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Future Directions of Disability Health in the ACT:
Phase One of the ACT Disability Health Strategy Project

Final report

September 2021



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We also acknowledge this country as belonging to the Aboriginal and Torres Strait Islander peoples of Australia. We pay our respects to the Elders and leaders of all communities – past, present and emerging - and acknowledge their right to self-determination. We honour their culture and traditions, the significant contributions those cultures and traditions make to Australian society and their inclusion of people with disabilities in their cultural life.

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A: Key considerations for improving the health of people with disabilities

1. People with disability benefit strongly from person-centred care.
2. A strengths-based social model of disability relies on 'reasonable adjustment' (also known as 'reasonable accommodation') to achieve equitable access.
3. The concept of reasonable adjustment is currently embedded in national and ACT anti-discrimination legislation.
4. 'Universal design' of health services (including facilities, equipment and processes) can improve access to care for the whole population, especially when co-designed with consumers.
5. The health care needs of people with disabilities needs to be considered along with their social and cultural backgrounds and/or additional health challenges.
6. People with disability are at high risk of adverse health outcomes, including premature death.
7. 'Patient held' health information helps to ensure safety and good health outcomes.
8. Proactive and regular health assessments have been shown to improve health outcomes for people with disabilities.
9. Patient navigation support is an effective strategy to manage known risks, increase safety and reduce unplanned readmissions.
10. Capacity for effective reasonable adjustment relies on clear organisational processes.
11. Positive attitudes and behaviours of individual health care professionals and health care support staff have a significant impact on people with disability.
12. Training and development of health care providers supports them to become experienced and confident in dealing with people with disabilities and their support networks.
13. Clearly established and monitored performance indicators has been shown to be a key driver of accountability and positive change.
14. Collection of relevant data is critical for quality assurance and quality improvement.

B: Executive Summary

Achieving equitable access to the full range of societal activities and services is a key aim for people living with disability in Australia and for the broader society. Despite progress, this aim is still a work in progress. Equitable access to good health and to the services that support that goal remains a challenge for many people with disability, particularly if their needs also intersect with other diverse lived experiences. This report provides a summary of the key frameworks (legislative and policy) that have been put in place to support better access and highlights the issues faced by people with disability and the strategies for improvement that have been identified as part of a rapid literature review process.

Since 1991 (ACT) and 1992 (national), there has been a legislated protection against discrimination on the basis of disability. A core principle underpinning that legislation is the concept of 'reasonable accommodation' or 'reasonable adjustment' to allow the participation of people with disabilities on an equal basis with other citizens. This responsibility for adjustment is particularly significant in the areas of employment, education and health service provision.

In 2006, the United Nations Convention for the Rights of Persons with Disabilities was signed by 83 Member Nations and was formally ratified by the Australian Government in 2008. This Convention provides a comprehensive overview of the ways in which the rights of people with disability can be ensured. At least six of the Articles in the Convention are directly relevant to achieving equitable health access and provide guidance on how that can be done. This Convention was also significant because it formally embedded the principle of a 'social model of disability', which turns the focus of achieving access for people with disabilities to the removal of barriers that inhibit their participation.

The social model of disability aligns well with a key concept in the health policy and practice domain – the 'social model of health'. Using this lens to view health and the achievement of equitable health for all population groups, this model reflects the evidence that an individual's health is strongly influenced by the social determinants that affect their life. This can include access to basic health-supporting infrastructure such as food and clean water and air but also includes determinants such as income, education, employment, housing, social inclusion, early childhood development and access to affordable, safe health care.

The social determinants of health can be further influenced by the diverse experiences of different population groups, both positively and negatively. It is now widely acknowledged, for example, that health services that incorporate the cultural determinants of First Nations peoples and also support self-determination are likely to achieve better health and social outcomes for people in those communities. For people in other population groups, equitable access to health and health services can be affected by other issues, such as the need for access to interpreting and translation services for people from Culturally and Linguistically Diverse communities, previous experiences of trauma and/or their experiences of discrimination or racism. All of these population groups will include people with disabilities. This will have an impact on their needs for reasonable adjustment in the health care system and requires those working in that system to be well informed about those needs as well as clear policies and procedures to support compassionate and effective responses on an individual basis.

The 7 universal design principles established in the US in 1997 provide guidance about the value of using proactive design thinking at the early stages of any infrastructure, equipment or service planning initiative. This allows for a broad set of needs and enough flexibility of service approach that barriers to access are removed. Application of these principles support the aims of the Convention by treating the needs of people with disability as just one aspect of community requirements and mitigates against the need for person-specific reasonable adjustments to be made, especially where those needs are entirely predictable and widely understood.

In the absence of universal design influence, however, an active and accountable approach to ensuring reasonable adjustment in the health care system is particularly important. The literature reveals that Australian advocacy groups and clinicians have been leaders in pointing to the poor health outcomes experienced by people with disability in Australia and in providing guidance about how to adapt service provision more effectively to the needs of people with disabilities. The literature reveals the international influence of Australian health clinicians and researchers, such as Professor Nick Lennox and Professor Julian Trollor, in developing an understanding of where health systems go wrong for people with disability and how they can be influenced to do better.

This report points to a range of useful examples of Australian and international legislative and policy frameworks that have been developed and implemented to guide health systems, organisations, individual health practitioners and consumers and carers in their efforts to improve health outcomes and the experience of health care for people with disabilities. Common and effective reasonable adjustment strategies have been summarised from the literature. Particular focus areas for reasonable adjustment are:

- inclusion of the person with disabilities in all aspects of care planning and delivery (including consent procedures)
- partnership approach to include carers
- proactive and personalised approaches to communication with people with disabilities
- engagement with patient-held health information (such as health passports) to promote quality and safety of care, and
- inclusive adaption of the physical environment of service provision (including physical access and accommodation of sensory issues).

Strategies identified for improving the health of people with disability can be categorised at both the system level of influence and at the organisational and individual level of service provision. The key areas of focus in these strategies are:

- promoting a prevention and wellbeing focus to health service design and delivery
- organisational management responsibility, accountability and monitoring
- ensuring a responsive service infrastructure and workforce
- provision of tailored service models where needs are more complex
- consideration of other barriers, such as financial barriers to care and access to transport to get care.

Underpinning all of these strategies is an urgent need for access to relevant performance data, combined with regular monitoring and review processes. Australia and the ACT share this requirement with all jurisdictions pursuing better health for people with disabilities. The revised UK legislation is reported to have assisted with achieving an increased level of accountability but there is work still to do.

C: Introduction and context

Outline of this project

This report has been commissioned to provide relevant material from existing literature and other published information that will support the development of an ACT Disability Health Strategy and First Action Plan.

The literature search process commenced with broad searches on comparable international jurisdictions (UK, Canada, US, New Zealand, The Netherlands, and all Scandinavian countries) to identify high level policy frameworks and legislative reform processes associated with improving access to and the quality of health care available to people living with disabilities. Further searches on this broad scale were undertaken for Australian and state/territory jurisdictions.

At this point, it was clear that policies and strategies could be usefully categorised according to system-level responses or personalised responses that were being implemented to improve access to care and health outcomes for people living with disability. Within those broad categories, a series of topics emerged. Findings around those topics are summarised in the format of identified issues and related improvement strategies. Where there are clearly relevant and current ACT policy and/or strategy settings defined relevant to a particular topic, reference has been made to those.

