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

April 2021

About The Royal Australasian College of Physicians

The RACP trains, educates and advocates on behalf of over 18,863 physicians and 8,830 trainee physicians, across Australia and New Zealand. The RACP represents a broad range of medical specialties including general medicine, paediatrics and child health, cardiology, respiratory medicine, neurology, oncology, public health medicine, infectious diseases medicine, occupational and environmental medicine, palliative medicine, sexual health medicine, rehabilitation medicine, geriatric medicine, and addiction medicine. Beyond the drive for medical excellence, the RACP is committed to developing health and social policies which bring vital improvements to the wellbeing of patients.

Physicians from a range of specialities have specific interest in disability, including:

- **Paediatricians.** Paediatricians manage the health of children, including physical, behaviour and mental health issues experienced by children with disabilities. They diagnose and treat childhood illness, infections and disease. Paediatric health care is delivered by general, community and subspecialty paediatricians in both public and private sectors. General paediatricians play an important role in meeting the needs of children and adolescents with disabilities, supplemented by community and subspecialty paediatricians.

- **Neurologists.** Neurologists are involved in the diagnosis and treatment of children and adults living with neurological and or physical disabilities like cerebral palsy, acquired brain injury, Autism Spectrum Disorder (ASD), spinal injury and progressive neurological disabilities.

- **Rehabilitation physicians.** Rehabilitation physicians diagnose, assess and manage people with disabilities and have a central role in preparing their patients for participation in society and employment. Rehabilitation physicians work to enhance and restore functional ability, independence and quality of life.

- **General and acute physicians.** General and acute physicians treat patients with acute illness and are also specialists in multimorbidity and the management of chronic disease. General and acute physicians can also provide care to adults with intellectual and or physical disability, including adults with congenital or acquired brain injury or physical disability and those with neurodegenerative conditions affecting them in childhood or early to middle aged adulthood.

- **Public health physicians.** Public health medicine physicians train in both clinical medicine and public health and are primarily concerned with the health and care of populations. The work of a public health physician includes: health promotion, prevention of disease and illness, assessment of a community's health needs, provision of health services to communities and smaller population groups and public health research.

- **Geriatricians.** Geriatricians are specialists in understanding the needs and challenges of an ageing population. They are trained to identify and assess decline or the need for decline preventing strategies in an older person. Such strategies are critical to minimising or reversing any negative impact on function.

- **Sexual health physicians.** Sexual health medicine physicians work collaboratively with a multidisciplinary team to improve the sexual health outcomes of the individual and the community by identifying and minimising sexual health issues through education, behaviour change, advocacy, screening, clinical service provision, surveillance and research.

Contents

Executive summary

The RACP welcomes the opportunity to contribute to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Commission).

The RACP recognises the overwhelming evidence that people with disability have poor mental and physical health compared to others in the community. People with disability experience increased risk factors for health conditions, increased morbidity, and increased mortality. Many of the health conditions that are experienced by people with disability across the life span are often unrecognised, misdiagnosed and poorly managed compared to the general population.[1] People with disability are more likely to live in poverty, have poor-quality or insecure housing, low levels of workforce participation and education, and be socially excluded or marginalised. They are particularly vulnerable to violence and discrimination.[2]

This disparity, along with ensuing stress to family members and carers, is totally unacceptable. The health sector, including medical colleges and health professionals, has a responsibility to demonstrate leadership in this area. Individually, and via health and medical organisations, medical practitioners across Australia have the capacity to influence perceptions and attitudes to people with disability at all levels of society. Health care policies and programs should include specific consideration of how the needs of people with disability will be met.

The RACP urges swift action in these areas to improve the lives of people with disability and reduce the clear and present health disparities. To promote this swift action, Section 1 of the submission outlines five areas of transformational change to the health and disability sectors that the RACP believes are necessary to improve the healthcare of people with disability:

- **Ensure a human-rights centred approach** - Human rights should be central to the planning and delivering of services for people with disability, and that all services should include reasonable adjustments, strategies to address health literacy and the inclusion of people with disability at all levels of decision-making.
- **Reduce levels of violence, abuse, neglect and exploitation of people with disability** – Health services should provide clinicians with adequate support to better understand and respond to potential abuse of people with disability and the specific needs of people with disability should be addressed in the National Standards for Disability Services, including information about safeguarding and support services.
- **Provide person centred, integrated care** - Person centred, integrated care involving collaboration and cooperation between providers and services across primary, secondary, and tertiary care would significantly improve health care for people with disability.
- **Improve the National Disability Insurance Scheme (the NDIS**) - The NDIS must improve access and navigation of the scheme, implement the Tune review recommendations, and ensure adequate training and expertise of staff and service providers.
- **Enhance the systems which support the health and disability sectors** - Data should be consistently collected from a range of sources to contribute to a greater understanding about disability in Australia and the proposed Disability and Health Sector Consultation Committee should be established to ensure coordination of policy initiatives across Government.

Section 2 focuses on the experiences of specific population groups when accessing or receiving health care and improvements that can be made. This section includes specific recommendations that, if implemented, would enhance health care for people with disability across the life span, including the transition between child and adult care. Actions are also included that would improve healthcare for people living in rural and remote regions, people in contact with the criminal justice system, culturally and linguistically diverse (CALD) populations and Aboriginal and Torres Strait Islander peoples with disability. The RACP supports the ten priorities to address disability inequity developed by the First People's Disability Network Australia (the FDPN).

The RACP's commitment to working with the Commission to enhance the education and training of health professionals in relation to people with disability and how we are progressing this work is outlined in Section 3.

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[1] Beange H, McElduff A, Baker W. Medical disorders of adults with mental retardation: A population study. American Journal on Mental Retardation. 1995;99(6):595-604

[2] World Health Organisation & World Bank. (2011). World report on disability 2011. World Health Organisation

Section 1: Transformational changes to health care

There is increasing evidence that the social determinants of health,[3] have a marked influence on a person's health status, and this is particularly true for people with disability. [4] [5] [6] Addressing these inequities requires dealing with their root causes: the unequal distribution of power, income, goods and services in our societies.[7] This is a key and integral part of improving the health of people with disability, including being central to the National Disability Strategy which is currently under revision.

The impact of the COVID-19 pandemic on the lived experience of people with disability, cannot be underestimated. Overall, the pandemic is a clear demonstration of the need to urgently implement transformational changes in a range of areas to redress inequities. The five areas of change outlined in the following section would make significant positive change to the health and wellbeing of people with disability.

A. Ensure a human rights centred approach

The human rights of people with disability have not been central to the planning and delivering of services for people with disability in Australia.[8] Clear policies and guidelines must be put in place that are built on human rights and practices which maximise the empowerment of people with disability and person-centred approaches. All Governments, policy makers and health and disability services providers must aim to eliminate discrimination and ensure better access and inclusion of persons with disability. Healthcare professionals specifically should have sound disability awareness and be able to advocate for the rights of persons with disability.

Reasonable adjustments

Ensuring that a person's right to access services is protected involves all services making reasonable adjustments. These adjustments should include both changes to physical environments and adapting service provision for people with different needs, such as visual, hearing and intellectual disabilities, for example providing information in an Easy Read format. Making these adjustments is most efficiently achieved when they are considered when services are being planned. However, adjustments can and should also be made iteratively following service development to enable continual improvement.

In addition to reasonable adjustments at the service level, funding arrangements such as the Medicare Benefits Schedule (MBS) and the NDIS may present barriers to the provision of reasonable adjustments.. These systemic barriers include physical, policy, procedural and attitudinal barriers across the health system. Specific examples include:

- The need for special transportation to the hospital (and potentially within the hospital).
- Accommodations that may need to be made to hospital infrastructure.
- Provision of carers to ensure that different requirements and experiences are respected.
- Additional time taken on behalf of physicians and other medical professionals to work in partnership with patients to ensure that care is tailored and equitable.

The RACP suggests that one way to change this in hospitals is through the Independent Hospital Pricing Authority investigating whether systemic cost factors associated with disability may require a separate adjustment to the National Efficient Price for this group of patients so that they have equitable access to public healthcare.

Collaborative planning and decision making

People with disability have a right to, and must, be included in all aspects and levels of decision-making in their own care and within the healthcare system. Consumer groups and individual advocates play significant

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[3] The social determinants of health include: education, employment status, housing, income level, gender and ethnicity

[4] World Health Organization. 2020 10 facts on health inequities and their causes [Internet]. [cited 2 July 2020].

[5] Kavenagh M, Aitken Z, Devine A, What's driving health inequalities for Australians with disability? Victorian Council of Social Service: [Accessed 9 September 2020]

[6] Green C, Dickinson H, Carey G. DEBATES IN DISABILITY AND HEALTH POLICY. Centre of Research Excellence in Disability and Health, 2018; 4-5.

