensure all allied health professionals, such as physiotherapists, speech pathologists, and audiologists working in the disability sector are credentialled for work in their respective areas. [Through the credentialing process, common in the health sector, the qualifications of licensed professionals are assessed, together with their background and relevant experience and specific clinical privileges are determined.]

Introduction

RACMA is a Specialist Medical College, recognised by the Medical Board of Australia and the Medical Council of New Zealand, to deliver education and training programs to medical practitioners who are occupying leadership and management roles and positions in the public and private health and disability systems.

Members of this College write as system overseers in our work settings, to add our advocacy for people with disabilities to the voices which have already been heard by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. This submission has been prepared following publication of the Interim Report of the findings of the Disability Commission, and its plans for further review, in late 2020; and recent release of commissioned research reports and documents prepared for hearings in early 2021.

RACMA advocates that Australia requires an inclusive disability care system, which is substantially funded, to:

- promote the health and welfare of people with disability
- identify their health and welfare care risks early
- achieve best practice in person-centred care
- improve care to prevent and protect people with disability from experiencing violence, abuse, neglect, and exploitation.

RACMA acknowledges Australia has a strong history of reform in legislation and service provision for people with disabilities in recent decades. The College is expectant of the influence the Royal Commission on Violence, Abuse, Neglect and Exploitation of People with Disability will have on future Commonwealth legislation and allocation of funding for services.

SECTION 1

1.1 Clinical governance

RACMA Members have comprehensive formal training and extensive experience with the delivery of acute healthcare, which align to the standards published by the ACSQHC⁸. The experience of our Members in relation to the disability sector has highlighted concerns about poor clinical governance in DCPs, thus potentially exposing people with disability to delayed, inferior, or possibly, unsafe care.

RACMA's concerns with governance and safety issues within the disability sector include:

- the general level of standards required of DCPs regarding capability and capacity
- safety and quality frameworks of the services provided
- transparency of reporting of compliance with standards
- the need for more qualified and trained staff working within a regulated framework.

From our experience in the health sector, RACMA believes DCPs should have systems of clinical governance in place where the top management, such as a Board of Directors, is responsible and held legally accountable. The clinical governance framework should:

- define the required standards of care
- assign responsibilities and accountabilities to meet those defined standards
- foster a culture of a continuous improvement
- define the necessary level of skills, training, and accreditation of DCP staff.

RACMA recommends note is taken of the recommendations of the Royal Commission into Aged Care Quality and Safety Final Report - Care, Dignity and Respect regarding governance standards and a similar approach is applied and contextualised to the disability sector (refer to the Recommendations section).

'Recommendation 90' of the Royal Commission into Aged Care Quality and Safety Final Report, states that approved providers of care should attest annually they have in place the structures, systems and processes to deliver safe and high-quality care.⁹

The suggested aged care framework includes:

...a care governance committee, chaired by a non-executive member with appropriate experience in care provision, to monitor and ensure accountability for the quality of care provided, including clinical care, personal care, and services, and supports for daily living...¹⁰

And

...a system of regular feedback from and engagement with, people receiving aged care, their representatives, and staff to obtain their views on the quality and safety of the services that are delivered and the way in which they are delivered or could be improved...¹¹

And

⁸ Australian Commission on Safety and Quality in Healthcare, National Safety and Quality Health Service Standards, 2019, viewed February-August, <https://www.safetyandquality.gov.au/standards/nsqhs-standards>

⁹ Hon Gaetano (Tony) Pagone QC, Ms Lynelle Briggs AO, Royal Commission into Aged Care Quality and Safety, 'Final Report: Care, Dignity and Respect, Volume 1 summary and recommendations', p.267, 2021, viewed February-August 2021, <https://agedcare.royalcommission.gov.au/publications/final-report>

¹⁰ Ibid

¹¹ Ibid

*...a complaints system, effective risk management practices covering care risks as well as financial and other enterprise risks, and that a nominated member of the governing body...*¹²

Many system deficiencies of the disability sector would be improved through the inclusion of clinical governance within the overall corporate governance frameworks (which are in place under the NDIS accreditation). Clinical governance makes explicit the relationships and responsibilities required to ensure high quality and safe care and support.

In relation to the quality of services in the disability sector, RACMA understands the disability accreditation system tries to ensure each NDIS participant has an individually tailored care plan implemented. It is important the governance boards of DCPs have independent assurance each care plan has been properly developed and has been implemented. Such an approach of checking and auditing is commonly used by commercial and other companies in their management of risk and is based on the commonly used “three lines of defence in effective risk management and control” model¹³. This was developed for HSBC Bank by KPMG (United Kingdom) in the 1990’s, and later adopted by the Bank for International Settlements ‘Basel Committee on Banking Supervision’ as a quality model for internal control management¹⁴.

The requirement that there be a clinical governance framework, where clinical care is being provided, may not be an easy undertaking for many DCPs. Whilst the experience of the healthcare sector can be a guide, a disability sector clinical governance framework will need to be expertly designed and implemented. To do this, it will be necessary to define a common set of safety and quality performance indicators that include health issues. These will need to be monitored across DCPs. The health system bases its quality management systems on eight domains of safety and quality designed to ensure care is effective, safe, patient centric, equitable, efficient and demonstrates timely access¹⁵. RACMA notes that currently, the NDIS standards for disability care providers do not refer to several of these quality domains.

The system of governance in the disability sector needs to consider both the care and support for clients, as well as their clinical care. This is due to many people with disability also suffer from a range of other health issues, including mental health problems, chronic illnesses associated with their disability, various co-morbidities, intermittent acute illnesses, and/or physical and cognitive impairment.

¹² Ibid

¹³ P Jones, ‘Risk and compliance: rethinking the three lines of defence’, The Institute of Internal Auditors on Australian Institute of Company Directors. October 2020, viewed February-August 2021, <https://aicd.companydirectors.com.au/membership/company-director-magazine/2020-back-issues/november/risk-and-compliance-rethinking-the-three-lines-of-defence>

¹⁴ Bank for International Settlements Basel Committee on Banking Supervision, ‘The Basel Framework’ 2021, viewed February-August 2021, https://www.bis.org/basel_framework/index.htm?m=3%7C14%7C697

¹⁵ Australian Commission on Safety and Quality in Health Care, ‘National Safety and Quality Health Service Standards Guide for Hospitals’, 2017, viewed February-August 2021, <https://www.safetyandquality.gov.au/sites/default/files/migrated/National-Safety-and-Quality-Health-Service-Standards-Guide-for-Hospitals.pdf>

The NDIS Quality and Safeguards Commission, outlines NDIS Practice Standards that touch on aspects of clinical governance, as it is understood in the health sector. Under the NDIS Practice Standards and Quality Indicators for Quality Management, 'participant's benefit from a quality management system relevant and proportionate to the size and scale of the provider, which promotes continuous improvement of support delivery'¹⁶ and outcomes.

The practice standard requires the demonstration of evidence of a quality management system, which is maintained and defines how the requirements of legislation and the standards are met including financial, legislative, regulatory and contractual responsibilities. The practice standard is as follows.

- Skills knowledge and training required for the governing body to govern effectively
- Strategic and business planning that consider legislative requirements, organisational risks, and other relevant requirements
- Management by suitably qualified and/or experienced persons with clearly defined responsibility, authority and accountability, clear delegations and whose performance is monitored
- Regular review of the quality management system, including documented internal audits, to ensure continuous improvement in management practices
- Perceived and actual conflicts of interest are proactively managed and documented
- Evidence of opportunities for people with disability to contribute to the governance of the organisation and have input into the development of organisational policy and processes relevant to the provision of supports and the protection of participant rights

RACMA makes the following observations in relation to these NDIS standards.

- There is little emphasis on clinical governance.
- The focus is on the provider, not the participant's care and outcomes.
- The documentation sets no objective / measurable standards of care.
- The documentation sets no minimum standard of care.
- The documentation does not require a provider to have a healthcare plan for each participant.
- The documentation does not require a provider to verify if a healthcare plan is in place for a participant, it is implemented.

The Accreditation Standards for Disability Care NDIS Providers (and DCPs)¹⁷ as outlined by the NDIS Quality and Safeguards Commission, require independent audits against the standards. As the current NDIS Quality Commission Standards place little emphasis on clinical governance, these audits of DCPs do not address many of the eight domains of the national quality (health) standards.

¹⁶ NDIS Quality and Safeguards Commission, 'NDIS Practice Standards and Quality Indicators', Version 4, p.9, November 2021, viewed February-August 2021, <https://www.ndiscommission.gov.au/sites/default/files/documents/2019-12/ndis-practice-standards-and-quality-indicators.pdf>

¹⁷ NDIS Quality and Safeguards Commission, 'NDIS Practice Standards and Quality Indicators', January 2020, viewed February-August 2021, <https://www.ndiscommission.gov.au/sites/default/files/documents/2019-12/ndis-practice-standards-and-quality-indicators.pdf>

Rowan's personal story is referenced as follows:

Rowan's Story*

Rowan was born many decades ago into a sibship of 6 as the youngest child in a rural region. Rowan was diagnosed with Down Syndrome by a specialist in a major centre and his mother was initially advised she should consider placing him in care at an early age 'and leaving him'. But she did not take this advice and took Rowan home.

With severely impaired speech, Rowan required considerable support during his childhood years, but, in many ways, the specialist support he required was limited.

Rowan has been subject to physical and sexual abuse throughout his life in various care organisations. He was also subject to threats against his family if he spoke out, psychological trauma, and other major deprivations of liberty.

Rowan was largely unable to communicate these abuses until he was able to develop an alternative communication method. However, his father noticed various bruises and other physical manifestations of abuse. While the centres where his abuse occurred have now been closed, the care providers of these centres and the perpetrators of the abuse have, in the view of Rowan's parents, never been brought to justice. Rowan and his parents have never received an apology for what happened to him.

As well as physical and sexual abuse, Rowan has, unfortunately, also experienced many problems with the disability sector itself. These problems have included difficulty navigating 'the system', financial misappropriation and abuse. He has often had his care packages removed or re-directed and he has been subject to fraud when his parents were asked to contribute additional funds when they did not have to do so.

Rowan's mother has also reported difficulty in accessing services in rural locations, difficulties in being able to communicate clearly with various government agencies and providers, and often being 'cut off' with little explanation or no reason at all.

*The name has been changed for privacy

By contrast, the ACSQHC publishes very comprehensive standards, with associated (detailed and mandatory) action items and implementation tools for providers. As part of clinical governance, healthcare providers must show that they monitor performance against national standards and take corrective action where necessary at a systemic or individual patient /participant level. In this context, it is relevant to note private and charitable healthcare providers are licensed under State/Territory government legislation and a condition of licence is 100% compliance with ACSQHC standards.¹⁸

¹⁸ Australian Commission on Safety and Quality in Health Care, 'The NSQHS Standards, 2019, viewed February-August 2021, <https://www.safetyandquality.gov.au/standards/nsqhs-standards>

The ACSQHC Standards feature:

- a comprehensive system of clinical governance, which is clearly defined to enunciate the respective responsibilities of boards, executives and healthcare workers for the care delivered to patients (i.e., 'participants'). It is relevant to note the standards define a series of major adverse patient outcomes (never events), which are reportable to the Commission, as well as within the provider's system of clinical governance
- a requirement that every patient /participant has a healthcare plan in a prescribed, structured format, that is well documented, easily accessible, and is implemented
- a requirement that personal care records are audited to ensure compliance with clearly defined standards, both of documentation and of care delivery
- a national collection of clinical outcome measures, which is used to set benchmarks for patient / participant care.

Some of the Key Performance Indicators (KPIs) common in healthcare may be relevant to the disability sector, such as mandatory reportable incidents, medication review, reporting of injuries, consumer engagement in service planning and service delivery, and complaints management systems. If similar KPIs were adopted for the DCPs, compliance with these standards would need to be monitored and assessed as part of the accreditation of a DCP.

People with disability may receive services in both the disability sector and health services. Yet these two sectors operate under different quality standards. RACMA undertook a high-level review of the standards against which performance is assessed in the disability, health, and aged care sectors ([see Appendix 1, page 63](#)). The various standards frameworks have many areas in common. In addition, each framework could be considered to have omissions, which if addressed would strengthen that standard framework. This raises the question of whether each sector could improve their standards frameworks by examining the frameworks of other sectors and making modifications.

However, our review raises a more fundamental question as to why there are three different frameworks for these three human services sectors?

RACMA recommends it is more appropriate to have one common set of core standards, with each sector adding context relevant to their domain.

Accordingly, RACMA has identified a common set of standard “themes”, which could be used in the development of a nationally agreed set of human service standards. While we recommend a single set of standards be adopted by the three human services sectors, we recognise there needs to be scope that allows contextualisation (interpretation) for each sector. For example, all sectors should have a standard about ‘Partnering with consumers in relation to planning and outcomes assessment’ (which each Aged Care standard has now included). Only the health sector would need a standard regarding the use of blood products.

Along these lines we note the Royal Commission into Aged Care Quality and Safety Final Report has suggested there be one standard setting body for both the health and aged care sectors.

‘Recommendation 18’ of the Royal Commission into Aged Care Quality and Safety Final Report states Section 9 of the National Health Reform Act 2011¹⁹ (Cth) should be amended to ‘rename the Australian Commission on Safety and Quality in Health Care’ as the Australian Commission on Safety and Quality in Health and Aged Care and confer upon that body the functions of formulating standards, guidelines and indicators relating to aged care safety and quality.²⁰

RACMA suggests the same principle should apply to the disability sector and that there should be a single human services standard setting body, based on the ACSQHC.