This report defines the concept of health according to the World Health Organisation (WHO) definition of health:

Health defined as: 'A state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' (WHO Constitution, 1948).

Overview of the health system in the ACT

The schematic at Figure 1 below provides an overview of the health system of the ACT and identifies the key types of health services or initiatives that currently exist (ACT Government, 2020). The schematic uses a consumer's perspective to describe this local service map. This service map places people at the centre of a three-pronged service delivery strategy for the general population – preventive health, care in the hospital and care in the community. This 'person-centred' approach to conceptualising health services also assumes that 'by shifting the culture from 'doing to' to 'doing with', significant clinical improvements can be made'.

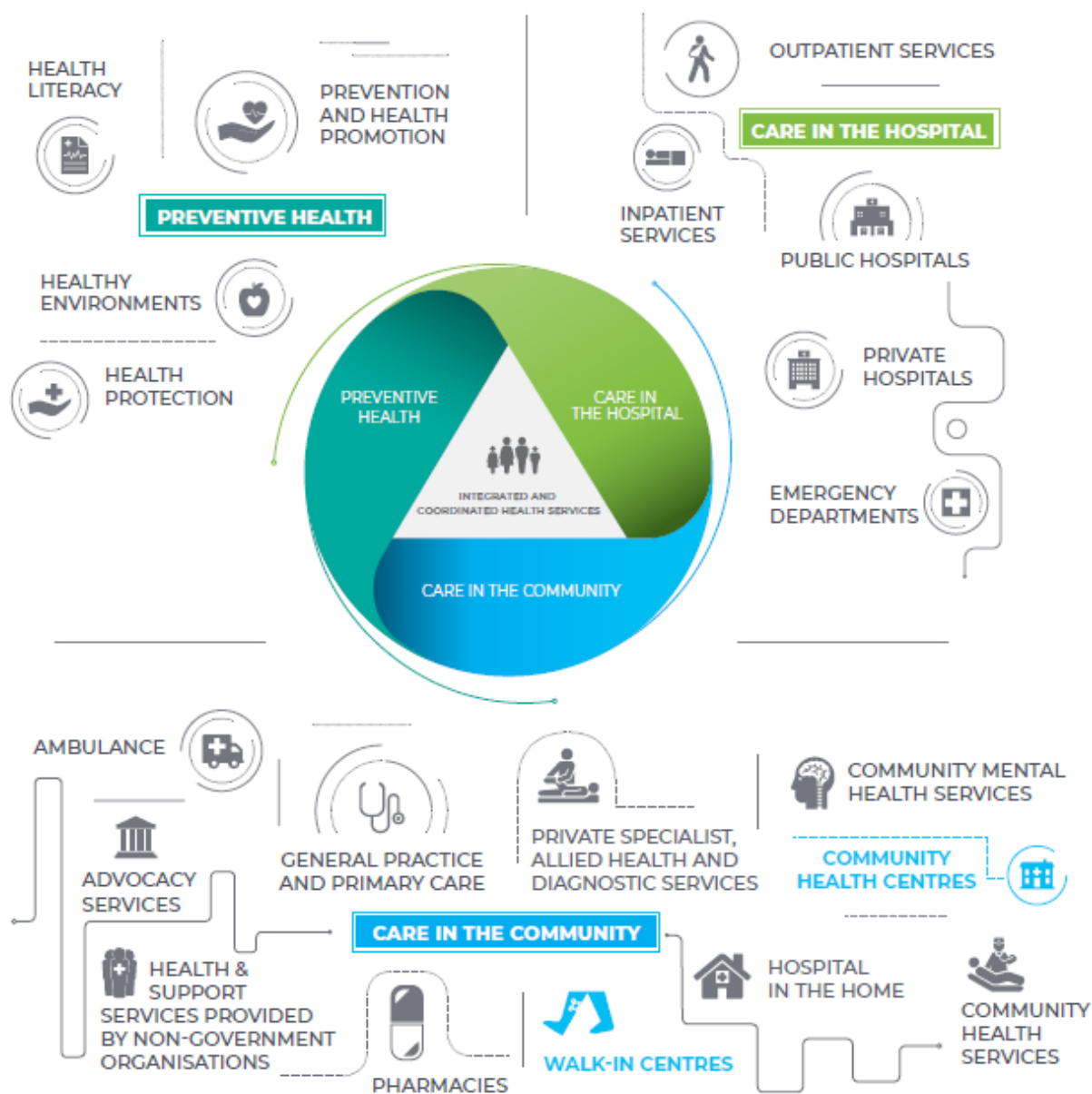


Figure 1: Schematic of the health system in the ACT - Accessible, Accountable, Sustainable: A framework for the ACT Public Health System 2020–2030, p.2

The ACT Health Directorate has responsibility for implementing the priorities set out in *Accessible, Accountable, Sustainable: A framework for the ACT Public Health System 2020–2030* ‘in partnership across governments and community’. Carrying out this responsibility involves working in a range of ways to influence the way services are designed and delivered. This can be done, for example, by:

- carrying out direct service provision responsibility;
- contracting/commissioning;
- health promotion/prevention strategies;

- professional networking and influence (ACT representation and opportunities for influence);
- consultation and partnership relationships with relevant peak organisations; and/or
- active engagement with clinical educators and educational institutions.

Key legislation and policy

Legislation

Australia’s approach to disability inclusion and action against discrimination on the basis of disability is guided by a range of formal agreements, legislation and standards at the international, national and jurisdiction-specific levels. The United Nations Convention on the Rights of Persons with Disabilities is a highly influential, internationally endorsed framework for improving inclusion and outcomes for people with disabilities and their families. Relevant Articles can be found at [Appendix 1](#). Legal rights against discrimination are protected by both national and jurisdiction-based legislation, as outlined from the ACT perspective in Figure 2 below.