[7] Commission on Social Determinants of Health Final Report. Health equity through action on the social determinants of health [Internet]. World Health Organisation; 2008. Available from:

[8] Evans E, Howlett S, Kremser T, Simpson J, Kayess R, Trollor J. Service development for intellectual disability mental health: a human rights approach. Journal of Intellectual Disability Research. 2012;56(11):1098-1109.

roles in ensuring that the needs and experiences of people with disability are effectively included in decision-making and planning processes in the health and social service sectors. When consumers are involved, professionals may learn by example ways to better advocate for the service needs and rights of consumers and to promote further collaborative co-design methods throughout the health system.

Recommendations

1. Governments at all levels and health services should adopt and implement a rights-based policy foundation for people living with disability underpinned by the following:
    - A human rights-based approach: people with a disability have the same human rights as others in the community and are empowered to live independently.
    - Equity of health care outcomes.
    - Care delivered in a supportive, multi-disciplinary environment.
    - Services will be easy to navigate, accessible to people with a disability and administrative barriers will be removed.
    - Amplify the voices of people with disability.
    - Communication and support will be timely and appropriate.
2. All health services should ensure reasonable adjustments are provided to improve access for people with disability.
3. All health services should provide patient and service information in Easy Read format and have in place other strategies to address health literacy, such as providing appropriate information about medicines and how they are administered.
4. The Independent Hospital Pricing Authority (IHPA) should specifically address the needs of people with disability in their pricing framework to ensure systemic barriers to health care are addressed.

B. Reduce levels of violence, abuse, neglect, and exploitation of people with disability

People with disability experience violence, abuse, neglect, and exploitation at levels significantly higher than experienced by their non-disabled peers.[9] [10] Sexual abuse and being a victim in an abusive relationship are known to be especially common in people with intellectual disability.[11] For people with limited spoken communication skills, behaviour may be an important means of communication, such as to convey pain. However, in many cases behaviours are often misattributed to other causes. These experiences are discussed further in Section 2.

A recent report by the University of New South Wales showed that inadequate health care and poor practice from service providers is causing people with disability to die up to 36 years earlier than the general Australian population.[12] The report identified a number of areas of poor practice that have contributed to premature deaths, including failure to comprehensively support client access to preventative health measures such as recommended vaccinations, annual physical examinations and dental appointments and people with known health risks not referred in a timely manner for specialist help. The report highlighted the existing gaps in tracking and publishing mortality data, which this submission talks about further below in Section 1E: *Enhance the systems which support the health and disability sectors*.

The RACP holds the view that life-diminishing events such as violence, abuse and neglect arise from a conjunction of pervasive negative attitudes and social exclusion, inadequate access to good quality health and social care including for preventive healthcare, and limited educational and occupational opportunity. Increased mortality among Australians with disability, particularly from causes that are potentially avoidable, is a core failure of our current health system and requires urgent action across Governments and health systems.

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[9] Araten-Bergman T, Bigby C, Ritchie G. Literature Review of Best Practice Supports in Disability Services for the Prevention of Abuse of People with Disability. Report for the Disability Services Commissioner. 2017 Sep.

[10] Fraser-Barbour EF, Crocker R, Walker R. Barriers and facilitators in supporting people with intellectual disability to report sexual violence: perspectives of Australian disability and mainstream support providers. The Journal of Adult Protection. 2018 Feb 12.

[11] Eastgate G, Van Driel ML, Lennox N, Scheermeyer E. Women with intellectual disabilities: a study of sexuality, sexual abuse and protection skills. Australian Family Physician. 2011 Apr;40(4):226.

[12] Salomon, C & Trollor, J. Findings: Scoping review of causes and contributors to deaths of people with disability in Australia (2013-2019)

Recommendations

5. Governments should urgently commit to eliminating preventable deaths and ill-health and to establish systems to measure and publicly report on progress to these goals.
6. Health services should provide clinicians with adequate support to better understand and respond to potential abuse of people with disability.
7. The Commonwealth Government should ensure that the specific needs of people with disability are addressed in the National Standards for Disability Services, providing information about safeguarding, advocacy services, helplines and other community-based support services, in a format accessible to service users and carers.

C. Provide person centred, integrated care

Health services at all levels are designed in a way which often results in people with disability having to navigate between a wide range of services, coordinate their own care, describe the reasons that clinical decisions have been made, and understand and remember complex health information. These challenges demonstrate that the healthcare of people with disability is best suited to an integrated model of care characterised by effective and sustained collaboration across sectors including, health, disability, education, justice, police and family and community services.

New models and expansion of existing best practices

Integrated care involves collaboration and cooperation between providers and services and occurs across primary, secondary, and tertiary care. It extends beyond a patient's regular primary medical provider and includes primary care, specialists, hospital services, allied health providers and social services. Best practice integrated care is patient centred, with informed and active shared decision-making between the patient, their support/carer and their clinicians. Fundamentally, it requires appropriate and effective systems and structures to facilitate, drive and support this collaboration and coordination.[13] One RACP Fellow gave an example of a case where they worked collaboratively with the Special Care Dentistry service to coordinate investigations for a person with intellectual disability who was undergoing a general anaesthetic for dental care. With the person's consent and approval, the general anaesthetic allowed several specialists to undertake a physical examination and identify new health concerns, while minimising distress to the patient.

The RACP has developed an integrated model of chronic care management to recruit, manage and treat patients with chronic multi-morbidities, the Model of Chronic Care Management (MCCM). The MCCM is a non-fee for service model that has two pathways to the integrated care program for multi-morbidities: from primary care or from secondary (specialist) care. The model is designed to be adapted for people with intellectual disability and/or physical disability and to particular circumstances, including: location, population and demographic characteristics such as socio economic status, age, and specific cultural groups. At present, this model is yet to be fully adapted for people with disability. If it were to be implemented, further work to develop it and associated funding to implement the new model would be required.

It is important to recognise that, while the model described above is best practice and should be strongly encouraged and considered, models tend to work most effectively in large metropolitan centres. In rural and remote areas, there is often a paucity of practitioners (particularly allied health staff) to allow models to exist. Where these models are not adaptable to regional areas, other appropriate models should be developed based on the goal of achieving multidisciplinary care, by visiting health professionals (preferable) or telehealth. The RACP recognises the vital role of general physicians, specialised services, allied health and community resources in providing high quality care to people with disability who do not have access to multidisciplinary care models.

Information sharing

Information management and digital health systems are an integral part of a well-functioning integrated health care system. Digital health systems allow real time communication between multiple members of the health care professional team and ensures the most up-to date information is available. Technological 'connecting mechanisms' (moving health care plans and other information) between different parties, including consultant physicians, GPs, allied health and different health care sectors are essential to creating a more efficient, integrated, patient-centred and population-oriented health system. This is particularly helpful for people with cognitive disability, memory difficulties, or who use non-standard communication methods as it will reduce the number of times they have to repeat or remember their healthcare history. It is vital that the current barriers in

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[13] RACP Integrated Care: Physicians supporting better patient outcomes Discussion paper March 2018

electronic communication between medical and other specialists and primary health care providers are revised to significantly improve the experience people with disability have with health services.

Collaboration between sectors

It is clear that collaboration between sectors - in particular, health, disability and aged care - is critical to ensuring that people with disability receive the services they need. In principle, the health system is responsible for diagnosing and treating conditions and providing rehabilitation, while the NDIS and state and territory-based services are responsible for improving functional capacity. However, the division of responsibility between the health and disability sectors is not always clear. It is recognised that both health and disability inputs may be needed at the same time, and there is a need for planning and coordination to ensure smooth transitions between services.[14]

One way to increase collaboration is the formal establishment of a community of practice for key stakeholders in this area. A structured and supported community or network would help facilitate and improve collaboration between the health and disability sectors by allowing key stakeholders from all districts and networks to work in partnership to provide expert advice and guidance to solve the problems faced at the interface of these sectors.

Recommendations

8. The Commonwealth Government should invest in, pilot, and expand, integrated, multidisciplinary models of care which are person centred and collaborate across sectors including health, disability, education and family and community services, such as the RACP's Model of Chronic Care Management, that specifically address the needs of people with disability.
9. The Commonwealth Government must address the barriers in electronic communication between health care providers to improve the accuracy of healthcare information transfer for people with disability.
10. Communities of practice should be established to support and enhance collaboration and reduce challenges at the interface between health and disability sectors.

D. Improve the National Disability Insurance Scheme (NDIS)

The RACP strongly supports the NDIS, its underlying values and principles, including individual autonomy, non-discrimination, and full and effective participation and inclusion in society. While the NDIS does not fund or replace mainstream services such as healthcare, the health sector and health professionals have an important role to play in providing the right information to NDIS participants, their families, carers and planners, to assist them to make decisions in relation to individual NDIS plans and their implementation.

As the NDIS has developed and rolled out a range of issues have emerged. These issues are explored below and need to be addressed to ensure that people with disability can equitably access services and support.

Service and system navigation

In 2018 an independent evaluation of the NDIS found the experience of the NDIS was highly varied among people with disability.[15] The evaluation reported that people with intellectual disability, psychosocial disability and complex needs faced difficulties accessing and navigating the scheme. NDIS participants from Culturally and Linguistically Diverse (CALD) backgrounds and living in rural areas faced similar barriers. The RACP would like to see the NDIS adopt the principle of proportionate universalism where enhanced support is provided to address access barriers for people from priority populations.