RACMA recommends the following themes, to form the basis of an agreed set of National Standards for human services sectors as follows:

Theme	Example of Standard*	Sector		
		Disability	Aged Care	Health
Consumer rights, dignity, and choice	The organisation has a culture of inclusion and respect for consumers, supports consumers to exercise choice and independence in decision-making and respects consumers’ privacy.	Yes	Yes	Yes
Personal safety	The organisation actively prevents abuse, harm, neglect, and violence.	Yes	Yes	Yes
Partnering with consumers in the planning and delivery of services and the assessment of outcomes	The leaders of the organisation develop, implement, and maintain systems to partner with consumers. These partnerships relate to the planning, design, delivery, measurement, and evaluation of care. The workforce uses these systems to partner with consumers.	Yes	Yes	Yes

¹⁹ Australian Government Federal Register of Legislation, ‘National Health Reform Act 2011’, viewed February-August 2021, <https://www.legislation.gov.au/Details/C2016C01050>

²⁰ Hon Gaetano (Tony) Pagone QC, Ms Lynelle Briggs AO, Royal Commission into Aged Care Quality and Safety, ‘Final Report: Care, Dignity and Respect, Volume 1 summary and recommendations’, p. 222, 2021, viewed February-August 2021, <https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-volume-1.pdf>

Theme	Example of Standard*	Sector		
		Disability	Aged Care	Health
Feedback and complaints	The organisation regularly seeks input and feedback from consumers, carers, the workforce, and others and uses the input and feedback to inform continuous improvements for individual consumers and the whole organisation.	Yes	Yes	Yes
Service access	The service manages access, commencement and leaving a service in a transparent, fair, equal, and responsive way.	Yes	Yes	Yes
Governance and service management	The organisation's governing body is accountable for the delivery of safe and quality care and services.	Yes	Yes	Yes
Human resources	The organisation has a workforce that is sufficient, and is skilled and qualified to provide safe, respectful, and quality care and services.	Yes	Yes	Yes
Personal and clinical care	The organisation delivers safe and effective personal care, clinical care, or both personal and clinical care, in accordance with the consumer's needs, goals and preferences to optimise health and well-being.	Yes	Yes	Yes
Preventing and controlling cross and care-associated infection	Leaders of the organisation describe, implement, and monitor systems to prevent, manage or control care-associated infections and antimicrobial resistance, to reduce harm and achieve good health outcomes for consumers.	Yes	Yes	Yes
Medication safety	Leaders of the organisation describe, implement, and monitor systems to reduce the occurrence of medication incidents, and improve the safety and quality of medicines use. The workforce uses these systems.	Yes	Yes	Yes
Communicating for Safety	Leaders of the organisation set up and maintain systems and processes to support effective communication with consumers, carers, and families; between multidisciplinary teams and clinicians; and across the organisation. The workforce uses these systems to effectively communicate to ensure safety.	Yes	Yes	Yes

Theme	Example of Standard*	Sector		
		Disability	Aged Care	Health
Recognising and responding to deterioration	Leaders of a health service organisation set up and maintain systems for recognising and responding to a deterioration in a consumer's condition. The workforce uses the recognition and response systems.	Yes	Yes	Yes
Blood management	Leaders of a health service organisation describe, implement, and monitor systems to ensure the safe, appropriate, efficient, and effective care of patients' own blood, as well as other blood and blood products. The workforce uses the blood product safety systems.	No	No	Yes
Services and supports for daily living	The organisation provides safe and effective services and supports for daily living that optimise the consumer's independence, health, well-being, and quality of life. Services and supports for daily living include, but are not limited to, food services, domestic assistance, home maintenance, transport, recreational and social activities.	Yes	Yes	No

*Taken from existing wording from the Standards framework for one of the three sectors

Our review also highlighted that, in the absence of a single human services set of standards, the health standards might be strengthened by a more explicit reference to meeting the needs of people with disability. For example, the Health Standards²¹ require organisational policies and procedures be in place that cover:

- healthcare rights
- informed consent, including financial consent
- shared decision-making and planning care
- health literacy and effective communication with patients, carers, families, and consumers
- partnering with consumers in governance

While commendable, the standards do not require or relate specifically to people with disability. As a way of improving the complex inter-relationships between the healthcare system, disability service providers and people with disability, **RACMA recommends the health standards be amended to specifically require engagement with people with disability.**

²¹ Australian Commission on Safety and Quality in Healthcare, 'The NSQHS Standards', 2019, February-August 2021, <https://www.safetyandquality.gov.au/standards/nsqhs-standards>

1.2 Systemic complexity

The support for a person living with disability can range from an individual care plan that supports them in their own home, through to a variety of forms of institutionalised care depending on the complexity of needs and available resources.

RACMA recognises that overall, people with disability receive better support and resources since the implementation of the NDIS, which has assisted with:

- funding
- planning and delivery of care needs, especially allied health services
- specialised nursing for complex care including social care
- restorative disability care (such as Activities of Daily Living (ADL))
- educational activities and vocational training for achieving independent living

People with disability interact with various public and private providers for education, childcare, jobs, transport, public housing, and health (state or territory and primary healthcare). People with disability may be subject to violence, abuse, neglect, and exploitation, by omission as they seek services that are difficult to access, or which may not be available for them or in their local area.

Many people with disability, and their carers/guardians, have expressed concern about difficulty in navigating the disability support system. This is a particular issue for people with intellectual disability, and those who have little access to professional support.

The term 'system' implies the component parts are connected in a way that is clear to system users ensuring 'the whole is greater than the sum of its parts'. However, our observations and experience in the healthcare system with people with disability, suggest the 'dots are not joined' and the links between the NDIS, DCPs, and the health and social security systems can be fragile at best. There is a silo effect which creates barriers to access, as each of these larger systems have different policies and processes. This can create onerous barriers when accessing any appropriate support.

Multiple funders, service providers and system fragmentation in both the disability and health sectors, contribute to system complexity. This makes it difficult for many people with disability to understand what they are eligible for, and to whom they should turn to for service. The many small-scale providers of disability care, such as home services, allied health, home nursing, and personal carers, mean a person with disability may have to engage with a number of providers, in order to obtain the full suite of services they need.

Peter's personal story is referenced as follows:

Peter's Story*

When Peter, who has three older siblings, was born in 1981, his mother was told he had some problems. His mother said that 'you don't expect to have a handicapped child'.

Peter's problems have followed him all his life. He is now 39 years old, but weighs 37kg, is about the size of an eight- to 10-year-old boy and has the intellectual capacity of an early school age child, though he does have enough understanding to use computer games in a limited way and pick things on the television. His mother describes him as being both 'child size and child like', saying he has the intellectual capacity of a three- to 4-year-old for some things, but is better than that in other areas. He has a permanent tracheostomy, and while he can walk in a limited way around the house, he needs to be taken in a wheelchair for any external excursions.

Peter's life was close to normal, despite his disability, until 1994 when he was about 13 years old. At that time, doctors noticed Peter's respiratory function was impaired. He was found to have a narrowing lower down in the windpipe (trachea), for which he would require a permanent tracheostomy. This meant an external opening was made in the windpipe, and a tube inserted in order to keep the opening patent. From that time, everything changed for Peter. His windpipe deformity is such that he requires a specially made tracheostomy tube, which must be imported from the USA at some expense.

Prior to this he was attending a special school, but the 'introduction of the permanent tracheostomy' meant he could no longer attend that school. His parents had not expected the difficulties they experienced in finding another school that could take him. His mother said the education authorities told her that due to his 'extremely high medical and physical needs' they could not place him. However, his mother did find a suitable school, where the principal was willing to take Peter. They encountered another hurdle when the authorities intervened to say he lived too far from the school. Not to be put off, his mother sought assistance from others, including another parent who had a severely disabled child. Together they approached the education authorities again and, eventually, after what his mother described as 'much running around and artificial barriers', Peter was accepted for a special placement and began to attend the school whose principal had originally accepted him. This school had a nurse on site, which was a requirement for a child with a tracheostomy.

Peter stayed at that school until he was about 19 years old, even though his parents were originally told he could not remain at school after he had turned 16. His school days were exceptionally long. He was usually the first child to be picked up by the special bus, and the last child to be brought back home, but Peter did not complain.

From the time he was 19 years old, he was eligible to attend Day Respite Centres, but there were difficulties finding a place that would take him, given the centre needed to have a nurse on site to manage Peter's tracheostomy. But a centre was found. Again, Peter had long days, usually being picked up by the bus at 7.30am and not returning home until about 5.30 pm. His mother said there

Peter's Story* continued

were occasions when Peter had a coat on when he left in the morning as it was cool, but that he returned home still in his coat even if the main part of the day had been hot. Peter was unable to recognise how he should be dressed, or to complain if he was hot.

Peter's mother said the NDIS has resulted in new service providers 'popping up' all over the place, many near Peter's home, but not all can meet his needs. Day Centre visits are complicated by Peter's difficulty with toileting. He struggles with managing his own hygiene after going to the toilet. Peter is unable to say he needs help. On several occasions when complaints have been made about Peter 'messing up the bathroom', his mother has been told clients are able to choose the care they need, and Peter had not asked for bathroom assistance. Even though his mother has advised he is unable to recognise his need for care and to ask for assistance, this remains a 'sore point'.

Peter is eligible for support from the federally funded NDIS and is also eligible to receive certain medical equipment (such as catheters for suction; tracheostomy support) through the State health service. But the public health service does not provide certain medical equipment (such as syringes; saline solution; dressing etc) which Peter's parents must purchase themselves and then claim these expenses from the NDIS.

Peter's parents have been caring for his tracheostomy since 1994 with no ill effects. But they have come up against differing guidelines about tracheostomy care, and these differing guidelines, rather than Peter's needs, are influencing the type of medical equipment that Peter can receive free of charge.

From the time he was about 14 years old, Peter was no longer able to receive care through a paediatric hospital, despite his size being that of an eight -to 10-year-old boy. Since then, he has attended an adult hospital. However, because of his size, the adult hospital equipment is too large for him, and the smaller specialty equipment he needs must be brought over from a paediatric hospital.

Family excursions are limited as Peter needs a wheelchair outside the home, and a suction pump needs to be attached to the back of the wheelchair.

Peter's problems have dominated his parent's lives since he was born. Among their current concerns is the major issue of what will happen to Peter when they can no longer care for him. Peter's parents are adamant that they do not want Peter to be cared for by his siblings. With their first-hand knowledge of what it means to look after Peter, they fear for the impact on the lives of their other children should one of them take on his care. To this end, his parents, who have very modest means, have tried to carefully save in order to make as much provision for Peter's future as possible.

* The name has been changed for privacy

RACMA is aware changes in the pattern of service provision under the NDIS arrangements has also created major service gaps. For example, some community services previously provided by the various jurisdictional health departments have been restructured or closed. A major concern is service gaps may impact adversely on the options, choices, and control by a people with disability. This may be considered to be a form of institutionalised violence, abuse, neglect and exploitation towards people with disability.

The service gaps may include:

- the NDIS service is not as comprehensive as the former state/territory government services
- healthcare providers are withdrawing and increasingly passing the community support work to private providers funded by the NDIS. However, there may be little supervision by the NDIS of the care provided. The NDIS providers lack staff with clinical expertise.

RACMA recommends assessments are standardised using trained providers via an on-line portal, rather than through a multi-disciplinary team. This contributes to inadequate assessment and care of people with disability, exacerbating violence, abuse, neglect, and exploitation.

Equipment

Under current NDIS rules, most complex equipment (i.e., human movement equipment) must be prescribed by an NDIS provider in the community. Each assessment of equipment needs starts afresh. RACMA has been advised occupational therapists, who undertake this work within the health services, are usually not available for NDIS assessments, due to time and cost constraints. It is common for the NDIS assessor not to access previous equipment lists/care needs assessment reports, (such as those done through hospitals) which facilitates care planning and development.

Problems arise when:

- the client has difficulty finding a provider (particularly in regional, rural, and remote areas)
- the community provider does not have the experience/ training to complete the prescription
- the client is unable to find out whether the provider has the necessary skills and experience to complete the prescription
- the provider runs out of funded time.

RACMA acknowledges this has been flagged by the NDIS. For example, arrangements have been made with various acute spinal units and brain injury units in health services and hospitals to ensure appropriate equipment and support packages are put in place prior to the initial discharge of the patient back into the community. However, for longstanding patients the experience is still variable.

Frank's and Pamela's stories are referenced as follows:

Frank's story*

Frank has a congenitally acquired spinal cord malformation which has caused severe lower limb weakness and dependence on a wheelchair for all mobility. However, with the use of orthoses (callipers) Frank can manage his transfer from his wheelchair to chairs and his bed through a 'standing transfer'. This, seemingly small, activity means he does not require a hoist to transfer and is able to live independently.

When the NDIS was introduced, Frank applied (as part of his plan) to have his new orthoses funded. For many years Frank had been receiving care from his spinal cord specialist and the nurses and allied health staff working in this area. He was aware they had done a thorough assessment of his needs and had prescribed the type of calliper that best suited his condition. But on making his NDIS application, Frank became aware the NDIS did not take that health assessment into account and needed to make its own assessment anew. This new assessment was undertaken by an NDIS officer.

Frank was dismayed that initially the NDIS planner (who Frank believes has a clerical background) said he was not eligible for orthoses as he was in a wheelchair and not walking. However, the application was eventually accepted, and the plan was finalised.

Frank was further distressed to learn that only orthoses were approved but not the specialised shoes that are required in order for the orthoses to function. Frank was aware that callipers can only 'work' when connected with shoes, and that both together are what is usually meant when people talk about 'callipers'. Although very intelligent, Frank was used to receiving care from specialised service providers who would have automatically known the shoes and orthoses were part of the same unit and did not need to have that spelled out to them, and so he had not specified them. Now he found that since 'the shoes were not in the plan' he had to go through an appeal process, lasting several months, to have them added. Frank bemoaned the fact the planner seemed to have little idea of the support/equipment needs of someone with a high level of disability and that no mechanism existed for communication with previous prescribers within the Department of Health, who had looked after his complex needs for 40 years.

His new application was eventually approved. But the whole 'saga' left Frank and his healthcare workers wondering why the initial health prescription for callipers could not have been accepted by the NDIS, so his new ones came fitted to shoes at the outset.

*The name has been changed for privacy

Pamela's Story*

Pamela is a young person who has a high-level complete tetraplegia. She lives on a rural property with her mother, depending on a disability pension and a carer support pension. Over the six months previously, her NDIS plan had allocated substantial funds for her care, including continence needs, avocational activities, and home modifications. But she had not used any of the funds.

Pamela and her mother were left to manage the NDIS plan themselves and had no idea how to do that. They lived too far out of town to be able to find a personal care support to hire, so her mother continued to provide the care Pamela needed. They had been told to order the continence aids and then seek a refund, but they were not able to afford to pay for them in the first place and no one had told them that an account, which could bill the NDIS, could be set up. In addition, they had no idea how to find the occupational therapy support, who could prescribe Pamela's new equipment, so she made do with her old defective chair.

*The name has been changed for privacy

Disability-health interface

It is acknowledged the legislation about eligibility for NDIS funding for care is quite clear that the NDIS funds support services for people with disabilities and it does not fund health and hospital care. However, it is clear from the Interim Report of the Disability Royal Commission, many instances of neglect may relate to lack of awareness and partnership at the disability-health interface.