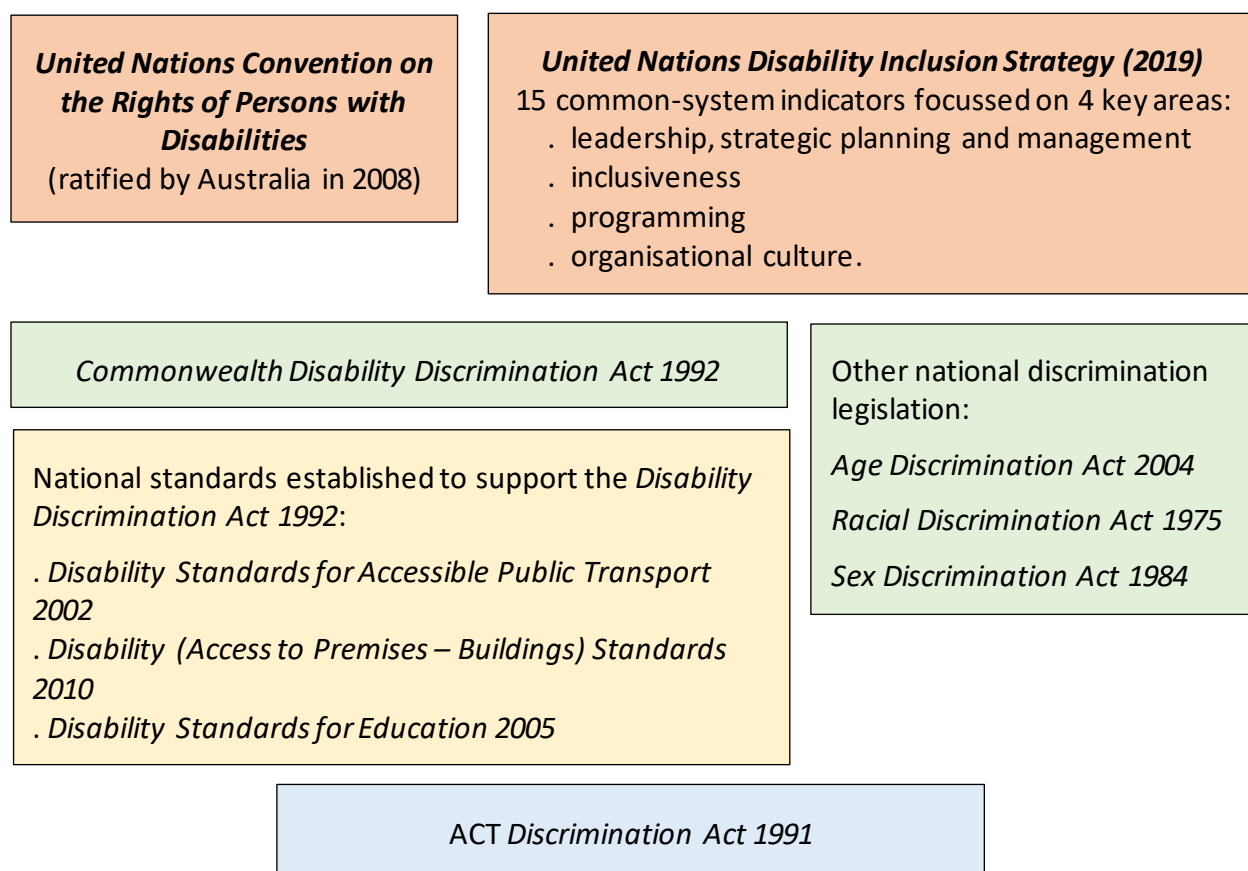


Figure 2: Schematic of relevant legislation, regulation and standards

In their publication ‘A quick guide to Australian discrimination laws (AHRC, 2014)’, the Australian Human Rights Commission (AHRC) notes that ‘Commonwealth laws and the state/territory laws generally overlap and prohibit the same type of discrimination. As both state/territory laws and Commonwealth laws apply, you must comply with both. Unfortunately, the laws apply in slightly different ways and

there are some gaps in the protection that is offered between different states and territories and at a Commonwealth level.’

Relevant national and ACT policy frameworks and strategies (current and planned)

The planning, design, and delivery of health services, and consumers’ engagement with those services, are strongly influenced by the relevant policy frameworks and strategic plans that are developed and published by government agencies and key service delivery organisations.

Figure 3 below provides a summary of the most influential current and planned policy documents that will inform development of the ACT Disability Health Strategy and First Action Plan. Naturally, since people with disabilities have the same rights and experience similar health issues as the remainder of the population, many of these documents address the broader population health care priorities. However, there are many overlapping priority issues and strategies in these policy documents that will need to be taken into account in the development of the Disability Health Strategy and First Action Plan in order to align and amplify relevant opportunities for improvement.

ACT representatives have been active participants in a recent series of policy discussions about the health needs of people with disabilities and priority national strategies. The outcomes of these discussions have been published as the *National Roadmap for Improving the Health of People with Intellectual Disability* (July 2021).

The key objectives of this Roadmap, which has a strong primary health care focus, are to:

- improve support for people with intellectual disability, their families and carers,
- develop better models of care for people with intellectual disability,
- provide support for health professionals to help them deliver quality care for people with intellectual disability,
- improve the oral health of people with intellectual disability, as a central requirement for improving their general health and overall wellbeing,
- strengthen research, data and measurement to monitor the health outcomes of people with intellectual disability, and assess the effectiveness of initiatives in improving their health, and
- improve emergency preparedness and response to ensure that the needs of people with intellectual disability are considered and met.

Consultations are also underway to develop the framework and priorities for a revised national disability strategy, which will be known as *Australia’s Disability Strategy* and is currently scheduled for release in December 2021. A 10 year ACT Disability Strategy is in turn scheduled for release in December 2022.