In particular, RACP Fellows reported that Early Childhood Early Intervention (ECEI) approach can be confusing for families to navigate. Further changes are required to make it more easily accessible, and to increase its focus on optimising health outcomes. Consumer information needs to be clearer, more extensive, and easier to find both on the NDIS website and through other access points (e.g., information provided to medical professionals, schools, childcare centres etc.). The webpage must clearly state the role and function of the ECEI, the role of Local Area Coordinators and transition requirements from the ECEI to the NDIS.

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[14] RACP Position Statement on Health and the National Disability Insurance Scheme 2017

[15] Mavromaras K, Moskos M, Mahuteau S, Isherwood L, Goode A, Walton H, Smith L, Wei Z, Flavel J. Evaluation of the NDIS. Final report. Adelaide: National Institute of Labour Studies, Flinders University. 2018 Feb.

Collaboration between the NDIS and other sectors

As noted in the previous section (Section 1C), improving collaboration between the many sectors which support people with disability is critical. This is particularly true of how the NDIS works with other systems and sectors. People with disability often need the help of a disability support worker who knows their needs, can help them communicate, and provide reassurance at a distressing time. However, neither the NDIS or healthcare services take responsibility for the funding of support workers while clients are inpatients in acute care services. Consequently, disability service providers are forced to bear the costs of providing this support, or else break with their principles and commitment to ensuring their clients' needs are met. This creates an unsustainable financial situation for providers and increases the risk of burnout for support workers.

This lack of collaboration also results in NDIS funding for supports activated too late for people in hospital who are ready for discharge, extending hospital stays which can cause significant psychological harm to patients. In 2019 the COAG Disability Reform Council endorsed a National Hospital Discharge Action Plan which commits the NDIA, Department of Social Services (DSS) and State and Territory governments to resolve key discharge delay issues. The RACP encourages further cross sector work in this to further develop and implement this Action Plan. In response to the COVID-19 pandemic, temporary pathways were introduced into the NDIS which streamline many of its processes to actively support earlier discharge of NDIS participants who did not need to be in hospital. The NDIA should ensure that as many of these streamlined processes as possible are maintained permanently following the pandemic.

Whole of system changes to the NDIS

The 2019 review of the NDIS Act (the Tune Review) highlighted several issues than have emerged with the scheme, including those outlined in this section. The review made 29 recommendations which if implemented in the person-centred way outlined below will help to cut wait times and red tape and introduce a Participant Service Guarantee. The RACP welcomes the Government's decision to support all of the recommendations in the Tune Review.

However, we are concerned about one particular element of the Government's response - the NDIS Functional Capacity Assessment Framework. The RACP supports funding for assessments and their important role in supporting NDIS access, planning and review. However, we are concerned that the proposed model has the potential to disregard relationships with health professionals who have developed a shared understanding of the person's individual needs. RACP Fellows noted that referrers often already have trust and a relationship with the person, which is particularly important for priority populations. The NDIS must consider how independent assessments will complement, rather than replace, the input of health professionals. Further support should also be made available in any assessment of non-English speaking participants.

The NDIS must consider carefully who is best placed to conduct independent assessments. Rehabilitation medicine physicians routinely undertake functional assessments and are therefore specifically skilled in conducting them. They also play an important role in assisting with access to the NDIS, including recommending the most appropriate allied health support, particularly for people with complex disabilities.

Skills and training provided to support coordinators and NDIS service providers

Ensuring that all people involved in providing services to people with disability are appropriately skilled and trained in an ongoing way is critical to help facilitate best practice supports. The NDIA should ensure that registration requirements for service providers include training and development of staff skills and practices so that they are equipped to support the health and wellbeing of people with disability.[16]

Support coordinators appointed by the NDIA can vary in skills and experience. Some RACP Fellows have reported that they attempt to assist in this area by helping coordinate care and linking patients with established organisations which specialise in the specific health condition. However, where there is not a coordinated patient voice or society for a person's condition, or no clearly defined diagnosis, it is important that support coordinators are adequately trained and equipped with the knowledge to link participants with relevant organisations and facilitate health professionals working together to provide better care.

Recommendations

11. The Commonwealth Government should implement the recommendations of the Tune review in a way that is genuinely person centred, guided by the participant and which ensures that the advice of

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[16] RACP Position Statement on Health and the National disability Insurance Scheme December 2017

treating medical professionals is taken into account in all assessments. Particular attention should be paid to the implementation of independent assessments.

12. The NDIA should improve communication channels on how to use the ECEI to make it easier for families of children with disability or developmental delay to access.
13. The Commonwealth Government should further strengthen and continue to fully implement the National Framework for Quality and Safeguards to protect NDIS participants from potential abuse by service providers.
14. The NDIA should ensure that planners have sufficient expertise to provide adequate support for participants with high or complex needs, particularly those with developmental or intellectual disability or children with challenging behaviours.
15. The NDIA should ensure that any NDIS processes that have been streamlined and improved in response to the COVID-19 pandemic, such as hospital discharge pathways, remain in place.
16. The NDIA should ensure that ensure that registration requirements for service providers include training and development of staff skills and practices so that they are equipped to support the health and wellbeing of people with disability.

E. Enhance the systems which support the health and disability sectors

While any person's life rarely fits neatly into government portfolio areas, people with disability face the particular challenge of requiring ongoing assistance from services from at least the health and disability sectors, and frequently also other sectors such as housing and education. Current, siloed, arrangements generate significant barriers for both policy makers and people with disability. A similar approach exists to the collection of data in Australia, which must be collected from a range of sources to contribute to a greater understanding about disability in Australia. Without good baseline data, it is difficult to measure the success of interventions, to be able to track, assess and modify them and to translate them into evidence-based policy.

Cross-sector collaboration

A policy shift towards inter-sector collaborative approaches is required to ensure a consistent approach between jurisdictions to improving service access for people with disability. This could be an opportunity for the health, education and social service sectors and their providers to work collaboratively in innovative ways. This cross-sector approach would also help considerably to address the social determinants of health.

In response to the COVID-19 pandemic, in 2020 the Commonwealth Government convened an Advisory Committee to oversee the development of the Australian Health Sector Emergency Response Plan for Novel Coronavirus (COVID-19) Management and Operational Plan for People with Disability and advise to the Chief Medical Officer about the ongoing needs of people with disability.

The advisory group is chaired by a senior official from the Department of Health and includes experts from the disability sector, academia, clinical practice, nursing, Australian government officials, and state and territory government representatives. This group has led policy development and work across sectors and in a rapid time frame. RACP Fellows have been involved throughout this work, as have consumers, disability services and advocates. The RACP is encouraged to see the Department of Health has indicated it will adapt this forum into a Disability and Health Sector Consultation Committee (DHSCC) to ensure the health needs of people with disability continue to be addressed, both in the context of the COVID-19 recovery and through the ongoing operation of the health and disability systems.

Collection and use of data

While there are four Commonwealth Government agencies which regularly collect and publish data about the health and welfare of people with disability,[17] inconsistencies between agencies have resulted in no single comprehensive dataset being available in Australia. A key area of disagreement between the data sources is the definition of 'disability' used. While some variation can be managed by careful analysis and reporting, strategies to improve the consistency of definition and coverage between sources of data need to be considered. It is vital that a coordinated national approach is taken on the collection of data to enhance consistency across jurisdictions.

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[17] The Australian Institute of Health and Welfare, the Australian Bureau of Statistics, the Commonwealth Department of Social Services, and the National Disability Insurance Agency

In particular there is a lack of routine collection and reporting of health outcomes and for people with intellectual disability. In 2017, the Centre for Disability Research and Policy (CDRP) at the University of Sydney updated an Audit of Disability Research. The audit not only identified concerns about the limitations of available data but also policy gaps such as Indigenous research, rural and remote research, policy studies addressing CALD populations with a disability, and research on lived experience of people with disability. Further gaps in data identified by RACP Fellows include routinely collected data on barriers to health care services and the adjustments required by people with disability on a regular basis.

A key example of data variation is mortality data for people with disability. Mortality data can provide crucial insight into population specific patterns and support the development of targeted health initiatives. One RACP Fellow commented that often the death of a person with intellectual disability is attributed due to their disability/vulnerability and therefore usual analysis of deaths is minimised. This highlights the need for review/analysis in monthly hospital mortality and morbidity meetings, specifically for cases relating to patients with physical and intellectual disability, to ensure reflection and improved care and outcomes.

Collection of data within the NDIA

A 2018 report by The Centre for Social Impact (CSI) said a lack of data transparency within the NDIA meant that disability service providers are expected to make large investment decisions in the absence of information about demand and with only incomplete information about supply. The report urged the NDIA to release data or more detailed position statements on supply and demand at a local level across Australia (i.e. LGA level nationwide). This would enable service providers to position themselves to meet gaps in the market where service provision is dangerously low or absent. Currently only some information on rates of application, acceptance, rates of plan activation, timeframes, plan contents and rates of review for people with disability is available for the NDIS.