Our College Members are particularly interested in commenting on the issues identified by the Commonwealth Government (Department of Social Services (DSS) regarding optimising outcomes in supported living for people with intellectual disability.²² These areas are seen as particularly prone to institutionalised oppression at the disability care/healthcare interface, with acts of omission being equally as important as acts of commission. This research indicated people with disabilities considered the benefit of supported living was increased levels of choice and control. They defined good support workers as people who listened and had expectations of them. They preferred to be appropriately informed about changes in support workers or timing of supports. Participants with structured activities to attend, such as paid or voluntary work, tended to report a higher quality of life.

Accordingly, the three main groups of people with disabilities for whom the disability-health interface needs attention are:

²² Australian Government Department of Social Services, Disability and Carers, 'Optimising outcomes in supported living for people with intellectual disability', March 2017, viewed February-August 2021, <https://www.dss.gov.au/disability-and-carers/optimizing-outcomes-in-supported-living-for-people-with-intellectual-disability>

- adults living with life-long intellectual developmental disorders, whose numbers are growing as they live longer²³
- young people following traumatic brain injury, for whom the rehabilitation phase of their management may take up to five years and they then need long term supported accommodation²⁴
- adults with mental illness, for whom homelessness becomes a reality²⁵

The key health practitioners in these situations are nurses²⁶, GPs, rehabilitation physicians, psychiatrists, psychologists, and occupational therapists, who have important functions in both health maintenance, long-term rehabilitation, and long-term care.²⁷

Accommodation

RACMA Members also report in many instances, there is a lack of sufficient suitable government housing (or safe houses), especially in regional Australia. This lack of housing adversely impacts the physical, social, and psychological wellbeing of people with disability, which can result in harm and neglect. Some people with disability have limited means to address the behaviour of others in shared accommodation and unable to access assistance. The poor behaviours from others within shared accommodation, exacerbates poorer health outcomes for people with disability and needs to be addressed.

People with disability as vulnerable persons, placed within inappropriate accommodation, are at risk of harm. There are issues of:

- assault
- accessibility to medications
- privacy issues
- duress in sharing goods
- theft
- fraud
- misrepresentation
- impropriety
- exploitation
- abuse.

Some accommodation providers may elect not to offer other care services and it may therefore be difficult for some people with disability to access care services while in the accommodation. Other negative treatment towards people with disability when living in government housing, includes conscious and subconscious bias from others.

²³ L. Lee, M. Heffernan, G. McDonnell, S.D. Short, V. Naganathan, 'A system dynamics modelling approach to studying the increasing prevalence of people with intellectual developmental disorders in New South Wales'. *Australian Health Review* (40), 2015, pp. 235-243

²⁴ F. Khan, I.J. Baguley, I.D. Cameron, 'Rehabilitation after traumatic brain injury'. *Medical Journal of Australia*, March 2003, pp. 178, 290-295

²⁵ C.N. Chin, K. Sullivan, S.F. Wilson, 'A snapshot of the health of homeless people in inner Sydney: St Vincent's Hospital'. *Australian Health Review* (35), 2011, pp. 52-56

²⁶ M. Applegren, C. Bahtsevani, K. Persson, G. Borglin, 'The Experiences of Nursing for Patients with Intellectual Developmental Disorders' in ResearchGate, June 2018, viewed February-August 2021, https://www.researchgate.net/publication/327052422_The_Experiences_of_Nursing_for_Patients_with_Intellectual_Developmental_Disorders

²⁷ F.M. Blyth, L. Lee, 'Giving a voice to the vulnerable'. *Pain*, 152(9), 2011, p. 1937

Intellectual disability and incarceration

In December 2001, the Victorian Law Reform Commission was asked to look into compulsory treatment of persons with an intellectual disability. The inquiry's findings highlighted people with cognitive disabilities from developmental disorders or mental illness, who have committed crimes, should not be incarcerated in the general justice system, and should be sent to a diversionary program for people with cognitive disabilities.²⁸

Availability of services

From the NDIS website, it is difficult to determine which service providers offer what service, as the NDIS website does not clarify the scope (clinical, functional, and geographical) and levels of service offered by each DCP. The information is lengthy and complex, which both patients and clinicians find hard to understand. The complexity is exacerbated by:

- the number of DCPs
- an ever-changing scope of services
- the list of DCPs is not being aligned to LHDs or PHNs, which maintain extensive directories of health services for consumers within their local region.

Crisis Funding

From time to time there may be a sudden change in the care needs of people with disability, or their carers may be suddenly unavailable, or needing some respite themselves. In these circumstances, planned alternative arrangements may need to be put in place quickly. RACMA Members have advised, unlike the aged care sector, there is currently limited crisis or respite funding available for people with disability.

Transitions

People with disability will make a number of 'transitions' in care during their lifetime. Age related transition issues arise when people with disability have to move from one organisation to another in order to continue receiving services which are structured in age cohorts. Many will experience problems with these transitions, due to the degree of differences between each system with transition policy and procedure.

For many, the first transition will be from hospital to out of hospital care, as they transition to receive care from a DCP identified in their NDIS support plan.

Where disability has been identified in childhood, a transition in care providers will be inevitable as the child moves from a paediatric/adolescent service to an adult health service. Children with disability usually have access to significant support services whilst at school. However, upon leaving school, they will often have little if any, guidance and support available to them at a time they will have to transition to different healthcare providers.

At 16-18 years of age, transitions from school to post-school education options as well as changes in care arrangements can cause distress. These transitions can be fraught, as the level of care coordination and case management can suddenly decline.

²⁸ Victorian Law Reform Commission, 'People with Intellectual Disabilities at Risk: A Legal Framework for Compulsory Care Report', November 2003, viewed February-August, https://www.lawreform.vic.gov.au/wp-content/uploads/2021/07/Report_People_with_intellectual_disabilities_at_risk-1.pdf

A particular example of healthcare service deficiency for people with disability at a point of 'transition' is evident for adolescents and young adults. This is particularly evident for those with intellectual disability, 'graduating' from the usually well-coordinated, multi-disciplinary care common in ambulatory clinics in tertiary paediatric centres, to the adult teaching hospital environment. The latter is characterised by an overwhelming emphasis on acute disease management, or the acute exacerbation of chronic disease, with a huge preponderance of elderly patients, in an institution organised into professional disciplines (e.g., orthopaedics, cardiology, neurology, oncology etc.). This environment is daunting, if not impossible, for any young person with complex ongoing care needs to navigate.

Some younger people may be unaware of the services they can access and how to source information or approach services for assistance. Some may experience a withdrawal of crucial care services due to their age change.

RACMA Members have reported that at these times of transitions (not all cases), there can be inappropriate requests for information from Services Australia and the NDIS, in regard to longstanding medical conditions present since childhood. These include known significant impairment unlikely to change and has persisted despite intensive support.

Applicants may be asked to obtain a new specialist review simply because of a change in age. The reason is that they may not have seen a specialist for many years and lack ready access to a specialist who is familiar with their history and condition. Sometimes applicants cannot readily obtain a specialist appointment in the public system within a suitable time frame. Others cannot obtain a private specialist opinion due to cost constraints.

For many, the completion of complex applications, and the requirement to attend various appointments with limited flexibility, may result in applicants being overwhelmed. They may have limited support to complete the applications or requests for further information. This can result in the applicant electing to discontinue the application, even though their support needs are high. Consequently, they may no longer receive the care and support they need. In some cases, this ultimately leads to poorer health outcomes.

Transition issues also apply to financial security. There are no systems to assist the transition of young people with disability to adult disability support services and/or pensions. In terms of funding support, a young person aged 17, may face particular challenges as they will not qualify for a disability support pension until they turn 18, subsequently leaving them in an administrative 'limbo'.

Applying for the DSP

RACMA notes for the Disability Royal Commission's attention, a major issue with legislation regarding the DSP. Currently, all applicants are placed on the Jobseeker Allowance (formally Newstart) which has no interim DSP allowance that provides income support, without the onerous reporting requirements for those awaiting a DSP Job Capacity Assessment and Government Contracted Doctor (GCD) Disability Medical Assessment (DMA).

There are exemptions for reporting and seeking jobs via the Jobseeker Allowance program. However, the overwhelming feedback is it is still as exceptionally difficult as the previous Newstart program. The big challenge for people with disability is to navigate the onerous process of payment for income support, which is still not sufficient for many people with disability to cover medications and cost of living expenses.

RACMA Members have indicated the program of support can cause a lot of distress for people with disability applicants, who clearly are unable to complete the onerous navigation process. They struggle to acquire the appropriate reports and evidence to demonstrate eligibility. People with disability are being blatantly ignored and refused the DSP (without a GCD DMA). RACMA Members have reported cases where people with disability applicants applying for a DMA were rejected if they were not (RACMA members) part of a review trial.

Applicants must meet the non-medical rules and the 'manifest medical rules',²⁹ and, if they do not meet these rules, then another onerous process must be met, i.e., the general medical rules. This means they must gather further appropriate evidence to support that their medical condition(s) are permanent (i.e., expected to persist for greater than 24 months), are fully diagnosed, are fully treated and are fully stabilised. Not all people with disability and a medical condition can get DSP.

RACMA believes the Jobseeker Allowance program is not suitable for people with disability application(s) as the system does not adhere to access and equity principles, is onerous and difficult to navigate, and requires significant clerical and medical support not normally available to vulnerable cohorts such as people with disability.

Zeke's personal story is referenced as follows:

Zeke's story*

Zeke is in his mid-teens. At a young age, he was noted to have features consistent with Autism Spectrum Disorder. Zeke saw multiple specialists when the formal diagnosis was first made and appropriate referrals for health professional input were made.

Family finances were always 'tight' but Zeke and his family received highly supportive assistance from family and friends. Zeke was able to obtain significant community health and school support throughout his childhood and early teenage years, eventually managing to complete high school with support from his treating GP and his school. Zeke had no intention of applying for undergraduate university or similar education and was considering what career pathways he may be able to pursue.

²⁹ Australian Government Services Australia, 'Medical Rules', in Disability Support Pension, February 2020, viewed February-August 2021, <https://www.servicesaustralia.gov.au/individuals/services/centrelink/disability-support-pension/who-can-get-it/medical-rules>

With the support of his family, Zeke is able to complete most tasks but, when he turned 16, he needed to transition from a highly supportive school-based environment to that of a young adolescent, which included applying for a Disability Support Pension (DSP). Zeke experienced major difficulties in applying, even with the support from his mother and other close family and friends. He struggled to navigate the application process and obtain the required evidence to satisfy the assessors.

Zeke's Mother reported that whilst the diagnosis of Autism Spectrum Disorder had been made by multiple specialists, who had advised Zeke needed long term support, and he had letters of support from his school and treating GP (who was very familiar with Zeke and his history), the family were instructed they would require a new formal report from a child psychiatrist or paediatrician. Unfortunately, due to multiple systems issues, Zeke was unable to afford to obtain a report from a specialist or access same via funded means, which led to the cancellation of the DSP application for failing to provide evidence.

Zeke's Mother reported that eventually through support and goodwill, they were able to obtain the required evidence from a specialist despite multiple reports from other professional practitioners, and they recommenced the DSP Application process again.

Zeke's story highlights the difficulties Applicants face when attempting to access the Disability Support Pension and navigate the systems involved with an application, including understanding requirements, interpreting forms, and obtaining necessary evidence. The story also highlights the implications of limited communication to Applicants, with the use of jargon and non-formal feedback methods that Applicants who may experience physical or intellectual disabilities, may be unable to understand.

*The name has been changed for privacy

Informal carers

According to the Australian Institute of Health and Welfare (AIHW) Informal carers are:

people who provide care to those who need it within the context of an existing relationship, such as a family member, a friend, or a neighbour. The demands of the role often go beyond what would normally be expected of these relationships. People who need help may also receive formal services from government and other organisations. The informal (unpaid) care often complements formal (paid) services.³⁰

The care and support provided by carers who are unpaid (other than through a pension or benefit) play a critical role in the community support for people with disability, but at times their needs may be overlooked.

RACMA has been made aware of situations where family carers may themselves be subject to some form of abuse or aggression from their loved one. There is an issue that informal

³⁰ Australian Government, Australian Institute of Health and Welfare, 'Informal Carers', in Australia's Welfare 2021, September 2021, viewed September 2021, <https://www.aihw.gov.au/reports/australias-welfare/informal-carers>

carers such family members are not able to access training to provide care or manage behaviour, such as “violence de-escalation” training that may be available to paid providers.

‘Recommendation 42’ of the of the Royal Commission into Aged Care Quality and Safety Final Report: Care, Dignity and Respect (Volume 3A), refers to support mechanisms for informal carers and improvements in services and support for informal carers. The recommendation states that from 1 July 2022 support for Informal Carers needs to be:

providing accurate and up-to-date information on My Aged Care about the range of supports locally available to informal carers, including training, education, counselling, respite, income support, and access to the Carers Hub network (once established).³¹

If these recommendations are accepted, then RACMA sees there should be no reason why they are not extended to informal carers in the disability sector.

NDIS & age discrimination

RACMA suggests there are some instances where certain individuals should be provided with services through the NDIS, regardless of their age. Whilst the variety of disability and individual circumstances may present difficulties in developing criteria for NDIS support qualification, **RACMA recommends the current age cut off threshold needs to be reviewed.**

For example, people with disability aged over 65 years do not qualify for NDIS support. This arbitrary age cut-off threshold is a form of age discrimination, such as people with disability being ventilator dependent, who should be provided with services through the NDIS, regardless of their age. Of particular concern to RACMA are ventilator dependent cohorts due to tetraplegia (VDT). Medical colleagues working within spinal units report they are often dealing with different funding models depending on age. Whilst numbers are small, their care is very expensive. If they are injured when they are relatively young and fit, they can live relatively long and productive lives. Home modifications are needed but these are a very small part of the cost of supporting a person with VDT in the community.

Some people who are ventilator dependent due to tetraplegia can live at home supported by carers trained in routine ‘tracheostomy/ventilator’ care, as long as they can call an ambulance if something goes wrong. Of course, where there are cognitive impairment issues as well as significant physical issues, supervision becomes important.