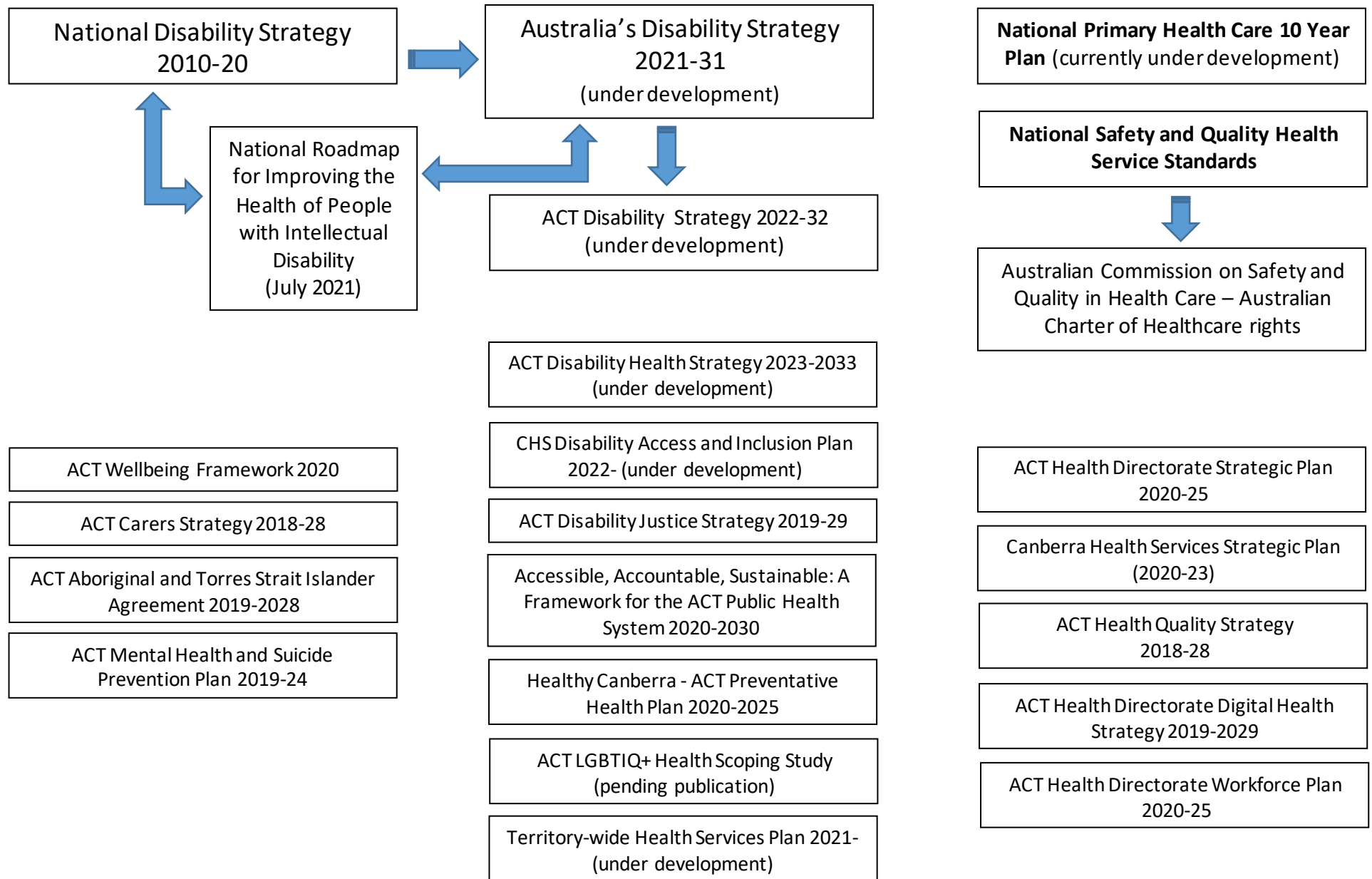


Figure 3: Overview of the national disability health policy and strategic planning documents

Recent relevant ACT reports

In recent years, several significant reports have been published in the ACT that provide useful research findings and other information that will support the development of an ACT Disability Health Strategy.

Some key examples of relevant ACT reports are as follows:

ACTCOSS (2019). ***Imagining Better Reflections on access, choice and control in ACT health services for people with disability: Report of the Appreciative Inquiry Project***, August 2019, ACT Council of Social Services, supported by the ACT Office for Disability

Coe, K. & Spiller, S. (2018). ***A model for patient navigation in the ACT for people with chronic and complex conditions***. Health Care Consumers' Association (ACT)

Towards Disability Justice for the ACT: Summary of research and consultations (2019). ACT Office for Disability

ACT COVID-19 Disability Strategy and ACT COVID-19 Disability Action Plan (2020). ACT Community Services Directorate, Inclusion and Participation

Hutchison, A. and Mollison, N. (2021) ***"I have to ask to be included..." ACT women with disabilities views about their health; their health needs; their access to services, supports and information; and the barriers to maintaining their health***. Women's Health Matters (embargoed).

Canberra Health Services (2021). ***Canberra Health Services Disability Needs Assessment (DRAFT)*** (embargoed).

ACT Health (2021). ***ACT LGBTQI+ Health Scoping Study*** (embargoed).

Key framework and policy documents from other Australian jurisdictions

There is considerable variability in what is published by health agencies to guide health care for people with disabilities in individual jurisdictions. The following documents offer examples of strategy building and guidance for their local health care system.

WA Disability Health Strategy 2015-25

Queensland Department of Health Disability Service Plan 2017-20

An Action Plan: Meeting the health needs of people in care with a disability. The Queensland Government's implementation plan in response to the Public Advocate's Report, 'Upholding the right to life and health'

NSW Health (2017). ***Responding to Needs of People with Disability during Hospitalisation: NSW Health Policy Directive***

Intellectual Disability: The Essentials. (2017). NSW Agency for Clinical Innovation

Victorian Service provision framework: Complex needs Including the Multiple and Complex Needs Initiative (MACNI) and Support for High Risk Tenancies (SfHRT) (2020)

Services Connect: Client support practice framework. Victorian Department of Health and Community Services (2015).

D. Social models of disability and health

The United Nations Convention on the Rights of Persons with Disabilities, which was ratified by the Australian Government in 2008, defines persons with disability as *‘those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others’*. This definition applies to the participation of people with disabilities in all aspects of the society we all share and calls upon all members of society to remove the societal barriers that hinder the full participation of people living with disability. In the health care sector, such barriers may include lack of affordable options for access to primary health care, physically inaccessible services, and limited availability to willing and disability-confident service providers.

Social model of disability

The term ‘social model of disability’ arose out of a UK-based movement called the Integration Alliance in the late 1980s, led by Richard Rieser and Micheline Mason (Rieser & Mason, 1990/1992) and initially focussed on integrating children with disabilities into mainstream schooling. This movement has been highly influential, and the term is now widely adopted internationally to apply to any setting where adjustment of that setting is required in order to ensure that people with disability can be included. It is a strengths-based approach, and in the health domain, has come to be compared with the ‘medical model of disability’, which is characterised as having a primary focus on disability as pathology that requires correction. The highlighted text below from People With Disability Australia is a useful description of the distinctions between social versus medical model of health care for people living with disability¹.

The social model of disability is now the internationally recognised way to view and address ‘disability’. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) marks the official paradigm shift in attitudes towards people with disability and approaches to disability concerns.

The social model of disability contrasts with what is called the medical model of disability. According to the medical model of disability, ‘disability’ is a health condition dealt with by medical professionals. People with disability are thought to be different to ‘what is normal’ or abnormal. ‘Disability’ is seen ‘to be a problem of the individual. From the medical model, a person with disability is in need of being fixed or cured. From this point of view, disability is a tragedy and people with disability are to be pitied. The medical model of disability is all about what a person cannot do and cannot be.

The social model sees ‘disability’ is the result of the interaction between people living with impairments and an environment filled with physical, attitudinal, communication and social barriers. It therefore carries the implication that the physical, attitudinal, communication and social environment must change to enable people living with impairments to participate in society on an equal basis with others.

¹ <https://pwd.org.au/resources/disability-info/social-model-of-disability/> - accessed 24 August 2021

People with disability are not 'objects' of charity, medical treatment and social protection but "subjects" with rights, capable of claiming those rights, able to make decisions for their own lives based on their free and informed consent and be active members of society.

In this context:

- **impairment** is a medical condition that leads to disability, while
 - **disability** is the result of the interaction between people living with impairments and barriers in the physical, attitudinal, communication and social environment.
- It is not the inability to walk that keeps a person from entering a building by themselves but the stairs that are inaccessible that keeps a wheelchair-user from entering that building.

A social model perspective does not deny the reality of impairment nor its impact on the individual. However, it does challenge the physical, attitudinal, communication and social environment to accommodate impairment as an expected incident of human diversity.

The social model seeks to change society in order to accommodate people living with impairment; it does not seek to change persons with impairment to accommodate society. It supports the view that people with disability have a right to be fully participating citizens on an equal basis with others.