The RACP notes that in 2019 the NDIA released their first annual report on outcomes for NDIS participants, which surveyed people with disability, their families, and carers across Australia. This is welcome, however, further mechanisms are needed to monitor the consistency, utilisation, quality, and outcomes of services with routinely collected data. This data needs to separate child health condition prevalence and relevant clinical outcomes by locality, ethnicity, and socioeconomic status.

Recommendations

17. The Commonwealth Government should establish the proposed Disability and Health Sector Consultation Committee to ensure coordination of policy initiatives across Government, supported by consumers, carers, health care professionals and disability experts.
18. The Australian Institute of Health and Welfare (AIHW) should be the lead body for a dataset which standardises and consolidates other information about the health of people with disability, and routinely report on the outcomes, including inputs from the health, education and disability sectors.
19. The NDIA should develop a strategy for regularly monitoring rates of: application, acceptance, plan activation, timeframes, plan contents and outcomes for NDIS participants in order to develop short and long term intervention strategies as issues arise. Particular focus should be on priority populations, for example children in out of home care and individuals with complex or unstable medical support needs.

Section 2: The experience of people with disability

The experiences of individual people with disability vary and are influenced not only by the nature of their disability but also other factors like their age, sex, gender identity, sexual orientation, ethnic origin, socio-economic status and race. While the experience of every person with a disability is unique and individual to that person, there are common impacting factors experienced by different age groups and populations that, if addressed, could improve the health of people with disability across different settings.

Depending on the point in the life span, individuals engage in different responsibilities and milestones at different points in their life. This results in disability potentially having a different effect on life satisfaction. Different population groups also face a range of distinct barriers when accessing or receiving health care and to their safety, wellbeing and inclusion in Australian society.

Section 2 focuses on the experiences of different age groups and specific population groups with disability when accessing or receiving health care and improvements that can be made.

A. Aboriginal and Torres Strait Islander peoples

The health and wellbeing of Aboriginal and Torres Strait Islander people is adversely affected by ongoing colonisation through structural oppression, racism, historical trauma and disruption to cultural practices, family structures and traditional lifestyles. [18] Aboriginal and Torres Strait Islander peoples aged 35–54 are 2.7 times as likely to have a disability as non-Indigenous people of the same age and are nearly four times as likely to have an intellectual disability as the general population.[19]

Many Aboriginal and Torres Strait Islander people face significant barriers to accessing disability planning and support services. Where adequate services exist, they are not always responsive to or compatible with the cultural values of some Aboriginal and Torres Strait Islander people and language is often not recognised or incorporated into service design and implementation. There are over 500 Indigenous nations and over 250 different language groups across Australia. Aboriginal and Torres Strait Islander people can often disproportionately experience barriers associated with socioeconomic factors.

It has been demonstrated that health strategies that involve Aboriginal and Torres Strait Islander peoples in leadership, decision-making, and management roles, are most likely to result in improved outcomes, due to Indigenous empowerment and control. The Aboriginal Community Controlled Health sector is of vital importance in delivering effective, culturally safe care; as such, service development and provision should be led by Aboriginal and Torres Strait Islander health organisations wherever possible. The sector must have long-term, legislated, sufficient and secure funding to both retain and grow their capacity.[20]

Alongside this, culturally safe practices in clinical and health care environments should be embedded across the health system to address inequalities in health access and outcomes for Aboriginal and Torres Strait Islander peoples. A culturally appropriate health service is one which takes into account local language or languages, beliefs, gender and kinship systems, delivers care in a manner which respects these important factors and is free of discrimination. To address the long-term implications of institutional racism, it is important for health services to undertake an honest evaluation of cultural safety and the competency of its health care professionals.[21]

The RACP has made a number of recommendations about improving health care for Indigenous people in our Aboriginal and Torres Strait Islander Health Position Statement and we are committed to Indigenous health equity and creating a culturally safe specialist workforce as set out in our Indigenous Strategic Framework. The RACP recently worked closely with Aboriginal, Torres Strait Islander and Māori people to develop a statement that sets the standard of what is required to meet the health needs of Indigenous children in Australia and Aotearoa New Zealand.

Recommendations

20. The RACP supports the ten priorities to address disability inequity developed by the First People's Disability Network Australia (the FDPN). As the FDPN outlines, these ten priorities are intended to form the foundation for a comprehensive national plan collaboratively created to ensure that the services and supports provided to Aboriginal and Torres Strait Islander people are disability accessible, culturally appropriate and will work in Aboriginal and Torres Strait Islander communities. The ten priorities are:
    - Invest to create an Aboriginal Community Controlled Disability Service Sector for the provision of disability supports by Aboriginal and Torres Strait Islander people with disability for their communities.
    - Address the barriers facing Aboriginal and Torres Strait Islander people accessing the NDIS.
    - Prioritise timely intervention to ensure supports and services are provided, and available over the long-term, and at the right time in people's lives.
    - Recognise and value the existing knowledge, skills and expertise within Aboriginal and Torres Strait Islander communities.

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[18] RACP Indigenous Strategic Framework.

[19] Department of Social Services (2017) Australian Government Plan to Improve Outcomes for Aboriginal and Torres Strait Islander People with Disability, p. 11

[20] Future-proofing the healthcare system - promoting sustainability, prevention and equity Australian Government RACP Election Statement 2019

[21] RACP Medical Specialist Access Framework

- Resource a community-directed research strategy which specifically focuses on Aboriginal and Torres Strait Islander disability.
- Endorse and support peer-to-peer leadership to ensure that Aboriginal and Torres Strait Islander people with disability lead the engagement with community themselves.
- Develop and implement an access to justice strategy for First People with disability, particularly those with cognitive impairment, sensory and intellectual disability.
- Develop and implement programs for inclusive education and employment for First People with disability in line with national strategies for their full societal participation.
- Create links between the National Disability Strategy and Closing the Gap Framework for coordinated policy and programs at the Commonwealth, State and local levels in partnership with Aboriginal and Torres Strait Islander people with disability and their organisations.
- Develop an Aboriginal and Torres Strait Islander Disability Performance Framework for the independent monitoring of the social and economic outcomes of Aboriginal and Torres Strait Islander people with disability.

B. Children and young people

It is estimated that 7.3% of children aged 0 to 17 years in Australia have a disability.[22] Children with disability are particularly at increased risk of experiencing health inequities, and these gaps widen as children grow up, resulting in adverse adult health, educational and vocational outcomes. If these impacts are not addressed, they can have an intergenerational effect with inequity passed on to a person's children. [23] These factors make it essential that children have access to multidisciplinary services and assistive devices in a timely fashion.

Early diagnosis is essential and early intervention has proven benefits. Early intervention for children with disability involves timely provision of an optimal nurturing and learning environment and evidence-based therapies that aim to maximise developmental and health outcomes and reduce the degree of functional limitations. [24] For example, research suggests that starting therapy with 12-month-old infants who show early behavioural signs of Autism Spectrum Disorder (ASD) may provide additional benefit. [25]

Neurodevelopmental and behavioural diagnoses often overlap and interact and for many children an accurate diagnosis may not be clear, or possible, early in their life course. Therapies should not just be targeted at symptoms but at the child holistically, reinforcing the need for functional rather than single diagnosis assessments. [26] Mental health and behavioural disorders are common in children with developmental disability and are frequently under recognised, highlighting the need for models of care which include regular health assessments. Ensuring that specialist mental health services are available to children, families and their health and educational providers is essential to early recognition and intervention for these conditions.

Transitions between child and adult care for people with disability

A person's experiences during this phase of development can play an important role in making the transition into adulthood both positive and successful, and the progression from paediatric to adult services provides an important opportunity for the health system to respond to their changing needs. Failing to ensure a positive transition can add a significant, avoidable cost burden to health and community services.

When transitioning from childhood to adulthood, young people with disability and their families may experience a number of additional challenges compared to their non-disabled peers. Young people become over-age for paediatric services, as well as leaving the supports and structure of the school system, and the respite facilities available to them as children often cease.