The ongoing personal care and equipment support of this cohort, if fully funded, is approximately \$150K to \$200K, p.a. RACMA has been advised there is no consistency in the mandated care requirements, even for those aged less than 65 years. Consistency would be helpful as those who have adequate care hours can live at home supported by carers. In this regard, care hours may be more than 24 hours daily due to the need for two-people care at times during the day.

³¹ Hon Gaetano (Tony) Pagone QC, Ms Lynelle Briggs AO, Royal Commission into Aged Care Quality and Safety, ‘Final Report: Care, Dignity and Respect, Volume 3A The New System,’ p. 203, 2021, viewed February-August 2021, <https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-volume-3a.pdf>

Martin's personal story is referenced as follows:

Martin's story*

Martin was an active 69-year-old professional when he suffered a high-level spinal cord injury whilst in the surf. Martin was successfully resuscitated and then required a prolonged hospital admission as he was quadriplegic and dependent on a ventilator.

Martin is now dependent on 24-hour personal care for all activities of daily living (ADLs) including self-care and the management of the ventilator. Martin has a permanent impairment that results in substantially reduced functional capacity in all activities. He has reduced capacity for social and economic participation and requires lifelong support.

Because of his age, Martin is not eligible for NDIS support. He was not under the age of 65 at the time of his injury or at the time of requesting access to support from the National Disability Insurance Agency (NDIA).

As per the NDIS, the intention is 'that people over 65 should access the aged care system' and 'if a prospective participant is 65 years of age or older when the access request is made, the NDIA must decide that they do not meet the access criteria'.

Unfortunately, while Martin has not received any NDIS support, it was highlighted during his prolonged hospital admission there were limited aged care providers who were able to manage a ventilator-dependent person. Martin and his wife were told placement in an aged care facility would not be appropriate and would be deleterious. Martin felt he 'was falling between the gaps between NDIS and aged care'. He did, however, initially receive significant support from the Health Department in his state but that has now ceased.

Due to his disability Martin has extremely high care requirements. He has been reliant on crowdfunding to assist with converting his primary place of residence to be suitable for his care requirements. Also, while he was provided with significant medical supplies at the time of discharge from hospital, he now requires replenishment of these costly supplies but has no funding support. Martin has not received any funding or assistance with home and vehicle modifications, nor for the single largest expense, which is 24/7 Care.

Martin's wife reported she was largely unable to navigate the different systems that provide insurance, support, and funding and would spend many hours per week on phone calls attempting to obtain support and information.

Martin and his wife report that he may have been eligible for the planned Traumatic Injury Insurance Scheme. However, as this scheme has not progressed nor entered legislation, there has been no further support available.

Martin and his wife have felt utterly dismayed and, ultimately, unsupported with little suitable options that would not cause harm to him, such as an inappropriate aged care placement, or a seemingly never-ending hospital admission where Martin would be at risk of developing other medical issues or contracting an infection, not to mention the cost to the health system.

Martin feels the NDIS Act and the NDIS have failed at a legislative level and discriminated by omission. This has had major implications for Martin and continues to do so, which may ultimately result in a poor outcome.

- <https://www.ndis.gov.au/about-us/operational-guidelines/access-ndis-operational-guideline/access-ndis-age-requirements>
- <https://www.legislation.gov.au/Details/F2018C00165>

*The name has been changed for privacy.

1.3 Better healthcare for people with disability

- i. Historically (and currently), the disability sector has excluded health needs and health services from the planning for disability needs, as it is considered healthcare and maintenance of wellness is a separate responsibility. There are often health issues associated with disability and feedback from RACMA Members and clinical colleagues, indicate the care planning and coordination available via the NDIS does not extend to comprehensive clinical and healthcare planning or delivery for people with disability. There is no requirement that NDIS plans include a clinical or comprehensive health plan endorsed by the person's regular medical and clinical team as part of their disability support plan. The NDIS, as an insurance provider, has not developed the competencies required to assess and fund those health needs of people with disability, which are not covered through Medicare/ State Health Funds/ Work Cover/Third Party insurance and or private health insurance.
- ii. People with disability with highly complex health needs require assessments to be performed by a multi-disciplinary team that includes medical, nursing, and other allied health professionals. This is a well-established clinical model (e.g., multidisciplinary cancer clinics) which can easily be adapted to the disability services environment. Over-reliance on solo practitioners and reports by non-clinical support workers and planners can contribute to poor health and life outcomes.
- iii. Many DCPs supervise the healthcare of their clients with disability, such as medication management with some clients being on multiple medications. However, in many instances this care is supervised by carers, who may not have sufficient training to monitor the ongoing healthcare status and needs of their clients, which may change over time. This may be a particular problem for clients with mental health and intellectual disabilities and may also be exacerbated if people with disability do not have regular primary medical care, as has been outlined in the Recommendations section. It is noted that 'Recommendation 64' of the Royal Commission into Aged Care Quality and Safety Final Report (Volume 3A) addresses the issue of medication management reviews by recommending a greater role for pharmacists in this area. Accredited pharmacists performing medication management reviews, can look at whether the long-term medicines a person is taking are still necessary or appropriate based on changes to the person's health condition.³² According to the Royal Commission into Aged Care Quality and Safety Final Report, Pharmacists can also look at whether medicines are interacting with other medicines or causing potentially harmful side effects. People receiving aged care need improved and more frequent medication management reviews.³³ Similar recommendations should be considered for the disability sector.
- iv. All people with disability have a right to expect their basic healthcare needs will be addressed in the same way they are for other Australians. Article 25 of the United Nation's Convention on the Rights of Persons with Disabilities, specifies that persons with disabilities have 'the right to the enjoyment of the highest attainable standard of

³² Hon Gaetano (Tony) Pagone QC, Ms Lynelle Briggs AO, Royal Commission into Aged Care Quality and Safety, 'Final Report: Care, Dignity and Respect, Volume 3A The New System,' p. 313, 2021, viewed February-August 2021, <https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-volume-3a.pdf>

³³ Ibid

health without discrimination on the basis of disability'.³⁴ Additionally, Article 25 (b) makes specific reference to the obligation of health professionals to:

*Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons.*³⁵

RACMA Members report the basic healthcare needs of some people with disability are not being met. This neglect is of itself, an 'omission', which we regard as a form of abuse and a health inequality issue that must be addressed. These omissions may include immunisations and vaccinations, screening for bowel, breast and cervical cancers, blood pressure checks, skin checks and routine dental care. In addition, people with disability may have additional healthcare needs by virtue of their disability, and people with intellectual disability may have more difficulty in accessing healthcare, including basic care. While the Commonwealth MBS does include a specific item number for comprehensive care planning for people with intellectual disability, many people with disability do not have a regular health assessment. In particular, those whose disability is due to mental health issues, drug and alcohol problems and chronic pain can, by omission, not receive an initial assessment and consequently may not get the appropriate care they deserve. RACMA offers several recommendations around this issue (refer to Recommendations section).

- v. The long-term healthcare of people with disability involves many institutions, many providers, and potentially many locations of service. Given the lack of case management, and subsequent fragmented care, access to an integrated electronic health record is an essential component of care, particularly if the clinical situation is complicated by communication issues. The infrastructure necessary for an integrated record for each participating people with disability exists in the Commonwealth's My Health Record system. The use of the My Health Record system is optional for health providers and for Australian residents, with a correspondingly low utilisation rate as a tool in healthcare management. It is noted 'Recommendation 68' of the Royal Commission into Aged Care Quality and Safety Final Report calls for the universal adoption by the aged care sector of digital technology and My Health Record. There is a requirement that every approved provider of aged care delivering personal care or clinical care, uses a digital care management system (including an electronic medication management system) meeting a standard set by the Australian Digital Health Agency and interoperable with My Health Record.³⁶

³⁴ United Nations, Department of Economic and Social Affairs, Disability 'Article 25 – Health', in Convention on the Rights of Persons with Disabilities, May 2008, viewed February-August 2021, <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-25-health.html>

³⁵ Ibid

³⁶ Hon Gaetano (Tony) Pagone QC, Ms Lynelle Briggs AO, Royal Commission into Aged Care Quality and Safety, 'Final Report: Care, Dignity and Respect, Final Report Volume 1,' p. 253, 2021, viewed February-August 2021, <https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-recommendations.pdf>

- vi. The UK National Health Service (NHS) National Institute for Health and Care Excellence has identified the life expectancy for people with Severe Mental Illness (SMI) is up to 15–20 years shorter than the general population. This is mainly due to preventable physical health conditions, such as cardio-vascular disease, which are associated with modifiable risk factors. According to the Quality Watch (2014) Cause for Concern annual statement, people with mental ill-health have 3.6 times more potentially preventable emergency admissions than those without mental ill health.³⁷ The reasons for the increased burden of physical ill-health and reduced life expectancy are complex, involving interrelated factors such as wider social factors, health risks, effects of medication and stigma and discrimination. The UK NHS has set the following targets³⁸ to address the health inequalities of people with severe mental illness (SMI):
- By 2020/21, 280,000 more people living with SMI will have their physical health needs met.
 - By 2023/24 an additional 110,000 people per year will have a physical health check (bringing the total to 390,000 checks delivered each year) in line with the NHS Long Term Plan [see 2.30, p41].
 - 10,000 more SMI patients on GP register will receive a blood pressure check if Clinical Commissioning Groups (CCG) achieved rate of five best peers.
 - 15,000 more SMI patients on GP register will receive an alcohol consumption check if CCGs achieved rate of 5 best peers.
 - 60% of people on SMI register will receive physical health check across primary and secondary care.
 - Reduction in number of SMI patients attending secondary care for CVD conditions.

While some similar aggregate/population data is available in Australia, such data is not readily available for people with disability. ‘What one can’t measure one can’t manage’ is an old truism but has substantial basis, not least in the healthcare sector. There should be greater collection and use of clinical and other data to inform service improvements and (clinical and life) outcomes for people with disability.

RACMA recommends similar data should be generated for the health and life outcomes for Australian population living with disability, and health system targets agreed to bridge the expected health inequality gap be included in the relevant funding agreements between the Commonwealth, NDIS and jurisdictional governments.

‘Recommendation 67’ of the Royal Commission into Aged Care Quality and Safety Final Report indicates the Commonwealth Government and state and territory governments should improve the data available to monitor the interaction between the health and aged care systems.³⁹ This then improves health and aged care planning and funding decisions. **RACMA recommends a similar approach be adopted for the disability sector.**

³⁷ Nuffield Trust and The Health Foundation, ‘Cause for Concern, QualityWatch Annual Statement,’ Chapter 3, p. 13-16, 2014, viewed February-August 2021, https://www.nuffieldtrust.org.uk/files/2018-10/1540334840_qualitywatch-annual-statement-2014.pdf

³⁸ NHS Long Term Plan, Mental Health, ‘NHS Mental Health Implementation Plan 2019/20 – 2023/24’, July 2019, viewed February-August 2021, <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/07/nhs-mental-health-implementation-plan-2019-20-2023-24.pdf>

³⁹ Hon Gaetano (Tony) Pagone QC, Ms Lynelle Briggs AO, Royal Commission into Aged Care Quality and Safety, ‘Final Report: Recommendations’, p. 252, 2021, viewed February-August 2021, <https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-recommendations.pdf>

- vii. A paper from the Netherlands (2017) titled *Mainstream health professionals, stigmatising attitudes towards people with intellectual disabilities (ID): a systematic review*, concluded the following:

*equal access to mainstream healthcare services for people with ID still requires attention...recent studies suggest that (while) health professionals (may) hold positive attitudes towards people with ID, stigmatising attitudes may influence their efforts to serve people with ID in community healthcare practice.*⁴⁰

To facilitate inclusion in mainstream healthcare services, the authors⁴¹ recommend:

- to include contact and collaboration with “experts-by-experience” in education programs of health professionals
- future research should progress beyond descriptive accounts of stigma towards exploring relationships between cognitive, affective, and behavioural dimensions as pointers for intervention
- inclusion would benefit from an understanding of ‘equal’ treatment that means reasonable adjustments instead of undifferentiated treatment.

The literature review undertaken by the authors, highlights the issue of ‘diagnostic overshadowing’ and the reports of perceived discrimination and negative comments as a significant experience in general hospitals. Research from a UK focus group study⁴² indicated:

- mainstream health professionals reported stress and a lack of confidence in providing care for people with ID
- health professionals were less confident and more stressed in relation to patients with ID than patients without ID or with physical disabilities⁴³
- sometimes, health professionals were negative because people with ID were seen as a burden on their time and that their cases were complex⁴⁴
- three studies indicated that 30% of psychiatrists and 15% of GPs would personally prefer not to treat people with ID^{45 46}

⁴⁰ H. A. Pelleboer-Gunnink, W. M. W. J. Van Oorsouw, J. Van Weeghel & P. J. C. M. Embregts, ‘Mainstream health professionals’ stigmatising attitudes towards people with intellectual disabilities: a systematic review’, *Journal of Intellectual Disability Research* vol. 61 PART 5, MAY 2017, pp. 411–434

⁴¹ Ibid

⁴² S. M. Gibbs, M. J. Brown, W. J. Muir, ‘The experiences of adults with intellectual disabilities and their carers in general hospitals: a focus group study’, *Journal of Intellectual Disability Research*, Wiley online Library, November 2008, viewed February-August 2021, <https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1365-2788.2008.01057.x>

⁴³ S. Lewis & B.S. Kroese, ‘An Investigation of Nursing Staff Attitudes and Emotional Reactions Towards Patients with Intellectual Disability in a General Hospital Setting’, *Journal of Applied Research in Intellectual Disabilities*, ResearchGate, April 2010, viewed February-August 2021, https://www.researchgate.net/publication/229639871_An_Investigation_of_Nursing_Staff_Attitudes_and_Emotional_Reactions_Towards_Patients_with_Intellectual_Disability_in_a_General_Hospital_Setting

⁴⁴ D.S. Eley, C.R. Cloninger, L. Walters, C. Laurence, R. Synnott, D. Wilkinson, ‘The relationship between resilience and personality traits in doctors: implications for enhancing well-being’, *Peer Journal*, November 2013, viewed February-August 2021, <https://peerj.com/articles/216/>

⁴⁵ N. Lennox, R. Chaplin, ‘The psychiatric care of people with intellectual disabilities: the perceptions of trainee psychiatrists and psychiatric medical officers’, *PubMed*, December 1995, viewed February-August 2021, <https://pubmed.ncbi.nlm.nih.gov/8825826/>

⁴⁶ N.G. Lennox, M.P. Kerr, ‘Primary health care and people with an intellectual disability: the evidence base’, *Journal of Intellectual Disability Research*, Wiley Online Library, February 2007, viewed February-August 2021, <https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1365-2788.1997.tb00723.x>

US research also indicated 'Stigmatising attitudes towards people with ID have received limited research attention'⁴⁷. This recent attention is apparent in stigma reviews concerning members of the general public⁴⁸, medical students⁴⁹ and people with ID themselves⁵⁰. The research into the stigmatising attitudes of mainstream health professionals is also scarce and recommendations are that future research should progress beyond descriptive accounts of stigma of people with disability, especially for intellectual disability. More research is needed which explores relationships between the cognitive, affective and behavioural dimensions of stigmatising attitudes as better understanding in these areas may highlight areas for interventions to reduce stigma. RACMA suggests there is no reason to believe similar attitudes to people with disability do not exist in Australian healthcare practices and institutions.