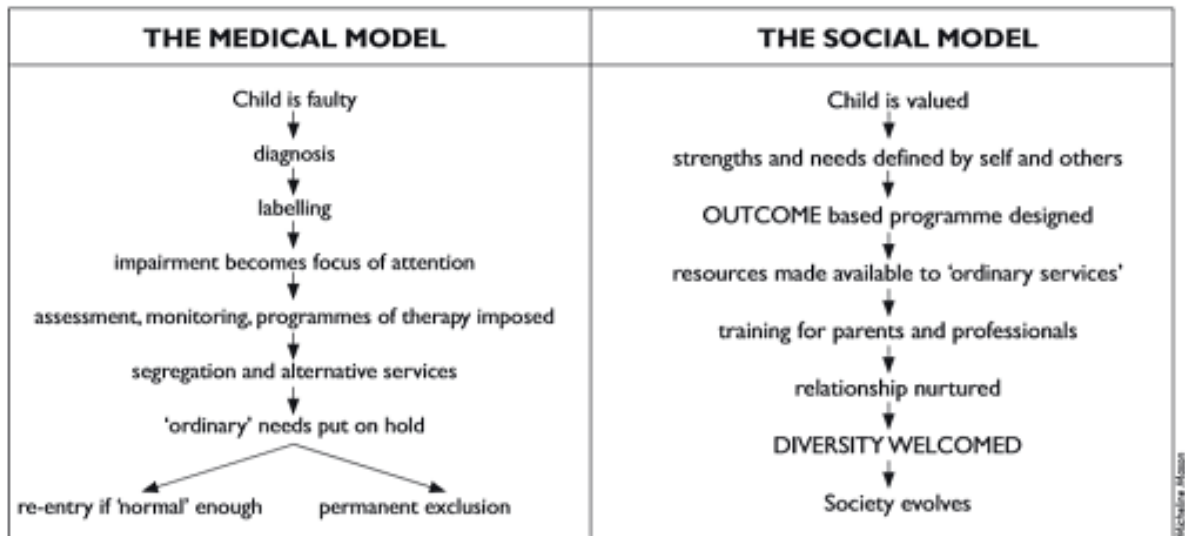


Figure 4: Example comparisons between perspectives from the medical model versus the social model (Mason and Rieser, 1994, p.19)

Social model of health

The emergence of the social model of disability aligns closely and has been informed by a similar shift in focus away from a strictly clinical or 'medical' model of health policy and care practices that has been occurring since systems theorist G.L. Engel postulated in the late 1970s that better health outcomes could be achieved if health care and health improvement efforts were viewed from a 'biopsychosocial model' perspective (Engel, 1978). Figure 5 below provides an overview of the relationships and influences that Engel saw as relevant to a comprehensive understanding of the key influences on health outcomes and therefore what types of inputs could lead to better health care and outcomes.

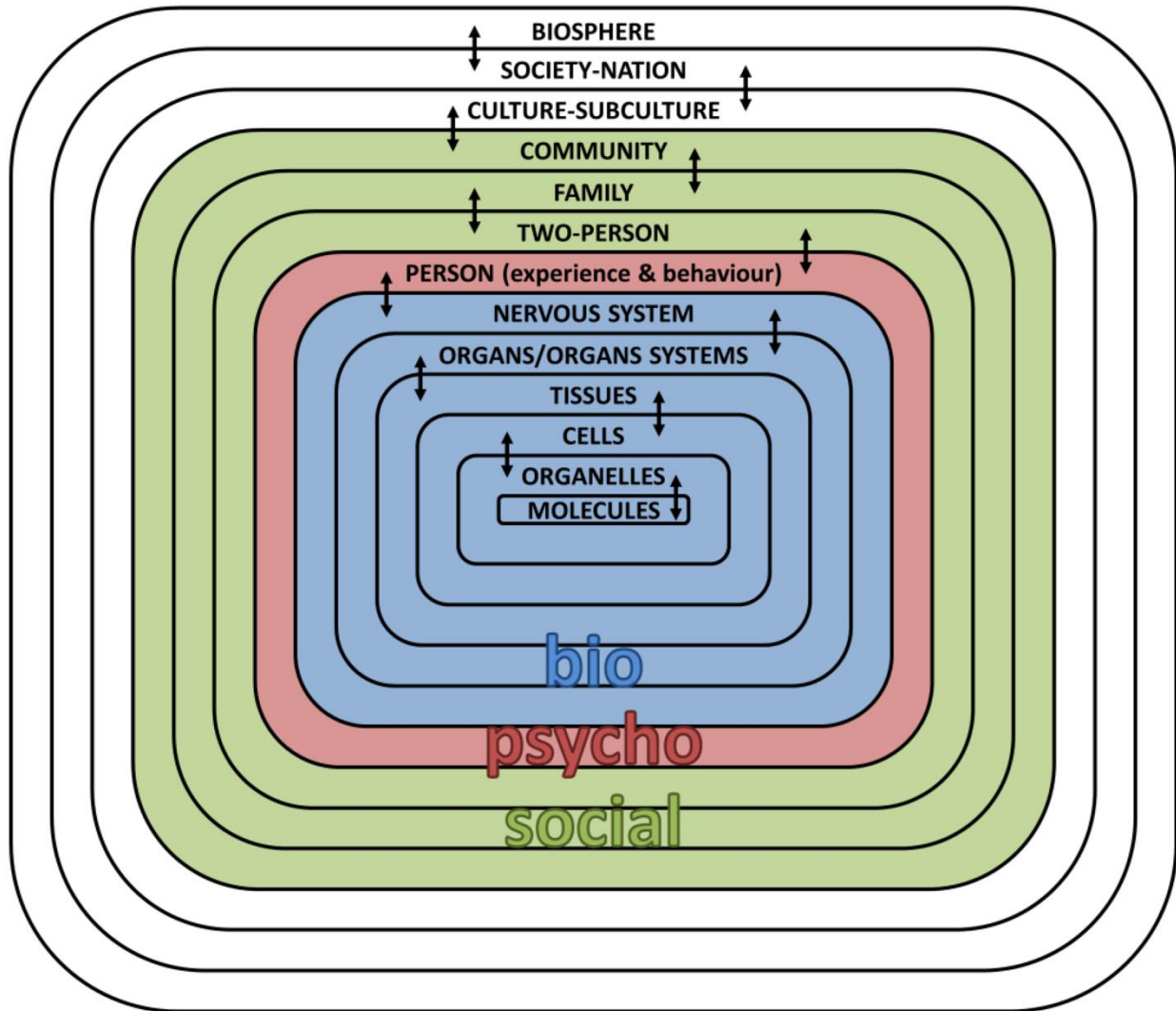


Figure 5: Schematic representation of the hierarchy and continuum of natural systems as applicable to Engel's definition of the biopsychosocial model – adapted from 'The clinical application of the biopsychosocial model'

This more multi-factorial and layered approach to understanding how health status can be influenced has continued to receive increasing support in health policy and practice since that time throughout the Western world (WHO, 2011; United Nations, 2015). The WHO (2011) describes social determinants of health and their impact as follows:

The social determinants of health (SDH) are the non-medical factors that influence health outcomes. They are the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life. These forces and systems include economic policies and systems, development agendas, social norms, social policies and political systems.

The SDH have an important influence on health inequities – the unfair and avoidable differences in health status seen within and between countries. In countries at all levels of income, health and illness follow a social gradient: the lower the socioeconomic position, the worse the health.

The following list provides examples of the social determinants of health, which can influence health equity in positive and negative ways:

- Income and social protection
- Education
- Unemployment and job insecurity
- Working life conditions
- Food insecurity
- Housing, basic amenities and the environment
- Early childhood development
- Social inclusion and non-discrimination
- Structural conflict
- Access to affordable health services of decent quality.

Research shows that the social determinants can be more important than health care or lifestyle choices in influencing health. For example, numerous studies suggest that SDH account for between 30-55% of health outcomes. In addition, estimates show that the contribution of sectors outside health to population health outcomes exceeds the contribution from the health sector (WHO, 2011).