Formal transition services should be provided, beginning in early adolescence, which should include a specific health care provider who accepts responsibility for active case management, helping the young person and their family and/or carers through the process and following up with them once the young person has left

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[22] Australian Bureau of Statistics – Disability, Ageing and Carers, Australia: Summary of Findings, 2012
[23] RACP Position Statement on Inequities in Child Health May 2018
[24] RACP Position Statement Early Intervention for Children with Developmental Disabilities August 2013
[25] Whitehouse, A, Varcin, K, Alvares, G. Pre-emptive intervention versus treatment as usual for infants showing early behavioural risk signs of autism spectrum disorder: a single-blind, randomised controlled trial. Lancet Child & Adolescent Health. 2019 3(9): 605-15
[26] Sandback M et al, Project AIM: Autism Intervention Meta-Analysis for Studies of Young Children, Psychological Bulletin, American Psychological Association 2020, Vol.146, No1,1-29 5

paediatric care. Health services for young people with disability should holistically address the same health issues of concern to all young people transitioning to a healthy adult life such as growth and development, mental health, sexuality, nutrition, exercise and health risking behaviours such as drug and alcohol use. Targeted flexible outreach services may assist in the delivery of high-quality evidence-based care to young people with intellectual disability. This is especially important in rural and remote areas, where care must be taken to ensure an appropriate adult physician is identified and handed over to specifically. [27]

The education system

Students with a disability have the same rights to education as other students. The Disability Standards on Education 2005 (reviewed in 2015) sets out the obligations of schools and post school educational services to provide education without discrimination on the basis of disability. The RACP supports the aim of the Disability Standards on Education and related initiatives such as the NSW Every School Every Student policy, which provides funding for teachers to study masters level subjects in special education, inclusive education and sensory disabilities.

The RACP is concerned about reports that many children and their families across Australia experience difficulty when accessing assistance within the education system for their child. In many states, children can only gain optimal assistance if they reach the criteria for certain disability diagnoses, such as ASD. This has the following impacts:

- Many children do not gain the assistance that is required, creating stress on the child and family, and ultimately leading to presentations to health services;
- There is great pressure on health systems to make diagnoses for the sake of the child getting assistance;
- Families who can afford private health services will obtain the required diagnoses much earlier than relatively poor families; and
- Diagnoses may be inappropriately made, contributing to an increase in ASD diagnoses in our society, and putting extra funding pressures on schools.

While the available support services in our schools are welcomed, there need to be appropriate mechanisms to review and improve services for individual children as required. Considerable applied behavioural analytic skills are required for these assessments, and many schools have access only to superficially trained behavioural specialists. Interagency models between Health and Education for school-aged students with disabilities are exemplified by clinics in special schools for school-aged children and youth transitioning paediatric to adult services.

Young people in the criminal justice system, including Aboriginal and Torres Strait Islander young peoples

There has been increasing international, national, and local recognition of the need for more appropriate responses and services for individuals within the criminal justice system who have disability. This issue, and in particular the over-representation of Aboriginal and Torres Strait Islander adolescents in custodial settings are issues of serious concern to the RACP. [28]

The incarceration of Aboriginal and Torres Strait Islander peoples with intellectual disability in the mainstream Australian prison system is arguably a violation of human rights, resulting from a lack of due process, equal recognition before the law, as well as accountable, transparent and culturally responsive processes and outcomes. [29] The younger the cohort of children in custody, the higher the percentage of this cohort is Aboriginal or Torres Strait Islander. [30]

It is essential that any young people who do come into contact with the criminal justice system undergo a comprehensive multidisciplinary medical history and examination. This includes assessing for the presence of developmental or intellectual disability as part of a comprehensive screening service, health promotion and an integrated mental health and drug and alcohol service. Involvement in the criminal justice system is not an appropriate response to problematic behaviour, and it disadvantages already traumatised young people. They should instead be provided with appropriate health care, protection, and support. The RACP supports

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[27] RACP Position Statement on Transition of Young People with Complex and Chronic Disability Needs from Paediatric to Adult Health Services 2014

[28] RACP Position Statement - The Health and Well-being of Incarcerated Adolescents 2011

[29] Brolan C, Harley D. Indigenous Australians, Intellectual Disability and Incarceration: A Confluence of Rights Violations. Laws. 2018;7(1):7.

[30] RACP submission to the Council of Attorneys General Working Group reviewing the Age of Criminal Responsibility July 2019

diversionary services which aim to link the person with the support needed with a focus on preventing the entry of first time or low risk defendants into the criminal justice system. The RACP strongly supports all governments raising the minimum age of criminal responsibility from 10 to 14 years, in line with the significant body of evidence on child brain development and the United Nations recommendations.[31]

One of the significant obstacles in obtaining care for these people is the relative lack of expertise available to provide specialised care. RACP Fellows report that child protection workers do not have the training to take on cases involving children with complex disability needs. Cognitive and academic testing has shown that around three-quarters of young detainees have impaired cognitive functioning and around one-third have literacy and numeracy abilities typically seen in young people with intellectual disabilities.[32] These issues are likely to result in greater difficulty coping in prisons and greater vulnerability to bullying and financial, physical and sexual abuse. [33] Additionally, these children are much more likely to be disengaged from the education system.

Recommendations

21. Health services should improve the quality and accessibility of services which help young people with disability to transition between paediatric and adult health services, including ensuring that there are identified health care provider who take responsibility for managing the transition.
22. State and Territory Education departments should support access to appropriate services to review and support individual children with complex disability, including improving access to applied behavioural analytic services and interagency school clinics/ case conferences.
23. State and Territory Governments should ensure incarcerated adolescents undergo a comprehensive, multidisciplinary medical history and examination promptly during and after incarceration, which includes assessing for the presence of developmental or intellectual disability.
24. Commonwealth, State and Territory Governments should consult with groups with expertise in community led justice reinvestment with a focus on strengthening communities, improving health outcomes and reducing contact with the criminal justice system.
25. Commonwealth, State and Territory Governments should utilise diversionary services which focus on preventing the entry of first time or low risk defendants into the criminal justice system.

C. Adults and older people

Adults with a disability can experience a wide range of societal impacts as a result of their disability. These include reduced employment opportunities, social exclusion, sustained economic hardship, inappropriate housing and an increased risk of social, physical, financial and sexual abuse. In the health care setting, compared to non-disabled adults, adults with intellectual disability are higher users of inpatient and outpatient health services [34] [35] [36] and experience higher rates of preventable in-hospital mortality and morbidity. [37] [38]

Compared to their peers, adults with intellectual disability have, on average, 5 to 6 more health problems which may not be diagnosed or treated. Even though some may be related to the underlying aetiology of the disability, many are unrelated, preventable, health conditions. Different types of health conditions may be seen

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[31] RACP Submission to the Council of Attorneys General Working Group reviewing the Age of Criminal Responsibility 2019

[32] Bower C, Watkins RE, Mutch RC, et al Fetal alcohol spectrum disorder and youth justice: a prevalence study among young people sentenced to detention in Western Australia BMJ Open 2018

[33] Boer, Harm, Regi Alexander, John Devapriam, Julio Torales, Roger Ng, Joao Castaldelli-Maia, and Antonio Ventriglio. 2016. Prisoner mental health care for people with intellectual disability. *International Journal of Culture and Mental Health* 9: 442–46

[34] Ouellette-Kuntz, H., 2005. Understanding health disparities and inequities faced by individuals with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities, 18(2), pp.113-121.

[35] Janicki, M.P., Davidson, P.W., Henderson, C.M., McCallion, P., Taets, J.D., Force, L.T., Sulkes, S.B., Frangenberg, E. and Ladrigan, P.M., 2002. Health characteristics and health services utilization in older adults with intellectual disability living in community residences. Journal of Intellectual Disability Research, 46(4), pp.287-298

[36] NSW ADHC (2012): Use of emergency and inpatient hospital services by ADHC clients - Final report. (accessed 3 July 2020)

[37] Wallace, R.A., Webb, P.M. and Schluter, P.J., 2002. Environmental, medical, behavioural and disability factors associated with Helicobacter pylori infection in adults with intellectual disability. Journal of Intellectual Disability Research, 46(1), pp.51-60.

[38] Carey, I.M., Shah, S.M., Hosking, F.J., DeWilde, S., Harris, T., Beighton, C. and Cook, D.G., 2016. Health characteristics and consultation patterns of people with intellectual disability: a cross-sectional database study in English general practice. Br J Gen Pract, 66(645), pp.e264-e270.

in people, depending on the severity of the disability, with more complex health needs requiring specialist input. [39] [40] [41] [42] [43] [44] [45] Some of the specific issues in health care settings include:

- Physical, policy, procedural and attitudinal barriers in hospital; [46]
- More often provided with palliative care status for conditions that would be treated in their peers;[47]
- Diagnostic overshadowing, which occurs when a health professional attributes symptoms to a person's disability, rather than investigating a specific health issue;
- Negative experiences in the hospital setting including poor communication between staff and patient, over sedation, insufficient pain management and poor discharge preparations,[48] and some hospital staff displaying a lack of knowledge about intellectual disability;[49]
- Limited health literacy - difficulties with learning and applying health knowledge, and in health decision making, and especially with communication, managing emotions and relating to other people;[50]
- Difficulties providing health information, or with understanding what will happen during a physical examination or other procedure such as CT scan; and
- Low degrees of health literacy amongst support workers, carers and family members.

For these reasons it is important that improvements are made to ensure adequate health provision for adults with disability. General Physicians and specialists in rehabilitation often lead or co-manage the healthcare of adults with disability. The work of those with specialist expertise in this area must be complimented with sustainably resourced, multidisciplinary health services. Trainee positions also need to be available within these services to ensure that trainees can receive the clinical training needed. The RACP supports mechanisms to enhance funded supervised clinical placements to promote and enhance learning and training in providing quality health care to adults with cognitive disability.