RACMA Members identify several contributors to this state:

The training of Australian GPs and most other medical specialists is unlikely to have included the broad area of dealing with people with disability. At the medical specialist level, the training for paediatricians includes care for children and adolescents with disability. The Faculty of Rehabilitation Medicine of the Royal Australasian College of Physicians (RACP) specialises in both the rehabilitation and health maintenance of people with a range of disabilities, in particular physical disabilities. Rehabilitation physicians have the skills to manage people with complex disability, however, are often not involved after the initial period of diagnosis, treatment, and rehabilitation. RACMA suggests there is little training in disability specific issues in most other College training programs. Medical and other community-based healthcare practitioners may not be sufficiently trained in the provision of ordinary primary healthcare to people with intellectual and other disabilities as this area is only a small part of general medical undergraduate and vocational training. From time-to-time people with disability will have health problems for which they need to see other medical specialists. In the absence of specialists trained to deal with these, often complex, clinical needs of people with disability, the people with disability or carer / guardian must attempt to navigate the professional boundaries of psychiatry, neurology, psychology, and other specialties in order to access appropriate care. This is an area which deserves more attention in postgraduate medical training programs so that all doctors, not only those trained in Paediatrics or Rehabilitation Medicine, are familiar with treating people with disability.

⁴⁷ N. Ditchman, S. Werner, K. Kosyluk, N. Jones, 'Stigma and Intellectual Disability: Potential Application of Mental Illness Research', PubMed, ResearchGate, May 2013, viewed February-August 2021, https://www.researchgate.net/publication/236956010_Stigma_and_Intellectual_Disability_Potential_Application_of_Mental_Illness_Research

⁴⁸ K. Scior, 'Public awareness, attitudes and beliefs regarding intellectual disability: a systematic review', PubMed National Centre for Biotechnology Information, National Library of Information, July 2011, viewed February-August 2021, <https://pubmed.ncbi.nlm.nih.gov/21798712/>

⁴⁹ T.A. Ryan, K. Scior, 'Medical students' attitudes towards people with intellectual disabilities: A literature review', ResearchGate, October 2014, viewed February-August 2021, https://www.researchgate.net/publication/263281784_Medical_students'_attitudes_towards_people_with_intellectual_disabilities_A_literature_review

⁵⁰ A. Ali, A. Hassiotis, A. Strydom, M. King, 'Self stigma in people with intellectual disabilities and courtesy stigma in family carers: A systematic review', ScienceDirect, Elsevier, Nov-Dec 2012, viewed February-August 2021, <https://www.sciencedirect.com/science/article/abs/pii/S0891422212001618>

- viii. Inadequate training may be compounded by “diagnostic overshadowing” which has been referred to in the Interim Report of the Disability Royal Commission⁵¹. Diagnostic overshadowing is the attribution of a person’s symptoms to an existing (usually psychiatric problem or a developmental disability) when such symptoms actually suggest a comorbid condition. The assumption a patient’s new problem is due to their disability or coexisting mental health condition rather than fully exploring all causes of the symptoms may lead the health professional falsely to attribute all new behaviours, or symptoms to the original diagnosis. Diagnostic overshadowing increases the risk of further health complications and delays in accurate treatment.

Ingrid’s story is referenced as follows:

Ingrid’s Story*

Ingrid was a 29-year-old Aboriginal woman with a profound Intellectual Developmental Disorder, who lived in a group home. Over three shifts of staff, her occasionally disruptive, ‘calling-out’ and head-banging behaviour became intense. Locum staff members noted her behaviour but were reassured by the local GP’s assessment that she may have had a urinary tract infection and the staff had given her medication.

When a regular staff member came on duty, she identified these outbursts as different to Ingrid’s usual behaviour, and, interpreting it as possible pain, she arranged for her to be taken to an Emergency Department. At the Emergency Department, the paramedics waited in the triage bay for two hours, before her transfer to hospital staff care in the resuscitation bay. During this time a triage nurse assessment noted a ‘rock-hard’ abdomen, along with intermittent periods of calm and agitation. Ingrid ‘crashed’ in the resuscitation bay and despite resuscitating actions, she died a couple of hours later. The Coroner identified peritonitis from a ruptured bowel as the cause of death.

The Coroner was critical of the systems of care in the group home and the Emergency Department, and of the biases apparently expressed by clinicians at all stages of care. Several clinicians were referred to their professional boards for assessment of their professional conduct.

The frequency of events such as those quoted above is declining, as responsibility for provision of services for people with disabilities has been relinquished by the states to the Commonwealth and rolled into the NDIS. However, they still exist, and many believe the funding has been diluted, as has the accountability.

* The name has been changed for privacy.

⁵¹ Hon R. Sackville AO QC, Hon. R. G. Atkinson AO, Dr R. L. Galbally AC, Mr A. J. McEwin AM, Ms B. Bennett PSM, Ms A. J. Mason OAM, Hon J. F. Ryan AM, ‘Interim Report of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability’, pp. 26, 271-272, 281, 285, October 2020, viewed February-August 2021, <https://disability.royalcommission.gov.au/system/files/2020-10/Interim%20Report.pdf>

'Recommendation 82' of the Royal Commission into Aged Care Quality and Safety Final Report⁵², addresses the issue of health professions' undergraduate curricula, recommending that the relevant accreditation authorities need to consider any changes to the knowledge, skills, and professional attributes of health professionals to meet the care needs of older people.

Furthermore, Recommendation 83 states the Commonwealth Government should fund teaching aged care programs for delivery to students in both residential aged care and home care settings⁵³. These programs, as per the recommendation, should have designated catchment areas which:

- collaborate with educational institutions and research entities
- facilitate clinical placements for university and vocational education and training sector students
- act as a centre of research and training for aged care in a catchment area
- act as a hub for approved providers in a particular region.

RACMA recommends this should also apply to the disability sector with tertiary specialist healthcare 'hubs' provided in each jurisdiction as a focus for referrals of people with disability with complex care needs, clinical workforce training and research.

In most Australian teaching hospitals secondary and tertiary healthcare services for people with disability, other than those associated with spinal cord and brain injuries, do not provide a multidisciplinary outpatient clinic assessment for very high complexity needs and where GPs can refer their patients with complex needs. A multidisciplinary approach is common in care planning and delivery in many other clinical situations, such as cancer care and palliative care.

- ix. While receiving health treatment, especially in hospital care, people with disability may receive treatment which does not include reasonable adjustments that need to be made for their specific circumstance. Changes are needed in the design of healthcare systems to meet the needs of people with disability, and the healthcare system needs to adapt and improve to ensure people with disability always receive the care they need. Such improvements would ensure, for example:
- there are procedures in place to ensure accurate, timely and clear instruction/communication upon discharge from hospital or if transferring to a step-down facility/another location
 - people with disability receive the in hospital care appropriate to their needs
 - improved clinical training of all healthcare workers in dealing with people with disability
 - hospitals have in place mechanisms to ensure that those persons, such as family members who represent themselves as having the power to make decisions on behalf of the people with disability have the legal power to do so

⁵² Hon Gaetano (Tony) Pagone QC, Ms Lynelle Briggs AO, Royal Commission into Aged Care Quality and Safety, 'Final Report: Recommendations,' p. 262, 2021, viewed February-August 2021, <https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-recommendations.pdf>

⁵³ Ibid, p.262

- engagement with people with disability and their advocates and supporters in the governance of healthcare providers.

One of eight mandatory ACSQHC standards for healthcare providers, which includes hospitals, day centres and special purpose health providers, is 'Partnering with Consumers' to improve governance of programs. This standard requires facilities partner with and engage consumers in the design and function of health services, as well as the assessment and improvement of health consumer outcomes, and the education of health workforce.⁵⁴

Furthermore, the standard requires organisational policies and procedures be in place to cover:

- healthcare rights
- informed consent, including financial consent
- shared decision making and planning care
- health literacy and effective communication with patients, carers, families, and consumers
- partnering with consumers in governance.

Whilst commendable, the standard does not require or relate specifically to consumers with disabilities. As a means to improve the complex inter-relationships between the healthcare system, disability service providers and people with disability, **RACMA recommends the National Standards be amended to specifically require engagement with people with disability.**

A concept for consideration is the use of 'Experts by Experience', as people who have recent personal experience (within the last five years) of using themselves or caring for someone who identifies as a person with disability and uses health, mental health, or disability care services.

⁵⁴ Australian Commission on Safety and Quality in Healthcare, 'National Safety and Quality Health Service Standards Second edition', pp. 14-19, November 2017, viewed February-August 2021, <https://www.safetyandquality.gov.au/sites/default/files/migrated/National-Safety-and-Quality-Health-Service-Standards-second-edition.pdf>

Amelia and Jenny's personal stories are referenced as follows:

Amelia's Story*

Shortly after her birth in 2000, Amelia was diagnosed with Down syndrome. She attended mainstream schools and has grown into a delightful young lady demonstrating a cheekiness and independence. She had no major health conditions or heart problems but is overweight as are other family members.

When she was 19 years old, Amelia had a stroke. But the diagnosis was initially missed. Having returned from a music concert, she said she was tired and worn out and would go to bed early. She went to school the next day but clearly wasn't feeling well.

Her father, who is a medical practitioner, and her mother became concerned, but it wasn't until a few days later they noticed she had a droopy right face. Her doctor father initially thought she had a nerve condition, called Bell's palsy. So, Amelia went to see her regular GP, who agreed with that diagnosis and prescribed oral steroid medication.

However, over subsequent days it became clear she may have had a stroke. So, Amelia was taken to the nearest large teaching hospital, where her father had previously worked. Initially, Amelia and her family found the hospital staff to be very helpful and she was quickly seen. Further examination concluded a stroke was more likely than Bell's palsy.

Then came the next hurdle.

Amelia is generally good with medical staff, but she is pretty needle phobic. Amelia needed an MRI scan, which her parents were concerned about, believing she would need sedation to have the test done. After quite a bit of 'discussion' it was agreed she would be given sedation, but this only partially worked, and the MRI was of a poor quality.

It became clear that, in order to do the appropriate investigations, Amelia would need a general anaesthetic (GA). For any major procedure, adult hospitals are generally not set up for this possibility. In contrast, at paediatric hospitals using a GA for investigations is 'par for the course'. With adults, the expectation is they will just cooperate when investigations need to be done. At 19 years of age, Amelia could no longer attend a paediatric hospital and was classified as an adult.

It took five days for an MRI to be done under general anaesthesia and another week before an echocardiogram could be done under general anaesthesia. During her stay in hospital, Amelia required an intravenous drip (IV) and a nasogastric tube, both of which bothered her. Her mother stayed with her the whole time to support her and cajole her to put up with her care.

Apart from her facial droop, Amelia lost a significant amount of speech. About day seven she regained a significant amount of her speech and hasn't really looked back since. She spent about two weeks in hospital and having found no real cause for her stroke, went home on a combination of aspirin and cholesterol lowering drugs.

Amelia's Story* continued

Her father reports that, while all the medical and nursing staff were incredibly attentive and cooperative to her care, it became clear a major teaching hospital is not set up to deal with the anxieties and difficulties of people with disabilities. There were considerable delays in investigations, largely because the idea somebody would need a general anaesthetic for investigations was not the normal routine of the hospital. Given her father knew most of the senior medical staff, it still took several days to get the appropriate investigations undertaken.

On reflection, Amelia's doctor father wondered how much his knowledge of the hospital and its systems, and his friendship with many of the medical and nursing staff, resulted in the management of Amelia's stroke going as reasonably smoothly as it did. He wondered how other 'Amelias' might fair whose parents did not have these advantages.

*The name has been changed for privacy

Jenny's Story*

'Anaesthetics for everyone'

John is the long-standing Director of Anaesthetics in a large regional hospital.

He has a niece who has severe autism and, as such, is aware of the difficulties some disabled people experience when they interact with the health system.

Over his career, John has tried to provide a tailored anaesthetic service for those individuals who have special needs. While he accepts standardising the model of care has led to greater efficiency and has improved throughput of hospitals, he also acknowledges the system has become less tolerant to variation. As the Director of Anaesthetics, he has been able to 'bend' the system to suit the individual.

Jenny is 32 years old and has severe autism.

She was booked in for a gastroscopy that had been delayed several times due to Jenny's significant distress when she came close to the hospital. The previous response of the hospital management had been that she was the problem, and they offered a standard service of gastroscopy so, if she could not cope, then they were not in a position to provide the service to her.

John decided to change the circumstances of her treatment. First, he decided he would have to go outside the hospital to appropriately sedate Jenny prior to her being transported to the hospital.

He also consulted with the Jenny's GP to work out if there are any other issues which needed to be resolved while she was anaesthetised and having her gastroscopy. It was agreed that, during the anaesthesia Jenny would have a routine Pap smear and breast examination, and blood would be collected as Jenny had not had any blood tests for many years.

He rearranged the roster, so he was the anaesthetist on for the gastroscopy list and then spoke to Jenny's mother and organised to put Jenny first on the list. So, he could meet Jenny, he had arranged about an hour with the family for afternoon tea.

On the morning of the procedure, he arranged to drive to their house to give Jenny pre-anaesthetic sedation before she was transferred to the hospital. As he had previously made contact with Jenny, he was not a complete stranger. John administered some anti-emetic and sedating medication in cooperation with her mother. Jenny's mother drove her to the hospital and John sat in the back seat with her so he could keep an eye on her vital signs.

Once they got to the hospital, Jenny was transferred to a trolley. She was first on the list and all proceeded without any incidents, including the Pap smear, breast examination and the routine blood collection.