In Australia, this broader approach to health has been expressed in particular in relation to policies for identifying and addressing social determinants of health affecting Aboriginal and Torres Strait Islander peoples. But, in a similar shift to that described above in relation to how disability is responded to in the social model of disability, Aboriginal and Torres Strait Islander communities have increasingly pointed to the need for a strengths-based approach to improve health outcomes in their communities. Cultural determinants of health provide this positive lens through which to view health improvement, as articulated by Professor Ngaire Brown in a 2013 Communique from the National Aboriginal Community Controlled Health Organisation (NACCHO):

Although widely accepted and broadly researched, the social determinants approach to health and wellbeing appear to reflect a deficit perspective – demonstrating poorer health outcomes for those from lower socioeconomic populations, with lower educational attainment, long term unemployment and welfare dependency and intergenerational disadvantage.

The cultural determinants of health originate from and promote a strength-based perspective, acknowledging that stronger connections to culture and country build stronger individual and collective identities, a sense of self-esteem, resilience, and improved outcomes across the other determinants of health including education, economic stability and community safety.

Exploring and articulating the cultural determinants of health acknowledges the extensive and well-established knowledge networks that exist within communities, the Aboriginal Community Controlled Health Service movement, human rights and social justice sectors.

Consistent with the thematic approach to the Articles of the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP), cultural determinants include, but are not limited to:

- Self-determination

- Freedom from discrimination
- Individual and collective rights
- Freedom from assimilation and destruction of culture
- Protection from removal/relocation
- Connection to, custodianship, and utilisation of country and traditional lands
- Reclamation, revitalisation, preservation and promotion of language and cultural practices
- Protection and promotion of Traditional Knowledge and Indigenous Intellectual Property; &
- Understanding of lore, law and traditional roles and responsibilities. (NACCHO, 2013)

In summary, the social models of both disability and health call for a holistic and person-centred approach to improving the health of society members. The ongoing challenge is to identify and remove barriers to care and adapt programs, services and behaviours to facilitate access to services for those with differing needs.

A recent factsheet published by the WHO (December 2020) highlights the public health issues and social determinants associated with improving the health of people with disabilities and points to the key known barriers facing this diverse population:

1. prohibitive costs,
2. limited availability of services,
3. physical barriers, and
4. inadequate skills and knowledge of health workers.

This fact sheet points to the following interacting areas for investment of effort to improve health outcomes for people with disabilities:

Policy and legislation: Assess existing policies and services, identify priorities to reduce health inequalities and ensure disability inclusion in the health sector. Establish healthcare standards related to care of persons with disability with enforcement mechanisms.

Financing: Use financial incentives to encourage healthcare providers to make services accessible and provide comprehensive assessments, treatment, and follow-ups.

Service delivery: Ensure access to effective promotion, prevention, treatment, rehabilitation and palliative health services. Provide a broad range of environmental modifications and adjustments (reasonable accommodation) to facilitate access to healthcare services.

Human resources: Ensure healthcare workers have the necessary competencies and skills to address the individual needs of people with disability.

Data and research: Ensure data disaggregation by disability, needs, barriers, and health outcomes for people with disability. (WHO, 2020)

This review process also found several other frameworks or strategy outlines that could provide useful guidance in the development of the ACT Disability Health Strategy and First Action Plan. These frameworks contain many of the same elements and together offer quite well defined guidance.

As indicated in Figure 3 above, for example, a National Roadmap for improving the Health of People with Intellectual Disability has recently been published by the Commonwealth Department of Health

(July 2021) after a process of consultation with State/Territory jurisdictions and a broad range of other stakeholder groups.

The key objectives of that Roadmap are to:

- improve support for people with intellectual disability, their families and carers,
- develop better models of care for people with intellectual disability,
- provide support for health professionals to help them deliver quality care for people with intellectual disability,
- improve the oral health of people with intellectual disability, as a central requirement for improving their general health and overall wellbeing,
- strengthen research, data and measurement to monitor the health outcomes of people with intellectual disability, and assess the effectiveness of initiatives in improving their health, and
- improve emergency preparedness and response to ensure that the needs of people with intellectual disability are considered and met. (Executive Summary, p. v)

In 2004, members of the European Association of Intellectual Disability Medicine published a manifesto on the standards of care they recommended as a basis for supporting good health care for people with disabilities in Europe (Meijer et al., 2004). They identified five core standards and associated priority issues to guide practice. These are summarised at [Appendix 2](#).

In 2006, Krahn and colleagues (Krahn et al, 2006) also published a comprehensive recommended set of actions to guide future improvements in the health of people with disabilities. An outline of those key actions is provided at [Appendix 3](#).

Though primarily writing in relation to the needs of people with disabilities and mental health issues, O’Hara (2008) outlined the following suggested list of quality standards that would assist in improving health outcomes for all people with disabilities:

- Accessible services – not just physical access but administrative access (i.e. how appointments are made and followed up)
- A safe environment
- Feeling respected as an individual
- Having one’s privacy and confidentiality respected
- Good communication – appropriate signposting, literature and written communication and complaints procedures
- Good personal communication – using aids and supports as appropriate; having things explained in a way that is understood
- Being listened to and having one’s opinions sought and respected
- High quality, evidence-based clinical care.

In 2019, the Alliance for Disability in Health Care Education (2019) published guiding principles and shared values that they deemed essential to providing quality care to people with disabilities and which establish the basis of core competencies on disability. The Alliance notes that high quality healthcare for people with disabilities depends, in part, on the values held by healthcare providers. Their guiding principles and values are as follows:

1. Culturally and linguistically competent care for patients with disabilities means recognizing that patients have diverse backgrounds and are influenced by multiple social, economic, and cultural factors, all of which should be included in a comprehensive view of a patient's health status and treatment.
2. People with disabilities should have equitable access to appropriate, accessible, and high-quality health care.
3. People with disabilities face barriers in accessing effective health care that may or may not be associated with their disabilities.
4. Training should be provided to all health care providers so that they are able to provide high-quality care to patients with disabilities.
5. Healthcare providers can maximize the quality of life of their patients with disabilities by preventing and treating health conditions.
6. People with disabilities are typically knowledgeable of their condition, and this expertise should be respected and used to improve healthcare decisions and care.
7. Quality of life and treatment goals should incorporate and reflect the patient's point of view.
8. Healthcare providers should communicate directly and respectfully with patients with disabilities, including them in the decision-making process.
9. Healthcare providers should know under what circumstances caregivers should be included in healthcare encounter and decision-making.
10. Provide the optimal patient experience by creating a respectful, accessible, and welcoming office environment using universal design principles. Accessible diagnostic/screening equipment and techniques are essential to quality health care for patients with disabilities.

E. People with disability in control of their own health

In line with the social model of disability and the now widely adopted motto ‘Nothing About Us Without Us’ (Charlton, 2000), quality health care for people with disabilities relies on the principle of participation. This principle should underpin all efforts to improve outcomes for this community.

The New Zealand Government has published a unique example of health policy and goal setting using a ‘first person’ voice. This demonstrates the principle of participation and leadership of people with disabilities from the outset (NZ Office for Disability Issues, 2017).