To help ensure that people with disability are active participants in their own care, it is important that health services provide plain English information or other alternative communication tools to address difficulties understanding medical terminology, likely processes, and risks and benefits of treatment.

The RACP acknowledges the importance of regular, structured screening and health promotion interventions to improve the health of people with intellectual and developmental disability. Validated instruments which can be used for this are available. An example includes the Comprehensive Health Assessment Program (CHAP), which is intended to minimise access barriers for high quality primary healthcare. Recently, the Queensland Centre for Intellectual and Developmental Disability (QCIDD) adapted the CHAP as part of work with the Autism Cooperative Research Centre for use with adults and adolescents with intellectual disability who have Autism Spectrum Disorder.

People with disability experience high levels of unemployment and underemployment compared to the rest of the Australian population.[51] The main barrier identified to people with disability gaining meaningful employment is the lack of opportunity due to employer attitudes, ranging from entrenched discrimination to

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[39] Beange, H., McElduff, A. and Baker, W., 1995. Medical disorders of adults with mental retardation: a population study. American Journal on Mental Retardation

[40] Schoeni, R.F., Freedman, V.A. and Wallace, R.B., 2001. Persistent, consistent, widespread, and robust? Another look at recent trends in old-age disability. The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 56(4), pp.S206-S218.

[41] Baxter, H., Lowe, K., Houston, H., Jones, G., Felce, D. and Kerr, M., 2006. Previously unidentified morbidity in patients with intellectual disability. Br J Gen Pract, 56(523), pp.93-98.

[42] Rimmer, J.H. and Yamaki, K., 2006. Obesity and intellectual disability. Developmental Disabilities Research Reviews, 12(1), pp.22-27.

[43] Smiley, E., 2005. Epidemiology of mental health problems in adults with learning disability: an update. Advances in psychiatric treatment, 11(3), pp.214-222

[44] Kavanagh, A.M., Aitken, Z., Emerson, E., Sahabandu, S., Milner, A., Bentley, R., LaMontagne, A.D., Pirkis, J. and Studdert, D., 2016. Inequalities in socio-economic characteristics and health and wellbeing of men with and without disabilities: A crosssectional analysis of the baseline wave of the Australian Longitudinal Study on Male Health. BMC Public Health, 16(3), p.23.

[45] Hatton, C. and Hatton, C., 2017. Living arrangements of adults with learning disabilities across the UK. Tizard Learning Disability Review, 22(1), pp.43-50.

[46] Lagu, T., Iezzoni, L.I. and Lindenauer, P.K., 2014. The axes of access--improving care for patients with disabilities. The New England journal of medicine, 370(19), p.1847

[47] Tuffrey-Wijne, I. and Hollins, S., 2014. Preventing 'deaths by indifference': identification of reasonable adjustments is key. The British Journal of Psychiatry, 205(2), pp.86-87

[48] Webber, R., Bowers, B. and Bigby, C., 2010. Hospital experiences of older people with intellectual disability: Responses of group home staff and family members. Journal of Intellectual and Developmental Disability, 35(3), pp.155-164

[49] NSW Health (2013): Service Framework to Improve the Health Care of People with Intellectual Disability.

[50] AIHW 2008. Disability in Australia: intellectual disability. AIHW bulletin no. 67. Canberra: AIHW.

[51] Disability, Ageing and Carers, Australia: Summary of Findings, 2018 [Internet]. Australian Bureau of Statistics. 2020

misconceptions about the adjustments required for some people with disability. [52] Evidence shows that work in general maximises health outcomes, financial security, self-esteem and independence.[53] The RACP Position Statements on 'Realising the Health Benefits of Work' and 'What is Good Work' have summarised other health benefits to employment, and the Productivity Commission has noted NDIS support for people living with disability to engage in healthy employment will have economic benefits for Australia.

Sexual health and contraception

The RACP recognises the importance of empowering people living with a disability to participate as fully as possible in their own sexual and reproductive health and in achieving a healthy relationship. All people deserve medical treatment with respect to fertility control that empowers them to make informed decisions about their reproductive rights.

Many women with intellectual disability can manage their own menstruation, and often it is simply further education and instruction that is lacking. [54] It is important that contraception is a choice made by the patient as much as is possible, and recommended treatment options must always be the least restrictive and in the person's best interests.

Health professionals may make assumptions about disability reducing sexual interest or activity and may not offer sexual and reproductive health care or feel poorly equipped to do so. All clinicians involved in the long-term care of people with disability should be willing to discuss sexuality and intimate relationships and use their expertise to support people with disability who are, or who would like to be, sexually active.[55]

Older People

Similar to the problems encountered by people with disability when transitioning between paediatric and adult care are the challenges experienced by people transitioning between adult and aged care. While the RACP recognises the necessity of the two systems being separate, clear consideration of the needs of people with disability who transition between the two systems is important.

NDIS participants must be under 65 years to access the scheme for the first time. This leads to inequities of access to disability and rehabilitation services for people who ho acquire disability after age 65. For example, a person who is 64 years of age and has access to the NDIS has significant advantages over a person who is 66 years of age and cannot access the NDIS, despite the fact that both may have been fit, healthy and independent prior to acquiring a disability and have the same level of disability and same prognosis after.

When a person turns 65, they remain an NDIS participant unless they choose to transfer to aged care funding for example on entry to a RACF. However, the NDIS supports do not recognise the unique needs of people who require both disability supports and aged care support, highlighting the need for the NDIS be more attuned to the often rapidly changing needs of people as they age and experience age related conditions and disability. An example provided by one RACP Fellow was of a person who transitioned to an aged care facility which resulted in the person also transitioning to aged care funding. Without their previous NDIS funding, the person was unable to access the community or receive the allied health supports necessary to maintain their function or the transport to medical appointments. The RACP has previously raised issues with resourcing and infrastructure of the aged care system in our submission to the Royal Commission into Aged Care Quality and Safety.

As stated in Section 1D, a higher level of collaboration between NDIS and aged care community services is also needed to address gaps arising from the way in which health care is organised for people with disability and patients who, for one reason or another, are not eligible for NDIS support, all of which can lead to gross inequities in health care and support delivery. [56]

In addition, it is important that the health and disability systems are equipped to provide support for people with disability who experience earlier onset of diseases of old age than their non-disabled peers. There is an

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[52] SHUT OUT: The Experience of People with Disabilities and their Families in Australia. National Disability Strategy Consultation Report prepared by the National People with Disabilities and Carer Council [Internet]. 2016 [cited 20 October 2020].

[53] RACP Position Statement Realising the Health Benefits of Work 2013

[54] RACP Letter to Senate Inquiry into the Involuntary or Coerced Sterilisation of People with Disabilities in Australia

[55] RACP Position Statement - Sexual and Reproductive Health Care for Young People November 2015

[56] RACP Submission to the Royal Commission into Aged Care Quality and Safety. December 2019

increased risk of dementia among people with some intellectual disabilities such as Down Syndrome. [57] The earliest signs of dementia are often overlooked or misattributed due to a lack of training for carers to interpret the signs, a lack of information in the community regarding dementia in people with disability and misattributing signs of decline to 'ageing', 'behavioural issues', or the disability itself. [58]

People who live in supported accommodation

Appropriate accommodation options can be difficult for people with disability to access, and where they are available are often chosen because they are the best option available, not because they are entirely suitable. This is particularly true for younger people (< 65 or < 50 for Aboriginal and Torres Strait Islander peoples), who are regularly placed in Residential Aged Care Facilities (RACFs). This often results in extended hospital stays while sourcing accommodation, and significant trauma for patient and families.

In the limited situations where appropriate accommodation can be accessed, people with disability face an increased risk of complications such as pressure injuries, falls and respiratory, urinary tract and other infections. These patients need:

- More specialised equipment and technology (specialised wheelchairs, mattresses, toilet and shower aids and communication devices) to maintain function but which are often not available in RACFs and which may not be supplied by other state-based equipment supply schemes.
- Better access to specialist rehabilitation medicine services, including "bursts" of rehabilitation to maintain function and manage / reduce the risk of complications and in some case longer formal rehabilitation programs. This could be achieved by increasing the number of community rehabilitation services which provide rehabilitation in the home (or nursing home).[59]
- Staff must have additional training and education of in in order to provide the necessary care.
- People with disability, their carer(s) and their families must be involved in decisions and their care preferences understood and respected. For example, a person with intellectual disability may prefer to reside with their older parent who is now needing aged care themselves, in which case it may be more appropriate for that person to be in an aged care facility close to the parent, rather than remain in supported community accommodation. This flexibility in choice needs to be seen against the background of available local supports for younger people with disability.