Jenny awoke about an hour later in the recovery bay at the day surgical centre with her mother sitting next to her. John was available just in case she became distressed. She left hospital about an hour later, a little ahead of time, but still while her sedation was having some effect. She was home before she was fully awake. John went to check on her and was satisfied she had made a full recovery from her anaesthetic.

Jenny's mum was immensely grateful as her previous experience with Jenny and hospitals had been distressing for all.

This story shows that by adapting the hospital system to the benefit of a somewhat unusual but not unique patient, treatment can proceed smoothly.

In discussion with John, he's not sure how he came to be a provider of a unique anaesthetic service for people with complex needs but his experience of people with disabilities clearly helped. He also thought the fact he was the 'boss' helped - when he wanted to rearrange the morning list to suit Jenny's needs, nobody argued back.

Unfortunately, in many hospitals the conversation often stops at the point when the disabled person can't fit into standard process and the patient is denied access to service.

Standardisation and routine service delivery has enormous benefits, but it must be remembered that when the patient doesn't fit the system, the system should adapt to fit the patient.

*The name has been changed for privacy

SECTION 2

Regional Australia and disability services

- i. Service provision for specific groups also raises questions about the degree to which people with disability experience neglect due to the absence of services for them. In this regard RACMA highlights the significant difficulty people with disability who live in regional Australia may face in obtaining support.
- ii. The RAI, which was founded in 2012 with seed funding from the Commonwealth Government, is a think tank devoted to issues concerning regional Australia. The RAI defines regional Australia as being, ‘the towns, small cities and areas that lie beyond the major capital cities (Sydney, Melbourne, Brisbane, Perth, Adelaide and Canberra)’⁵⁵. In 2019, the RAI published a report *Building the NDIS in regional Australia: a review of key policy approaches*.⁵⁶ This report stated the NDIS posed a unique set of challenges for those living in regional and remote Australia. Geographical remoteness may inhibit the intended goals of consumer choice and business growth.

In places that are rural or remote, service offerings may be scarce, particularly for people with complex and long-term needs. The inflation of prices, as providers struggle to build viable businesses in areas with fewer and more disperse clients, create challenges. Many places in regional Australia are at the forefront of service delivery gaps, as disability service providers in regional Australia face difficulties building a profitable business for various reasons including higher overheads, the costs of sales, lower EBIT's⁵⁷ and a smaller pool of clients. As a result, many people with disability in regional Australia may face higher costs for health and disability services and significantly reduced choice under managed plans, than those in metropolitan cities.

- iii. The RAI has identified a key issue is whether the control of NDIS services in regional Australia should occur in the same way as it occurs in metropolitan areas (i.e., by pricing, funding and regulatory mechanisms) or through other mechanisms, such as ‘place-based and flexible community approaches’.

⁵⁵ Regional Australia Institute, ‘What is Regional Australia?’, 2017, viewed February-August 2021, <http://www.regionalaustralia.org.au/home/what-is-regional-australia/>

⁵⁶ Regional Australia Institute, ‘*Building the NDIS in regional Australia: a review of key policy approaches*’, P. 2, 2019, viewed February-August 2021, http://www.regionalaustralia.org.au/home/wp-content/uploads/2019/11/RAI_SIP-2019-2-1-1_Building_the_NDIS_in_Regional_Australia.pdf

⁵⁷ C. B. Murphy, ‘Earnings Before Interest and Taxes (EBIT)’, Investopedia, May 2021, viewed February-August 2021, <https://www.investopedia.com/terms/e/ebit.asp>

RAI have also recommended changes to the way that the NDIS is rolled out in regional Australia. This includes alternatives to 'fee-for service' delivery models, such as:

- grants and seed funding
- allowing providers to charge a fee to travel for up to 45 minutes for providing health services in rural areas
- introducing quotations for the delivery of services in isolated regions
- the re-introduction of block funding in some rural areas
- facilitating a collaborative approach to skills development and shared workforces.

The challenge of balancing facilitating business profitability and growth, whilst ensuring affordability and access in regional areas is well known. Hence, some degree of government intervention is required in regional areas, such as the continued use of block funding or hybrid funding.

The 2019 RAI report identified six policy tools to address the issues:

1. Improving financial settings
2. Continued block and hybrid funding
3. Building the NDIS workforce
4. Connecting with communities
5. Innovative and collaborative service provision
6. Improving technology and data

iv. Whilst not listing specific recommendations in their report, the RAI has suggested that some of the options for change include:

- adjusting pricing to reflect the cost of doing business in a "thin" market (i.e., where there is a gap between the needs of the participants and the services that are available)
- considering the development of a variety of support occupations working under the direction of a qualified health professional, such as Allied Health assistants, who can provide routine elements of care in places that lack a consistent professional presence, as well as generalist supporting roles
- employing family and friends who are familiar with the participants to provide care
- building personalised and localised approaches to care by linking service providers, community leaders, and people with disabilities and their families to understand needs, gaps, and opportunities.
- pooling facilities, funds or establishing cooperative models of service delivery
- increasing the sharing of data between government agencies and the NDIS to help improve service provision
- using technology and data to adequately plan for the services that will be needed in an area in order to establish appropriate training pathways. Recruit for the appropriate workforce, to improve the awareness of participants about the NDIS and the opportunities available in their area and to find new ways to bridge distances.

- v. Quite a number of RACMA Members work in regional Australia. Their feedback supports the approach taken by the RAI report. **Based on this feedback, RACMA supports the approaches recommended by the RAI.**
- vi. RACMA Members working in regional Australia confirm there is a lack of disability services for regional communities (non-metro locations) with many communities not having any systems that support people with disability. The issues highlighted by these RACMA Members include the lack of a trained disability workforce for many areas, such as fewer allied health and other services. In many regional areas there is a greater reliance on others for care, with a requirement to upskill health professionals such as, the local GP, nurses, and family members. Additionally, there are large gaps in many areas where there are no people to coordinate, refer, and/or deliver specific disability services. RACMA Members report particular issues with respect to the lack of speech pathology services in regional Australia, as being an example. The lack of services, combined with high transport costs to a metropolitan centre and accommodation (whilst away), can result in a person with disability going without a service readily available to metropolitan locations.
- vii. RACMA Members suggest while telehealth can be of great assistance, there are numerous situations where a face-to-face assessment is needed. In those instances, an increase in the number and range of outreach clinics (from metropolitan centres) especially from an MDT, would have many benefits. Outreach clinics provide valuable services locally, as well as providing an accessible network for local practitioners to contact when requiring advice or needing to ‘talk over’ a clinical problem. These clinics mean in some instances treatment could be provided locally, thus reducing the need for some people to travel and assist in the upskilling and support of local professionals, such as GPs, general medical workers and emergency medicine specialists and nurses. RACMA Members report expectations by professionals and the local community in relation to services that are locally available in regional Australia are realistic.

‘Recommendation 58’ of the Royal Commission into Aged Care Quality and Safety Final Report, states access to specialists and other health practitioners, is greatly improved through Multidisciplinary Outreach Services.⁵⁸ These could be funded through an amendment of the National Health Reform Agreement, so all people receiving residential or personal care (at home) have access to healthcare based on a clinical need. Outreach services would involve multidisciplinary teams of nurses, allied health practitioners and pharmacists, and include other relevant core specialists. We recommend access to 24-hour-a-day, on-call services, with skills transfer for local staff.

RACMA recommends a similar set of recommendations should apply to the disability sector.

⁵⁸ Hon Gaetano (Tony) Pagone QC, Ms Lynelle Briggs AO, Royal Commission into Aged Care Quality and Safety, ‘Final Report: Recommendations,’ p. 248, 2021, viewed February-August 2021, <https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-recommendations.pdf>

- viii. Interface issues between health and disability services in regional areas may result in people with disability being overrepresented in regional health settings, resulting in significant resources of acute health facilities needing to be directed to the management of people with disability. RACMA Members report, in the absence of local disability coordinators and others, the hospital medical administrator (or Director of Medical Services) is often the person to who becomes responsible for sorting out what disability services are needed and what is available. They report many of these situations, present very complex cross sectoral challenges, as they try to develop a program of disability support.
- ix. Poor communication between metropolitan and regional hospitals can result in a people with disability with significant support needs, such as tracheostomy care or ventilator support, arriving home without the necessary supports being in place.
- x. Some causes of disability are more frequently seen in regional areas, such as road trauma leading to disability especially where seatbelts are not worn, and drug and alcohol use. Further research is needed to assess whether the causes of disability are the same in metropolitan and regional Australia, as well as mitigating the incidence of disability in regional areas. For example, with respect to road trauma and major impacts, such as brain injury, RACMA Members report a combination of varying rules (e.g., seatbelts are not mandatory when on a rural property) and a lower police presence may result in a higher incidence of disability resulting from road trauma.
- xi. A lack of reporting in regional Australia, may adversely impact on the ability to collect accurate data on which to base policy decisions. Reports from RACMA Members indicate in some small communities, some forms of reporting may not occur with issues such as domestic violence by professionals. This is because there are concerns about the lack of 'confidentiality' within in a small community. There are issues with the 'six degrees of separation' syndrome, i.e., where everyone in a small town is connected by just a few intermediaries.
- xii. Transport issues are also a problem in some regional areas with some RACMA Members reporting health workers have at times, themselves, transported locally those with disability. Other transport issues include when a person with disability requires an assessment by another medical specialist or allied health professional not available locally and requires a transfer to a metropolitan centre. The issue that funding is only available for such a transfer through the jurisdictionally based hospital transfer scheme. However, RACMA Members report these funds are limited and a people with disability may not be allocated as being a high priority, for example a patient with a newly diagnosed cancer. In the absence of local allied health professionals and certain disability specialists, separate funding for such transfers would mitigate issues of violence, abuse, neglect, and exploitation. This is a particular issue when the assessment is needed to determine eligibility for NDIS support as people are trapped within the interface between the health and disability systems when in a 'pre' NDIS phase.

Other barriers with a jurisdictionally based transport funding scheme are rules which allow only one escort (unless more are needed) on medical grounds. On occasions,

more than one escort may be needed for a people with disability which are not classified on medical grounds. The cost of transport and accommodation may also be a major issue when intermittent crises arise that require specialist MDT assessment or treatment in a metropolitan centre.

xiii. Infrastructure in many rural and regional areas are inferior to metropolitan areas.

Examples include:

- the lack of safe rooms for people with behavioural issues
- facilities to care for those with severe brain injury
- buildings with adequate safety features
- mental health facilities and nursing homes that will not admit elderly people with disability. In many instances such absences result in extended hospital stays.

We note that the Royal Commission into Aged Care Quality and Safety Final Report (volume 3) recommends the NDIS provide an annual “Specialist Disability Accommodation National Plan”, which outlines priority locations and proposed responses to thin or underdeveloped markets.⁵⁹

Sam’s personal story is referenced as follows:

Sam’s Story*

Sam lives in regional Australia. He has a diagnosis of chronic schizophrenia which, on the whole, is quite stable. But from time to time he experiences acute ‘flare ups’, which may require hospitalisation. In a recent such episode, the only mental health bed available to admit him was 400kms away, which was a one-way trip only via ambulance. But after discharge from hospital, he had no means to return home. While his medical treatment was satisfactory, the social issues of distance and transport caused him further distress as their handling was inappropriate.

* The name has been changes for privacy

xiv. Social context issues in regional Australia are more difficult to address. RACMA Members report this is a particular issue where people with disability prefer to remain living with family and in their community. When community populations are very small (e.g., 30 people and less) in remote and isolated areas, the provision of disability support in such circumstances presents significant challenges. Other examples are when people with complex disability needs, have been referred to a metropolitan specialist hospital, because their assessment determines the need for ongoing disability support. This issue arises when the metropolitan hospital is located at a great distance from a people with disability’s home, requiring that decisions must be made by distance and separation.

⁵⁹ Hon Gaetano (Tony) Pagone QC, Ms Lynelle Briggs AO, Royal Commission into Aged Care Quality and Safety, 'Final Report: Recommendations,' p. 256, 2021, viewed February-August 2021, <https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-recommendations.pdf>

SECTION 3

First Nations people with disability

There are particular issues for First Nations people with disability, which are not experienced by other cultural cohorts. Accordingly, when taking differences in the age structure of the Indigenous and non-Indigenous Australian populations into account, First Nations people, will access disability support services at a greater rate than non-Indigenous Australians⁶⁰.

Compared with non-indigenous Australians, First Nations people are:

- 2.0 times as likely to use disability support services under the NDA (2017-18)
- 1.8 times as likely to have a disability.

Glasson et al. in their Western Australian study⁶¹ found although First Nations people comprise 3.5 per cent of the population, they represented 7.4 % of all people registered with intellectual disability. Analysis of rates of childhood intellectual disability in WA⁶² indicates a significantly greater prevalence rate of 2.3 % for mild to moderate intellectual disability in children of Aboriginal mothers.

With many of Australia's First Nations people, living in rural and remote communities (non-metropolitan locations) RACMA Members as far North of Queensland and parts of Western Australia have reported Intellectual disability was most evident. This included early onset dementia. The issue being for these people with disability was lack of support, resources, and infrastructure available.

As well as the death of DCPs in remote parts of the country, RACMA Members also highlight the need to identify service providers who both understand and have the capacity to work in the area of disability, as well as an ability to engage with local First Nations communities and skills necessary to work with this group of clients.

A survey of First Nations people over 45 years of age in the Kimberley region, using the Kimberley Indigenous Cognitive Assessment (KICA) tool,⁶³ found a prevalence of 27% of participants over 65 years of age affected by dementia was five times higher than the overall Australian population after standardisation⁶⁴.

RACMA Members also report this population has high rates of comorbidities which further complicate required care and outcomes. This accords with generally higher risk factors recognised for dementia present in the First Nations people populations, such as higher rates of tobacco smoking, physical inactivity, and alcohol misuse, as well as poor diet and diseases such as coronary heart disease, stroke, and Type II Diabetes⁶⁵.

⁶⁰ E.J. Glasson, S.G. Sullivan, R. Hussain, & A.H. Bittles, 'An assessment of intellectual disability among Aboriginal Australians', *Journal of Intellectual Disability Research*, vol. 49(8), 2005 , pp. 626-634.