Our future and what needs to happen

What our future looks like

Healthcare professionals treat us with dignity and respect. We are seen as individuals and receive appropriate and timely support for all of our health needs, not just those related to our impairment. We do not face barriers accessing mainstream health services because of our impairments, in particular sexual and reproductive health services for disabled women and girls. When we need to, we can access services specific to our impairment (including habilitation², rehabilitation and recovery) in a way that provides early diagnosis and ensures our needs as individuals are taken into consideration.

We have choice and control over all the supports and services we receive, and information about these services is available in formats that are accessible to us. We also have access to information about us. Those of us who need support to communicate or make decisions receive it in an appropriate way at the right time, and those decisions are recognised and respected. We are not secluded within services, and not segregated from or isolated within our communities.

Issues of bioethics and bodily integrity are treated with sensitivity, with due regard for our rights and informed consent. This includes making sure our families, whānau and those who support us have the right access to the right information when they are involved in supporting us to make decisions. In the rare circumstances when decisions need to be made on our behalf, these are based on the best interpretation of our will and preference, as opposed to just thinking about what is in our best interests.

Access to high quality peer support enables us to recover from periods of being unwell, and flourish with the confidence that we are not alone. Our identity as members of other communities, such as Māori or Pacific, will be respected and we will have access to services that are culturally appropriate. The importance of belonging to and participating in our community to reduce social isolation, and increase our overall wellbeing, is recognised and supported. We get involved in sport, recreation and arts activities, and are recognised and valued for this. Those of us who identify as members of other communities do not face barriers participating in and contributing to cultural

² **Murphy, L. (2018). *Difference Between Habilitation and Rehabilitation*.**

Accessed online 24 September 2021 - <https://napacenter.org/difference-between-habilitation-and-rehabilitation/>

Habilitation refers to a process aimed at helping individuals with disabilities attain, keep, or improve skills and functioning for daily living. For pediatric patients, habilitative therapy often aims to help a child develop motor skills that they have yet to accomplish.

Rehabilitation refers to regaining skills, abilities, or knowledge that may have been lost or compromised as a result of illness, injury, or acquiring a disability.

activities because of our impairments. We are supported to be healthy and well and can participate in community activities on an equal basis with others.

What this means:

- Disabled people are consulted on and actively involved in the development and implementation of legislation and policies concerning health & well-being, including sport, recreation, arts & culture.
- Access to mainstream health services is barrier-free and inclusive.
- Services that are specific to disabled people, including mental health and aged care services, are high quality, available and accessible.
- All health and well-being professionals treat disabled people with dignity and respect.
- Participation in community activities if we choose (for example, sport, recreation, arts and culture), or just being present and belonging to our community is supported and valued.
- Decision-making on issues regarding the health and well-being of disabled people is informed by robust data and evidence.

F. People with disability have diverse needs

For those who face additional barriers related to culture, language, religion, gender or age, there will be additional potential barriers to engagement and inclusion that require active attention and analysis. As is the case with all consumers and their families, health care providers need to be aware of the diverse backgrounds of people with disability and their support networks. *Accessible, Accountable, Sustainable: A framework for the ACT Public Health System 2020–2030* identifies the following diverse populations in the ACT.

- Aboriginal and Torres Strait Islander peoples
- Children and young people
- Families with complex needs
- People with chronic conditions including mental illness
- People with disability
- LGBTIQ+ community
- Culturally and linguistically diverse peoples
- Older people
- Carers.

The **intersectionality** of those diverse needs with the experience of living with disability has been shown to have specific additional impacts. Health care providers should have the opportunity to learn about these intersecting factors so they can be proactively explored with consumers and care strategies can be delivered in the most person-centred and effective ways (Meade et al., 2015).

Figure 6 below provides a high level summary of particular needs, issues or sensitivities that are commonly experienced by people with disabilities in specific population groups. While not all members of each of these identified population groups may not experience barriers to care to the same extent or in the same ways, these experiences are well enough documented and statistically prevalent compared to the general population that the health system should be well prepared to adapt as needed for inclusion.

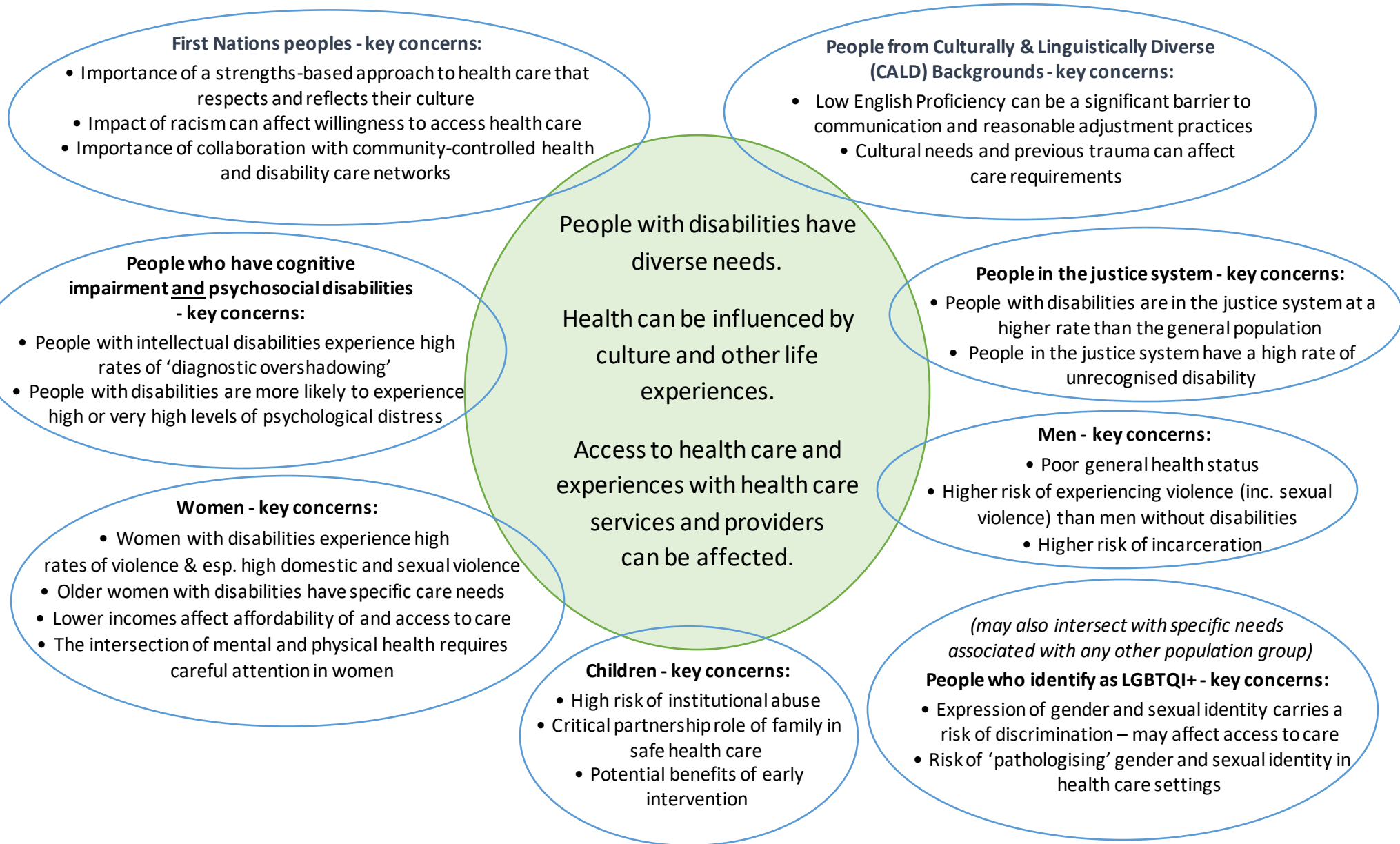


Figure 6: People with disabilities come from diverse backgrounds that can intersect with their health care needs and services

G. Poor health outcomes are common for people with disabilities

Poor health outcomes for people living with disability are widely reported internationally, nationally, locally in the ACT and in other Australian jurisdictions. In many cases, this information comes to light as a result of special inquiries associated with specific occurrences of harm, such as the often-cited UK report by Mencap (2007) and the current Australian Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2019 – present).