Palliative care

Palliative care plays a vital role at the end-of life for many Australians, reducing the physical and emotional distress of dying, and optimising quality of life for individuals, carers, family and friends. Palliative care should be culturally appropriate, person- and family-centred. Many of the same challenges e experienced in other parts of society outlined in the above sections also apply to ensuring access to quality palliative care that meets the needs of people with disability. One of the main barriers to appropriate palliative care identified by RACP Fellows is the regulatory processes/ framework in place by supported accommodation providers for people living in supported accommodation. An example given was if a person wishes for no resuscitation the accommodation provider will still put in place a first aid response until the ambulance arrives. Additional challenges to those receiving palliative care include:

- Lack of awareness/understanding of death, dying and palliative care.
- Distrust of health services and fear that their lives are considered less valuable than those without a disability.
- Lack of recognition that a person may benefit from palliative care, leading to late or non-referral to services (related to the concept of diagnostic overshadowing).
- Lack of integration between health, disability and aged care sectors.
- In community living settings, lack of organisational support for dying in place of choice.[60]

Communication issues, which can arise from cognitive, motor and/or sensory impairments, can raise a number of barriers to effective palliative care as health care providers may not be able to form a clear understanding of a patient's symptoms. This can cause difficulty in early identification and correct assessment and treatment of pain and other physical, psychosocial, or spiritual problems. There is a need to improve

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[57] Strydom, A., Chan, T., King, M., Hassiotis, A. and Livingston, G., 2013. Incidence of dementia in older adults with intellectual disabilities. Research in developmental disabilities, 34(6), pp.1881-1885

[58] Evans E, Trollor J. Dementia in people with Intellectual Disability: Guidelines for Australian GPs. Department of Developmental Disability Neuropsychiatry UNSW [Internet]. 2018.

[59] RACP Submission to the Royal Commission into Aged Care Quality and Safety. December 2019

[60] Australian Healthcare Associates (AHA). Exploratory Analysis of Barriers to Palliative Care [Internet]. Australian Government Department of Health; 2019.

health professionals' ability to have open, direct - yet sensitive - conversations with people with disability about their care preferences.

Because disability may increase the complexity of conditions, high-quality palliative care for people with disability should often involve input from disability and mental health specialists in addition to specialist palliative care. However, evidence suggests that, in many instances, multidisciplinary care may not be provided.[61] Collaboration between sectors is critical to ensuring that people with disability receive the services they need. In addition, many people with a disability who have progressive life-limiting conditions may benefit from palliative care involvement over a much longer period than current funding or service structure allows.

The NDIA should support funding of enhanced clinical support for people with complex medical needs or palliative care needs within their existing accommodation or support access to medical model supported accommodation options.

Recommendations

26. The Commonwealth Government should introduce mechanisms to enhance funded supervised training placements, especially for adult medicine and rehabilitation, to promote and enhance quality health care for adults with disability.
27. Commonwealth, State and Territory Governments must ensure that employment services for people with disability are provided using a flexible individualised approach to the person's specific needs ensure people with disability obtain the support required.
28. Health services should support clinicians to provide education, support and referral to specialised services as required so that people with disability are provided with opportunities to have the same sexual education and relationship/ intimate experiences as those without disability.
29. The Commonwealth Government should review and improve, and State Governments should fund, more appropriate accommodation options for people with disability. This should include options for young people who require a similar level of personal care as that provided to older persons in RACFs.
30. The Commonwealth Government should build linkages and reciprocal collaborations and a legal framework between all relevant sectors to develop best-practice approaches to palliative care service delivery for people with disability.

D. People in rural and remote areas

People with disability in rural and remote areas of Australia have comparatively less access to diagnostic and treatment services than their non-disabled and metropolitan peers, including poorer access to medication supply and review. A key reason for the disparity in rates of access and treatment is the lack of infrastructure and the subsequent lack of capacity of services in rural and regional areas to provide a complete range of supports. While these barriers are experienced by people with all levels of abilities, as with many areas of health care they are particularly acute for people with disability. RACP Fellows have reported that in some cases people with disability who live in rural and remote areas do not have adequate access to health care workers.

Telehealth has been a much needed and appreciated addition to the suite of services available in rural and regional areas but may not provide as much benefit for people with disability as for people without disability. For telehealth to be successful for this population, appropriate facilities and supports are required place to make this strategy successful. Given the communication challenges experienced by people with disability, they should have the opportunity to access their health care workers in person, not just via telehealth.

Recommendation

31. State and Territory Governments should consider increasing funding for medical, pharmacy and allied health outreach services for people with disability, including supporting health care providers working in rural and regional areas to expand their capacity to care for people with disability within their area of expertise.

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[61] Sampson, E. L. et al. Living and dying with advanced dementia: A prospective cohort study of symptoms, service use and care at the end of life. Palliat. Med. 32, 668–681 (2018).

E. People from culturally and linguistically diverse backgrounds

People from culturally and linguistically diverse (CALD) backgrounds have rates of disability similar to the rest of the Australian population. However, available evidence shows that people with a disability from CALD backgrounds have lower rates of utilisation of health care services than those who are Australian-born and migrants from English speaking countries. This is often due to experiencing stigma around disability, a distrust of government agencies, a lack of accessible information, and language barriers. [62]

Action is needed to enable people with disability from CALD backgrounds to achieve social and economic inclusion. Key areas which need improvement are:

- Difficulties experienced by CALD communities in understanding the NDIS model and access points. [63]
- The lack of direction for NDIA staff by the NDIA in working in culturally responsive ways, lack of translated and culturally appropriate resources, and limited staff awareness of different cultural understandings of disability. [64]
- Addressing the difficulties faced by many people in CALD communities in accessing interpreter services. [65]

Recommendations

32. The NDIA should adopt a comprehensive cultural competence framework to ensure access to appropriate NDIS funding and support for people with disability from culturally and linguistically diverse communities.
33. State and Territory governments should ensure equitable access to interpreter services across both public and private health services.

F. People who care for people with disability

Many, but not all, people with disability will require support from a carer at some point in their lives. Carers are often partners, parents, sons or daughters, siblings, other relatives, friends or neighbours. The role of carers varies considerably depending on the type of disability experienced and the age of the person and their carer. Supporting people living with complex disabilities can have a significant impact on carer energy, mental health, general health and welfare, employment opportunities and the ability to perform family responsibilities.

The RACP acknowledges the important role of people in caring and providing support to people with disability. The disability sector and NDIS providers must ensure adequate education and support of family carers to deliver optimum care for the person living with disability within the carer's capacity. Support and education around preventative strategies to manage the carer's physical and mental health is essential. Family carers require training in skills such as manual handling, managing challenging behaviours and specific health-based advice around optimum care of the person living with disability.

Recommendation

34. Commonwealth and State and Territory Governments should recognise the critical importance of the health and wellbeing of carers and family members and ensure they are supported socially, economically and medically.

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[62] Settlement Services International. Still outside the tent: cultural diversity and disability in a time of reform – a rapid review of evidence [Internet]. SSI Research and Policy Unit; 2018.

[63] Australian Centre for Community Services Research, Flinders University. Engaging CALD communities in the NDIS [Internet]. 2017.

[64] National Institute of Labour Studies (NILS), Evaluation of the NDIS. Final Report 2018, Flinders University: Adelaide.

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Section 3: Training and education of health care professionals

The RACP recognises that training institutions, including specialist training providers such as medical colleges, have a significant role to play in improving the lives of people with disability through improving the knowledge, skills and attitudes that health professionals have and display toward people with disability. Through collaboration, the RACP seeks to lead innovation in the delivery of specialist medicine and in the education of the trainee physicians and paediatricians, including in the area of disability.

The provision of high-quality health care for people with disability is everyone's business, not just of those who specialise in that field. Leadership by expert clinical care from specialised healthcare teams is an important element. However, it is important that *all* health professionals are equipped with the skills and knowledge in relation to the health conditions and related issues, such as consent, human rights approaches, experience by people with disability.

We acknowledge that the Commission is examining the need to enhance the education and training of health care professionals to address:

- diagnostic overshadowing and the misdiagnosis of health conditions in people with cognitive disability
- cultural attitudes, assumptions and beliefs about the quality of life of people with cognitive disability
- communication with people with cognitive disability and their families and carers, support person, and
- gaps in specialised knowledge in cognitive disability.[66]

The RACP was pleased to contribute evidence at Public hearing 10: Education and training of health professionals in relation to people with cognitive disability through our appointed representatives Dr Jacqueline Small FRACP and A/Prof Mitra Guha AM FRACP. As outlined at the hearing, the RACP is committed to further work in this area to ensure better quality health care and outcomes for people with disability in Australia.

The RACP is already began progressing work in this area, including:

- Renewing and developing curricula which reflects contemporary best practice. This will include strengthened reference to and assessment of practices in person-centred care, which is fundamental to meeting the needs of vulnerable patient cohorts such as those with an intellectual and/or cognitive disability.
- Involving consumers throughout the work of the College, including in the areas of education and training of physicians. The RACP *Framework for improving patient-centred care and consumer engagement*, implemented in 2016, includes actions to improve patient-centred care and consumer involvement in decision-making across the RACPs strategic priorities to 'educate, advocate and innovate'.
- Advocating for healthcare policies that promote the interests of the profession, of patients and of the community, including by engaging in Government Roundtables and publishing submissions in response to proposed policies and healthcare reforms.
- Addressing the issues raised with and by the Commission about physicians attitudes and beliefs towards people with disability through our continuing professional development program.