⁶¹ Ibid

⁶² H. Leonard, B. Petterson, C. Bower, R. Sanders, 'Prevalence of intellectual disability in Western Australia', *Paediatric Perinat Epidemiol*, vol. 17(1), 2003, pp. 58-67

⁶³ Kimberley Aboriginal Medical Services, 'Kimberley Indigenous Cognitive Assessment', 2004, viewed February-August 2021, <http://kams.org.au/wp-content/uploads/2015/04/KICA-Tool-2006.pdf>

⁶⁴ Ibid

⁶⁵ Australian Indigenous HealthInfoNet, 'Overview of Aboriginal and Torres Strait Islander health status 2019', 2020, viewed February-August 2021, <https://nacchocommunique.files.wordpress.com/2020/02/overviewofaboriginalandtorresstraitislanderhealthstatus2019.pdf>

Diabetes as a cause for dementia is of particular concern, with the rate of diabetes within the First Nations people community being three times the rate of the general Australian population. These risks appear to have a particular cumulative quality that may in part explain the significant excess in dementia in First Nations people populations.

Data from the Australian Bureau of Statistics (ABS) *2015 Survey of Disability, Ageing and Carers (SDAC)*⁶⁶ report among First Nations people living in private households (not those living in cared accommodation such as residential aged care):

- 24% (125,000 people) were living with disability
- 7.3% (38,100) had severe or profound disability, meaning they sometimes or always needed help with daily activities related to self-care, mobility, or communication (ABS 2017).

Recent estimates are also available from two other ABS data sources – the *2014–15 National Aboriginal and Torres Strait Islander Social Survey (NATSISS)* and the *2016 ABS Census of Population and Housing*.

Whilst each collection has different purposes and methodologies for capturing information about disability, their estimates of severe or profound disability among First Nations people are broadly similar. For example, among First Nations people aged 15 and over living in non-remote areas, the rate of severe or profound disability was 7.2% according to the SDAC, 7.8% according to the NATSISS, and 8.5% according to the Census (ABS 2019)⁶⁷.

Based on the SDAC in 2015:

- disability rates for Indigenous males and females were similar (23% and 25%, respectively)
- First Nations people aged 55 and over had a higher rate of disability than those in younger age groups. More than half (58%) of First Nations people aged 55 and over were living with some form of disability and 18% had severe or profound disability.

RACMA is aware of this data and has given considerable thought to whether, as an organisation, it is in a position to make any reasonable recommendations that might assist in ameliorating the current situation apart from highlighting that the disparity in rates of disability is another example of longstanding system failure the very existence of which a form of abuse.

When considering issues in relation to First Nations people, RACMA is guided by two key principles:

1. The fundamental basis of these health and disability statistics must be traced back to the effects of 'colonisation'⁶⁸ more than 200 years ago and the systemic discrimination and

⁶⁶ Australian Bureau of Statistics, 'Disability, Ageing and Carers, Australia: Summary of Findings', October 2019, viewed February-August 2021, <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release>

⁶⁷ Australian Government, Australian Institute of Welfare, 'Disability support for Indigenous Australians', September 2021, viewed February-August 2021, <https://www.aihw.gov.au/reports/australias-welfare/disability-support-for-indigenous-australians>

⁶⁸ Australians Together, 'Colonisation', August 2021, viewed February-August 2021, <https://australianstogether.org.au/discover/australian-history/colonisation/>

racism First Nations people experienced. There have been recorded incidents of forced relocation away from traditional lands, the trauma of the 'Stolen Generation'⁶⁹ and the loss of cultural identity, language, and way of life for many groups. In 2015, 15% of First Nations people with disability living in households, reported experiencing discrimination due to their disability, and 38% had avoided situations due to their disability in the previous 12 months⁷⁰.

RACMA believes the impact of 'colonisation' is a factor in the higher rates of alcohol consumption for all age groups of First Nations people, and volatile substance misuse, e.g., chroming. The estimated financial cost in Central Australia prior to the introduction of 'Opal' fuel⁷¹ (Opal fuel is a low-aromatic unleaded fuel which doesn't contain the properties that create a high when sniffed), was \$78.9 million per year. This was five times the rate of cannabis and amphetamine misuse, exacerbating the risk of brain injury. There is substantial medical research which demonstrates chronic misuse of amphetamines may lead to substantive changes in brain chemistry, particularly dopamine and glutamate, that may make the abuser vulnerable to psychosis.⁷²

2. 'Nothing about me without me' is a saying credited to Valerie Billingham at the Salzburg Global Seminar in 1998,⁷³ capturing the vision that medicine must always consciously respect human dignity. This statement has been taken up by healthcare systems as a way of emphasising patients should be engaged in their healthcare, including through shared decision-making. Hence, 'person-centred care'⁷⁴ is now a key component of healthcare and the needs, goals, and preferences of individual recipients of healthcare (the 'whole person') should guide the care that is given.⁷⁵

A key to person-centred care is understanding what matters most to individual recipients of healthcare. This change in focus has expanded the assessment of quality beyond diagnosis, treatment, and management of a patient's disease to also include a need to understand the broader needs of the patient. As well as being taken up in healthcare the term has also been used in disability activism and identity politics movements.

While it is important all people with disability are involved in determining what services and care they need, against this background RACMA believes it is most important that First Nations people with disability are consulted and determine what needs to be done to address the disability burden they carry. But beyond this RACMA believes the burden of the effects of colonisation must be addressed if we are to make meaningful progress in addressing the health and disability suffered by our First Nations people.

⁶⁹ Healing Foundation, 'Intergenerational Trauma', 2021, viewed February-August 2021, <https://healingfoundation.org.au/app/uploads/2019/12/Working-with-Stolen-Generations-GP-fact-sheet.pdf>

⁷⁰ Ibid

⁷¹ bp Australia, Opal Fuel, 'bp's Opal story', 2021, viewed February-August 2021, https://www.bp.com/en_au/australia/home/products-services/fuels/opal-fuel.html

⁷² Science Direct, 'amphetamines', collection of research abstracts 2005-2018, viewed February-August 2021, <https://www.sciencedirect.com/topics/neuroscience/amphetamines>

⁷³ Salzburg Global Seminar, 'Through the Patient's Eyes: Collaboration between Patients and Health Care Professionals', 1998, viewed February-August 2021, <https://www.salzburgglobal.org/multi-year-series/general/pageId/6381>

⁷⁴ Australian Commission on Safety and Quality in Healthcare, Our Work, 'Person-centred care', 2019, viewed February-August 2021, <https://www.safetyandquality.gov.au/our-work/partnering-consumers/person-centred-care>

⁷⁵ Ibid

It is not clear to RACMA whether available data presents a clear picture of the causes and burden of disability impacting the First Nations people, and to this end **RACMA highlights further work is required to ensure there is complete understanding of both the burden of disability and the causes.** For example, with respect to intellectual disability it is known that as well as an initial higher risk factor for intellectual disability in childhood (e.g., from Foetal Alcohol Syndrome; poor or minimal prenatal care and neonatal screening; infection) and early adult life, Aboriginal and Torres Strait Islander people appear to be more at risk from other factors related to intellectual disability across the lifespan.

Disability can affect participation in education and in the labour force. In 2015, among First Nations people living in households:⁷⁶

- 46% of those aged 15 and over with disability had Year 10 or below as their highest level of education (compared with 36% without disability). This was an improvement from 2012 when 60% of First Nations people with disability in this age group had Year 10 or below as their highest level of education.
- 33% of those aged 15–64 with disability were employed, compared with 65% without disability (ABS 2017).

Regrettably, many First Nations people live in poverty⁷⁷ and often cannot afford to care for more needy of their group as the added expense entailed in caring for a person with a disability can disadvantage other members of the family. People with disability can be very vulnerable to exploitation in environments where alcohol misuse and family breakdown have occurred. The burden of grief and stress carried in many communities can lead to inconsistencies in care. Family allegiances can make accessing services difficult, and many people are disadvantaged by not knowing how to care and what services are available.

First Nations people with cognitive impairment are overrepresented in the criminal justice settings across Australia⁷⁸. This group (compared to the general population) is more likely to come to the attention of police, more likely to be charged, more likely to be remanded in custody, and more likely to be sentenced and imprisoned. They spend longer in custody than people without cognitive impairment, have far fewer opportunities in terms of program pathways when incarcerated and are less likely to be granted parole.

They also have substantially fewer program and treatment options, including drug and alcohol support, both in prison, and in the community when released, than their non-disabled and non-Indigenous counterparts. RACMA suggests in some circumstances, the

⁷⁶ Australian Bureau of Statistics Disability, Ageing and Carers, Australia: Summary of Findings, 2015, 'aboriginal and Torres Strait Islander People with Disability', 2015, viewed February-August 2021, <https://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4430.0Main+Features802015?OpenDocument>

⁷⁷ Australian Council of Social Service and the University of New South Wales, 'Poverty in Australia 2018', p. 65, 2018, viewed February-August 2021, https://www.acoss.org.au/wp-content/uploads/2018/10/ACOSS_Poverty-in-Australia-Report_Web-Final.pdf

⁷⁸ S.M. Shepherd, 'Aboriginal prisoners with cognitive impairment: Is this the highest risk group?', Informit, October 2017, viewed February-August 2021, <https://search.informit.org/doi/abs/10.3316/ielapa.220961164186456>

placing of people with disability in an inappropriate location (e.g., jail) may be a form of 'restrictive' practice and as such, is a form of abuse. In addition, the negative environment of incarceration may have adverse consequences on the health and wellbeing of a people with disability, including on their subsequent rehabilitation, notwithstanding the support that may be available through the prison medical services.

In July 2020, for the first time, a National Agreement "Closing the Gap"⁷⁹ was developed in genuine partnership between Australian governments and the Coalition of Aboriginal and Torres Strait Islander Peak Organisations (the Coalition of Peaks).

'Recommendation 47' of the Royal Commission into Aged Care Quality and Safety Final Report states⁸⁰ the new aged care system makes specific and adequate provision for the diverse and changing needs of First Nations people.

RACMA recommends contextualising this standard to disability services for First Nations people.

⁷⁹ Closing the Gap in Partnerships, 'National Agreement on Closing the Gap', July 2020, viewed February-August 2021, <https://www.closingthegap.gov.au/national-agreement>

⁸⁰ Hon Gaetano (Tony) Pagone QC, Ms Lynelle Briggs AO, Royal Commission into Aged Care Quality and Safety, 'Final Report: Care, Dignity and Respect, Volume 3A, the new system', p. 246, 2021, viewed February-August 2021, <https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-volume-3a.pdf>

SECTION 4

Prevention of disability and deterioration of existing disability

- i. The mitigation of the burden of disability in our society, must go beyond the antenatal detection of genetic abnormalities. While RACMA is not exploring the ethical issues associated with antenatal diagnosis of disability, it is important parents are fully informed and supported through antenatal counselling and provided with all the options available to them regarding pregnancy.
- ii. Quality care and robust research must be prioritised in determining how best to reduce disability in its overall spectrum.
- iii. Under the National Disability Agreement, the Australian, State and Territory governments agreed to contribute a total of around \$11 million for a program of data, research and development. A National Disability Research and Development Agenda (The Agenda) was endorsed by Disability Ministers in November 2011.⁸¹ It was made clear at the time this funding pot was not intended to fund all the research directions of the Agenda. This was because the Agenda was seen as a way of influencing the inclusion and direction of research, relating to disability across a range of National research initiatives and sectors. The disability research agenda outlined:
 - disability demographic profile and trend information, including access to social and economic inclusion data
 - the need for connection for these points
 - disability-related social and economic inclusion research, including research which focuses on human rights, participation in community life, access to mainstream activities and services, and broader systems change
 - evaluations, reviews, and research to contribute to the evidence base to improve service delivery and support options
 - analysis of the factors that support sector sustainability, sector development and improved organisational capability
 - research on the profile, experiences and issues affecting diverse and/or disadvantaged groups of people with disability, such as:
 - First Nations communities
 - people from culturally and linguistically diverse backgrounds
 - women with disability
 - people in regional, rural, and remote areas.

RACMA notes these research priorities do not conduct any enquiry into ways of preventing disability, through evidence-based approaches, nor preventing deterioration of an existing disability.

RACMA strongly recommends research be undertaken as a priority in the National Disability Research and Development Agenda.

⁸¹ Australian Government Department of Social Services, Disability and Carers, 'National Disability Research and Development Agenda', November 2011, viewed February-August 2021, <https://www.dss.gov.au/disability-and-carers/programs-services/government-international/national-disability-agreement/national-disability-research-and-development-agenda>

- iv. RACMA has been unable to assess progress against the agreed 2011 National Disability Research and Development Agenda research priorities. This includes to what extent the research relating to disability, has been subsequently funded through other national research initiatives, such as the NHMRC.

The following list of research projects have been recently funded by the NHMRC⁸². RACMA recommends considering alignment with the disability sector.

- Diagnosing hereditary myopathies and dystrophies with RNA sequencing - translating research innovations into diagnostic practice
- Alcohol treatment for Aboriginal men in and out of prison
- Improving health outcomes of preterm newborns in low- and middle-income countries
- An imaging-genomic approach to advance understanding of early cortical development and outcome after preterm birth
- Computational modelling to understand early-stage neurodegeneration
- Improving the health outcomes for children with rare neurological diseases with genomic technologies
- A risk stratification tool for the prevention of avoidable perinatal mortality and morbidity
- Addressing the hidden epidemic of child and adolescent trauma
- Reducing global mortality and severity of disease in newborn infants through innovation and holistic interventions
- The Neonav ECG Tip Location System: Better & safer care for paediatric intensive care patients

- v. The NHMRC states its work is influenced by a wide range of factors⁸³, including:

- trends in the burden of disease and health service delivery
- advances in technology
- changes in research practices
- emerging ethical issues
- changes in research training environments
- international action in health and medical research, healthcare, and prevention
- the role of the states and territories in delivering health services
- the broader economic context.

⁸² National Health and Medical Research Council, 'Outcomes of Funding Rounds', 2021, viewed February-August 2021, <https://www.nhmrc.gov.au/funding/data-research/outcomes>

⁸³ National Health and Medical Research Council, 'Corporate Plan 2021-22', p.12, August 2021, viewed February-August 2021, <https://www.nhmrc.gov.au/about-us/publications/nhmrc-corporate-plan-2021-22>

And having research priorities⁸⁴ in:

- special initiative in mental health
- electromagnetic energy program
- community research
- addressing health implications of environmental change
- Northern Australia Tropical Disease Collaborative Research program
- dementia research.