To guide the RACP's further work in this area, we have developed seven high-level principles to inform our actions as follows:

1. Importance of a human rights-based and person-centered approach in healthcare
2. Responsibility to take a leadership role within specialist medical education to help reduce the significant inequities in healthcare experiences and outcomes for people with disability
3. Involvement of people with disabilities in physician training and education
4. Imperative to enhance physicians' attitudes, knowledge, beliefs and skills in providing care to people with disability
5. Equip and educate the physician workforce to embed culturally safe, quality health care for Indigenous peoples with disability
6. Expand the workforce and building communities of practice to enhance care for people with disability
7. Advocacy for health care system and policy change that reduces health inequities, reflects Indigenous views of health, and improve the lives of people with disability.

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[66] Public hearing 10: Education and training of health professionals in relation to people with cognitive disability

Appendix: Recommendations

Section 1: Transformational changes to health care

Ensure a human rights centred approach

1. Governments at all levels and health services should adopt and implement a rights-based policy foundation for people living with disability underpinned by the following principles:
    - A human rights-based approach: people with a disability have the same human rights as others in the community and are empowered to live independently.
    - Equity of health care outcomes.
    - Care delivered in a supportive, multi-disciplinary environment.
    - Services will be easy to navigate, accessible to people with a disability and administrative barriers will be removed.
    - Amplify the voices of people with disability.
    - Communication and support will be timely and appropriate.
2. All health services should ensure reasonable adjustments are provided to improve access for people with disability.
3. All health services should provide patient and service information in Easy Read format and have in place other strategies to address health literacy, such as providing appropriate information about medicines and how they are administered.
4. The Independent Hospital Pricing Authority (IHPA) should specifically address the needs of people with disability in their pricing framework to ensure systemic barriers to health care are addressed.

Reduce levels of violence, abuse, neglect and exploitation of people with disability

5. Governments should urgently commit to eliminating preventable deaths[67] and ill-health and to establish systems to measure and publicly report on progress to these goals.
6. Health services should provide clinicians with adequate support to better understand and respond to potential abuse of people with disability.
7. The Commonwealth Government should ensure that the specific needs of people with disability are addressed in the National Standards for Disability Services, providing information about safeguarding, advocacy services, helplines and other community-based support services, in a format accessible to service users and carers.

Provide person-centred, integrated care

8. The Commonwealth Government should invest in, pilot, and expand, integrated, multidisciplinary models of care which are person centred and collaborate across sectors including health, disability, education and family and community services, such as the RACP's Model of Chronic Care Management, that specifically address the needs of people with disability.
9. The Commonwealth Government must address the barriers in electronic communication between health care providers to improve the accuracy of healthcare information transfer for people with disability.
10. Communities of practice should be established to support and enhance collaboration and reduce challenges at the interface between health and disability sectors.

Improve the NDIS

11. The Commonwealth Government should implement the recommendations of the Tune review in a way that is genuinely person centred, guided by the participant and which ensures that the advice of treating medical professionals is taken into account in all assessments.
12. The NDIA should improve communication channels on how to use the ECEI to make it easier for families of children with disability or developmental delay to access.
13. The Commonwealth Government should further strengthen and continue to fully implement the National Framework for Quality and Safeguarding to protect NDIS participants from potential abuse by service providers.
14. The NDIA should ensure that planners have sufficient expertise to provide adequate support for participants with high or complex needs, particularly those with developmental or intellectual disability or children with challenging behaviours.

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[67] This is described in the literature as 'excess mortality'

15. The NDIA should ensure that any NDIS processes that have been streamlined and improved in response to the COVID-19 pandemic, such as improved hospital discharge pathways, remain in place.
16. The NDIA should ensure that registration requirements for service providers include training and development of staff skills and practices so that they are equipped to support the health and wellbeing of people with disability.

Enhance the systems which support the health and disability sectors

17. The Commonwealth Government should establish the proposed Disability and Health Sector Consultation Committee to ensure coordination of policy initiatives across Government, supported by consumers, carers, health care professionals and disability experts.
18. The Commonwealth Government should establish a dataset which standardises and consolidates information about the health of people with disability, and routinely report on the outcomes, including inputs from the health, education and disability sectors. The Australian Institute of Health and Welfare (AIHW) may be well placed to compile this dataset.
19. The NDIA should develop a strategy for regularly monitoring rates of: application, acceptance, plan activation, timeframes, plan contents and outcomes for NDIS participants in order to develop short and long term intervention strategies as issues arise. Particular focus should be on priority populations, for example children in out of home care and individuals with complex or unstable medical support needs.

Section 2: The experience of people with disability

Aboriginal and Torres Strait Islander peoples

20. The RACP supports the ten priorities to address disability inequity developed by the First People's Disability Network Australia (the FDPN). The ten priorities are:
    - Invest to create an Aboriginal Community Controlled Disability Service Sector for the provision of disability supports by Aboriginal and Torres Strait Islander people with disability for their communities.
    - Address the barriers facing Aboriginal and Torres Strait Islander people accessing the NDIS.
    - Prioritise timely intervention to ensure supports and services are provided, and available over the long-term, and at the right time in people's lives.
    - Recognise and value the existing knowledge, skills and expertise within Aboriginal and Torres Strait Islander communities.
    - Resource a community-directed research strategy which specifically focuses on Aboriginal and Torres Strait Islander disability.
    - Endorse and support peer-to-peer leadership to ensure that Aboriginal and Torres Strait Islander people with disability lead the engagement with community themselves.
    - Develop and implement an access to justice strategy for First People with disability, particularly those with cognitive impairment, sensory and intellectual disability.
    - Develop and implement programs for inclusive education and employment for First People with disability in line with national strategies for their full societal participation.
    - Create links between the National Disability Strategy and Closing the Gap Framework for coordinated policy and programs at the Commonwealth, State and local levels in partnership with Aboriginal and Torres Strait Islander people with disability and their organisations.
    - Develop an Aboriginal and Torres Strait Islander Disability Performance Framework for the independent monitoring of the social and economic outcomes of Aboriginal and Torres Strait Islander people with disability. [68]

Children and young people

21. Health services should improve the quality and accessibility of services which help young people with disability to transition between paediatric and adult health services, including ensuring that there are identified health care providers who take responsibility for managing the transition.
22. State and Territory Education Departments should support access to appropriate services to review and support individual children with complex disability, including improving access to applied behavioural analytic services and interagency school clinics/ case conferences.

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[68] First Peoples Disability Network | Ten priorities to address disability inequity in Aboriginal and Torres Strait Islander Communities for the National Disability Strategy and National Disability Insurance Scheme

Young People in the Criminal Justice System

23. State and Territory Governments should ensure incarcerated adolescents undergo a comprehensive medical history and examination promptly during and after incarceration, which includes assessing for the presence of developmental or intellectual disability and, as appropriate, diversion into care and treatment.
24. Commonwealth, State and Territory Governments should consult with groups with expertise in community led justice reinvestment with a focus on strengthening communities, improving health outcomes and reducing contact with the criminal justice system.
25. Commonwealth, State and Territory Governments should utilise diversionary services which focus on preventing the entry of first time or low risk defendants into the criminal justice system.

Adults and older people

26. The Commonwealth Government should introduce mechanisms to enhance funded supervised training placements, especially for adult medicine and rehabilitation, to promote and enhance quality health care for adults with disability.
27. Commonwealth, State and Territory Governments must ensure that employment services for people with disability are provided using a flexible individualised approach to the person's specific needs to ensure people with disability obtain the support required.
28. Health services should support clinicians to provide education, support and referral to specialised services as required so that people with disability are provided with opportunities to have the same sexual education and relationships as those without disability.
29. The Commonwealth Government should review and improve, and State Governments should fund, more appropriate accommodation options for people with disability. This should include options for young people who require a similar level of personal care as that provided to older persons in RACFs.
30. The Commonwealth Government should build linkages and reciprocal collaborations and a legal framework between all relevant sectors to develop best-practice approaches to palliative care service delivery for people with disability.
31. The NDIA should fund enhanced clinical support for people with complex medical or palliative care needs within their existing accommodation or support access to medical model supported accommodation options.

People in rural and remote areas

32. State and Territory Governments should consider increasing funding for medical, pharmacy and allied health outreach services for people with disability, including supporting health care providers working in rural and regional areas to expand their capacity to care for people with disability within their area of expertise.

People from culturally and linguistically diverse backgrounds

33. The NDIA should adopt a comprehensive cultural competence framework to ensure access to appropriate NDIS funding and support for people with disability from culturally and linguistically diverse communities.
34. State and Territory governments should ensure equitable access to interpreter services across both public and private health services.

People who care for people with disability

35. Commonwealth and State and Territory Governments should recognise the critical importance of the health and wellbeing of carers and family members and ensure they are supported socially, economically and medically.