RACMA is unclear where disability research is included and recommends priority be placed on its inclusion and disability directed research must have a strong 'footprint'. Accordingly, this will attract research funding and expertise in determining how to minimise its burden on society.

- vi. The Centre of Research Excellence in Disability and Health is a multi-university collaboration which 'aims to identify cost-effective policies that improve the health of people with disabilities in Australia'⁸⁵. Professor Anne Kavanagh is the Co-Director and Lead Investigator of the Centre. In a paper titled *Disability and public health research in Australia*, the author states despite the prevalence of disability:

*The health of disabled Australians has received little attention in public health research, yet disabled people experience significant disadvantage that may contribute to their poorer health. The application of social determinants and health equity frameworks present questions and potential policy solutions that could advance the health of people with disabilities. It is time public health stepped up to the challenge of providing evidence that will improve the health of disabled citizens.*⁸⁶

Kavanagh draws particular attention to the interaction of two public policy frameworks for people with disability being income support (which includes the NDIS, the DSP/or unemployment benefits) and health (which includes Medicare). Kavanagh argues in the absence of research data we do not know how the two frameworks are interacting in terms of inequality and health status, and whether some policy changes may actually be increasing disadvantage for some.⁸⁷ The author also argues improving the health of people with disability should be core business for public health researchers and this requires the application of social determinants of health and health equity approaches.⁸⁸

The WHO International Classification for Functioning Disability and Health (ICF), which underpins the conceptualisation of disability worldwide, is a biopsychosocial

⁸⁴ National Health and Medical Research Council, 'Research Priorities', 2021, viewed February-August 2021, <https://www.nhmrc.gov.au/research-policy/research-priorities>

⁸⁵ Centre of Research Excellence in Disability and Health, 'Background', 2018, viewed February-August 2021, <https://credh.org.au/>

⁸⁶ A. Kavanagh, 'Disability and public health research in Australia', in Wiley Online Library, June 2020, viewed February-August 2021, <https://onlinelibrary.wiley.com/doi/10.1111/1753-6405.13003>

⁸⁷ Ibid

⁸⁸ Ibid

model. The biopsychosocial model of disability aligns well with the social determinants of health approaches because it foregrounds how physical, social, economic, political, and cultural barriers prevent people with disabilities having access to the same opportunities as nondisabled people. These barriers flow through to social and economic disadvantage, which then produces poorer health, at least some of which is avoidable. Kavanagh argues for a shift in public health thinking from disability simply being an outcome to be avoided to a population group who may experience ill-health as a result of socioeconomic disadvantage.

- vii. A challenge for public health research on disability, socioeconomic disadvantage and health is disentangling the extent to which disability is a cause or consequence of disadvantage. Most public health research has concentrated on socioeconomic disadvantage as a cause of disability, but econometric studies have established disability is associated with downward social mobility.

Researchers need to consider the impacts of disability-specific policies and programs such as the NDIS as well as universal programs. These include Medicare with inequities between people with and without disabilities, as well as within the disabled population. In particular, groups may be more disadvantaged than others based on characteristics such as type of disability and socioeconomic status. It is possible the NDIS creates new gaps because some participants and families are better able to advocate for well-funded plans and exercise 'choice and control' in a marketised system.

- viii. These differences in capabilities are likely to be socioeconomically patterned. Similar inequities may arise between people with different types of disabilities, with people with intellectual and psychosocial disabilities, or disabled people in rural and remote regions who may fare worse because of the lack of availability of services. Such an evaluation would provide policymakers with evidence about whether or not the Scheme is delivering health benefits and not creating new inequities among people with disabilities.

- ix. 'Recommendation 107' of the Royal Commission into Aged Care Quality and Safety Final Report⁸⁹ states the establishment of an Aged Care Research and Innovation Fund, which is funded by an annual allocation equal to 1.8% of the total Commonwealth Government expenditure on aged care.

RACMA is of the view similar arrangements should be put in place for disability. This needs to occur without derogating from the amount of funding available for research and innovation through the Australian Research Council and the NHMRC.

- x. Research should also include exploring where innovation might improve the quality of life for some people with disability. In this regard examples might include the exoskeleton, the use of robotics and Artificial Intelligence initiatives.

⁸⁹ Hon Gaetano (Tony) Pagone QC, Ms Lynelle Briggs AO, Royal Commission into Aged Care Quality and Safety, 'Final Report: Care, Dignity and Respect, Volume 1, summary and recommendations', pp. 277-279, 2021, viewed February-August 2021, https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-volume-1_0.pdf

SECTION 5

Data

A key missing piece of data is any measurement of the overall well-being of people with disability, preferably before and after the provision of appropriate services. Longitudinal monitoring of well-being measures is an important tool in monitoring the effectiveness of NDIS programs, healthcare plans, and the adequacy of care and support being provided.

Data is a key requirement of any effort to improve the functioning of a system. As a minimum, data from Medicare, NDIS, the Australian Institute of Health and Welfare (AIHW), the ABS and the Pharmaceutical Benefits Scheme (PBS) should be accessible and evaluated to see what it tells us about service utilisation, service gaps and the like.

Accordingly, **RACMA endorses the AIHW position statement:**

knowing how many Australians have disability, and their characteristics, can improve our understanding of how the experiences of people with disability vary. It also helps to plan and provide the supports, services and communities that enable people with disability to participate fully in everyday life.⁹⁰

We recognise there are challenges in collecting trustworthy, indicative, qualitative, and quantitative data on vulnerable populations, as the sample size of some populations in national surveys as critical mass for robust representation is difficult to secure. As such, **RACMA supports both the AIHW framework for achieving quality data and AIHW's recommendations in relation to addressing the current challenges with existing data sources regarding disability.**

RACMA also endorses the suggestion improvements to data, for health outcomes, should address three key areas.

- Maximise the use of existing data sources
- Improve the quality and comparability of data across data sources
- Add to data sources, including by developing new data sources in priority areas and through data linkage.

We also make the following recommendations for producing quality data outcomes.

- Definitions of disability across data sources should be made consistent.
- All mainstream data sources should adopt the concept of a disability flag to identify people with disability.
- The fragmented, dispersed, and incomplete data about services used by people with disability (specialist and mainstream) should be addressed.
- The ability to reliably report on specific population groups within the broader disability population should be improved.
- Relevant data collected but not collated or otherwise available for statistical purposes should be made available.
- Data across settings and life area domains should be integrated in order to examine pathways and outcomes for people with disability.

⁹⁰ Australian Government Australian Institute of Health and Welfare, 'People with Disability in Australia', October 2020, viewed February-August 2021, <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/people-with-disability>

- Existing data sources should be improved to better capture data about subgroups in the disability population, such as special or vulnerable groups which include people with disability who are also First Nations people, live in rural and remote Australia, live in care settings, are also LGBTQI+ people, are culturally and linguistically diverse, have suffered abuse, have suffered discrimination and are homeless.

RACMA recommends data should also be collected about complaints of bullying, harassment, abuse, neglect, and violence in the disability sector. Similarly, reports from the Coroner and the Medical Board of Australia are made public. RACMA believes the new NDIS Quality and Safety Commission bodies in each jurisdiction (such as the Disability Ombudsmen in each jurisdiction) should provide information on complaints of bullying, harassment, abuse, neglect, and violence brought to their attention and follow-up on what changes have been implemented based on investigations. A key issue would be continual monitoring and follow-up on recommended changes required of the disability service organisations, to rectify issues identified through the complaints processes.

SECTION 6

Conclusion

We are enormously grateful to all those people with disability and their families for bringing us stories from the coalface and giving us a better understanding of what it is like to address violence, abuse, neglect, and exploitation in the community. The exploitation people with disability face on a day-to-day basis must be acknowledged and understood by the broader Australian community in order to prevent its continued recurrence.

Improving the quality-of-care people with disability receive can only be achieved through the collaboration of all stakeholders, including governments, service providers, professional bodies, employee representatives, carers, and healthcare providers, working together to stamp out violence, abuse, neglect, and exploitation.

SECTION 7

APPENDIX

Appendix 1. Comparison of Standards against which performance is assessed of Disability, Aged Care and Health Services

RACMA has undertaken a high-level review of the Standards against which the performance⁹¹ of Disability, Aged Care and Health Services is assessed. This review demonstrates there is considerable overlap in the various standard frameworks. For example, one of the eight mandatory standards for healthcare providers (which includes hospitals, day centres and special purpose health providers) is “Partnering with Consumers” to improve governance of programs.

This standard requires the organisation to partner with consumers, engaging them in the design and function of health services, the assessment and improvement of health consumer outcomes, and the education of the health workforce. A ‘Partnering with Consumers’ standard can be seen on all three frameworks.

With respect to the NSDS, the review highlights that these standards, while strong in the area of consumer rights, might be strengthened by further consideration of standards in relation to healthcare consumers of these services might require.

Theme	National Standards for Disability Services	Aged Care Quality Standards	ACSQHC National Safety and Quality Health Service Standards
	6 Standards	8 Standards	8 Standards
Rights/ consumer dignity and choice	<p>Standard 1</p> <p>The service promotes individual rights to freedom of expression, self-determination and decision-making and actively prevents abuse, harm, neglect and violence.</p>	<p>Standard 1</p> <p>The organisation: (a) has a culture of inclusion and respect for consumers. (b) supports consumers to exercise choice and independence. (c) respects consumers’ privacy.</p>	
Participation and inclusion/ services and supports for daily living	<p>Standard 2</p> <p>The service works with individuals and families, friends, and carers to promote opportunities for meaningful participation and active inclusion in society.</p>	<p>Standard 4</p> <p>The organisation provides safe and effective services and supports for daily living that optimise the consumer’s independence, health, well-being and quality of life.</p>	

⁹¹ National Standards for Disability Services, Australian Department of Social Services, December 2013, viewed February 2021, https://www.ideas.org.au/uploads/events/1122/nsds_full_version.pdf

		Services and supports for daily living include, but are not limited to, food services, domestic assistance, home maintenance, transport, recreational and social activities.	
Individual outcomes/ ongoing assessment and planning with consumers/ partnering with consumers	<p>Standard 3</p> <p>Individual Outcomes</p> <p>Services and supports are assessed, planned, delivered and reviewed to build on individual strengths and enable individuals to reach their goals.</p>	<p>Standard 2</p> <p>The organisation undertakes initial and ongoing assessment and planning for care and services in partnership with the consumer. Assessment and planning has a focus on optimising health and well-being in accordance with the consumer's needs, goals and preferences.</p> <p>Standard 5</p> <p>Organisation statement</p> <p>The organisation provides a safe and comfortable service environment that promotes the consumer's independence, function, and enjoyment.</p> <p>* An organisation's service environment refers to the physical environment through which care, and services are delivered, including aged care homes, cottage style respite services and day centres. An organisation's service environment does not include a person's privately</p>	<p>Partnering with Consumers Standard</p> <p>Leaders of a health service organisation develop, implement, and maintain systems to partner with consumers. These partnerships relate to the planning, design, delivery, measurement, and evaluation of care. The workforce uses these systems to partner with consumers.</p>

		owned/occupied home through which in-home services are provided.	
Feedback and complaints	<p>Standard 4</p> <p>Regular feedback is sought and used to inform individual and organisation-wide service reviews and improvement.</p>	<p>Standard 6</p> <p>The organisation regularly seeks input and feedback from consumers, carers, the workforce and others and uses the input and feedback to inform continuous improvements for individual consumers and the whole organisation.</p>	
Service access	<p>Standard 5</p> <p>The service manages access, commencement and leaving a service in a transparent, fair, equal, and responsive way.</p>		
Service management governance	<p>Standard 6</p> <p>Service management</p> <p>The service has effective and accountable service management and leadership to maximise outcomes for individuals.</p>	<p>Standard 8</p> <p>Organisational governance</p> <p>The organisation's governing body is accountable for the delivery of safe and quality care and services.</p>	<p>Clinical Governance Standard</p> <p>Leaders of a health service organisation have a responsibility to the community for continuous improvement of the safety and quality of their services, and ensuring that they are patient centred, safe, and effective.</p> <p>A clinical care standard is a small number of quality statements that describe the care patients should be offered by health professionals and health services for a specific clinical condition or defined clinical pathway in line with current best evidence.</p>
Personal care and clinical care/ Comprehensive Care Standard	Relevant	<p>Standard 3</p> <p>The organisation delivers safe and effective personal</p>	Leaders of a health service organisation establish and maintain systems and processes to support clinicians to

		care, clinical care, or both personal care and clinical care, in accordance with the consumer's needs, goals and preferences to optimise health and well-being.	<p>deliver comprehensive care and establish and maintain systems to prevent and manage specific risks of harm to patients during the delivery of healthcare. The workforce uses the systems to deliver comprehensive care and manage risk.</p> <p>Comprehensive Care Standard is the coordinated delivery of the total healthcare required or requested by a patient. This care is aligned with the patient's expressed goals of care and healthcare needs, considers the effects of the patient's health issues on their life and wellbeing, and is clinically appropriate.</p>
Human resources	Relevant	Standard 7 The organisation has a workforce that is sufficient, and is skilled and qualified to provide safe, respectful and quality care and services.	Relevant
Preventing and controlling healthcare - Associated Infection Standard	Relevant	Relevant	Leaders of a health service organisation describe, implement, and monitor systems to prevent, manage or control healthcare-associated infections and antimicrobial resistance, to reduce harm and achieve good health outcomes for patients. The workforce uses these systems.
Medication safety	Relevant	Relevant	<p>Medication Safety Standard</p> <p>Leaders of a health service organisation describe, implement, and monitor systems to reduce the occurrence of medication incidents, and improve the safety</p>

			and quality of medicines use. The workforce uses these systems.
Communicating for Safety Standard	Relevant	Relevant	Leaders of a health service organisation set up and maintain systems and processes to support effective communication with patients, carers, and families; between multidisciplinary teams and clinicians; and across health service organisations. The workforce uses these systems to effectively communicate to ensure safety.
Blood Management Standard	Not Relevant	Not Relevant	Leaders of a health service organisation describe, implement, and monitor systems to ensure the safe, appropriate, efficient, and effective care of patients' own blood, as well as other blood and blood products. The workforce uses the blood product safety systems.
Recognising and responding to deterioration	Relevant in a modified form	Relevant in a modified form	Recognising and Responding to Acute Deterioration Standard. Leaders of a health service organisation set up and maintain systems for recognising and responding to acute deterioration. The workforce uses the recognition and response systems.