This page provides a snapshot of poor health outcome-related statistics from the literature.

Adults with disabilities are **up to 4 times more likely** to develop cardiovascular disease than the general population.

(Krahn et al., 2015)

People with disabilities are more likely to experience an adverse event in hospital than the general population. Adverse events in Australia are estimated to account for **8.9% of total hospital expenditure.** (ACSQHC, 2017)

38% of deaths

of people with intellectual disability in NSW were **potentially avoidable** once their disability was removed as the cause of death.

(Trollor et al., 2017)

47% of people with disabilities have experienced violence after the age of 15 years, compared with 36% without disabilities. (AIHW, 2020)

24% of adults with disability rate their health as excellent or very good (65% of adults without disability). (AIHW, 2020)

32% of adults

with disability experience a high or very high level of psychological distress (8.0% without disability). (AIHW, 2020)

People with disabilities have a much **greater risk of dying from pneumonia** and aspiration pneumonia.

(Trollor et al., 2017)

In the UK, **men with mental health conditions die 20 years earlier** than the general population, and **women 13 years earlier** on average. Most of these deaths were judged preventable if timely medical intervention had been available.

(BMA, 2014)

H. Making the health system work for people with disabilities

The Principles of Universal Design

The '7 Principles of Universal Design' were developed and published in 1997 by The Center for Universal Design in collaboration with a consortium of universal design researchers and practitioners from across the United States. The principles they identified to guide the planning, design and delivery of facilities, equipment or services in order to maximise accessibility and also to reduce the need for ongoing 'reasonable adjustment' responses (see section below). These principles are:

1. Equitable Use
2. Flexibility in Use
3. Simple and Intuitive to Use
4. Perceptible Information
5. Tolerance for Error
6. Low Physical Effort
7. Size and Space for Approach and Use

Universal design, which was defined by the Center for Universal Design as 'the design of products and environments so that they are usable by all people, to the greatest extent possible, without the need for adaptation or specialised design', can apply to service delivery design as well as the physical products, environment and infrastructure. When universal design is applied (in conjunction with co-design methodology), the consequence is that fewer requests and requirements for specific access considerations, reasonable adjustments and accommodations, as more people (and ideally everyone) is able to use the same spaces, products and services.

The principle of reasonable adjustment

According to the definition included in the UN Convention, 'reasonable accommodation' (or the commonly used term 'reasonable adjustment') means the '*necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms*'.

This principle is strongly embedded in both the national and ACT laws that aim to prevent discrimination and it applies across a wide range of settings, including employment, education and health. In the health setting in particular, the absence of effective reasonable adjustment practices has been found to be directly related to adverse outcomes (including death) for people with disabilities using health care services (Mencap, 2007; 2012). A high profile and often-cited report on the experiences of people with disabilities with the National Health Service in the United Kingdom (Tuffrey-Winje et al, 2013) noted that quality for the National Health Service was understood to have three key dimensions – safety, effectiveness and patient experience – and noted that the provision of reasonable adjustments is central to each of these.

This mixed methods study by Tuffrey-Wijne et al. (2013) noted that examples of good practice were not consistently replicated hospital-wide and that the most common safety issues were delays and

omissions of treatment and basic care. The main **barriers** to better and safer hospital care for people with learning disabilities were:

1. the invisibility of patients with learning disabilities within hospitals, owing to a lack of effective flagging systems and a lack of staff knowledge and willingness to flag this group
2. poor staff understanding of the specific vulnerabilities of people with learning disabilities, the reasonable adjustments to services that these patients may need and the Mental Capacity Act 2005
3. a lack of consistent and effective carer involvement and misunderstanding by staff of the carer role
4. a lack of clear lines of responsibility and accountability for the care of each patient with learning disabilities.

The main **enablers** were the learning disability liaison nurse (LDLN), provided that this role was properly supported by senior management and carried sufficient authority to change practice; and ward managers who facilitated a positive ward culture and ensured consistent implementation of reasonable adjustments.

Since the introduction of the *Equality Act 2010* in the UK, there has been a renewed emphasis on the role of reasonable adjustment in ensuring equitable access to all aspects of societal activity and a strengthened emphasis on accountability of government agencies in particular to take responsibility for these practices (Heslop et al., 2019). A summary of the Equality Act can be found at [Appendix 4](#).

The Equality Act 2010 describes three main methods for providing reasonable adjustments:

- Changing a practice, policy or procedure that makes it challenging for disabled people to access or use services
- Changing a physical feature to remove, change, or provide a reasonable method of avoiding barriers such as steps, doors, toilets or signage
- Providing additional aids or services where it would assist disabled people, such as using British Sign Language interpreters, or providing information in an alternative format. (Heslop, 2019)

Phillips (2019) points out that reasonable adjustments must be person-centred and respond to the person's particular needs and that adjustments do not have to be costly and can be provided by anyone involved in the care of the person. This article provides the following examples of reasonable adjustments that have been used in practice in the UK and point out that this list is not exhaustive.

- Using simpler language and avoiding abbreviations and jargon
- Using communication aids, such as Makaton symbols, Widgit symbols or Talking Mats. Talking Mats is an interactive resource that uses symbols to help people with communication difficulties understand and consider issues discussed with them, express their opinions effectively and clarify what is to be included in decision making. It is particularly useful when obtaining consent for treatment
- Allowing extra time for appointments
- Providing written information in an accessible, easy-read format, and using symbols to reinforce the written word (as in the accessible summary in Fig 6 below)
- Providing a quiet waiting area

- Using a pager so patients can wait in a place of their choice until they are ready to be seen
- Inviting patients to pre-admission visits so they can familiarise themselves with the environment and know what to expect
- Giving people appointments at the start or end of clinics, when the environment is less busy
- Ensuring patients are first on the theatre list to reduce their waiting time
- Providing meals or overnight stays to family carers
- Arranging for multiple procedures to be carried out under one general anaesthetic.

Phillips (2019) also provides the graphic at Figure 7 below – an example of a poster that has been developed for use in a British hospital setting as a reminder for all staff members of their responsibilities to proactively support the design and implementation of reasonable adjustments where needed. It provides visual examples of the various ways that such adjustments can and should be made if necessary.

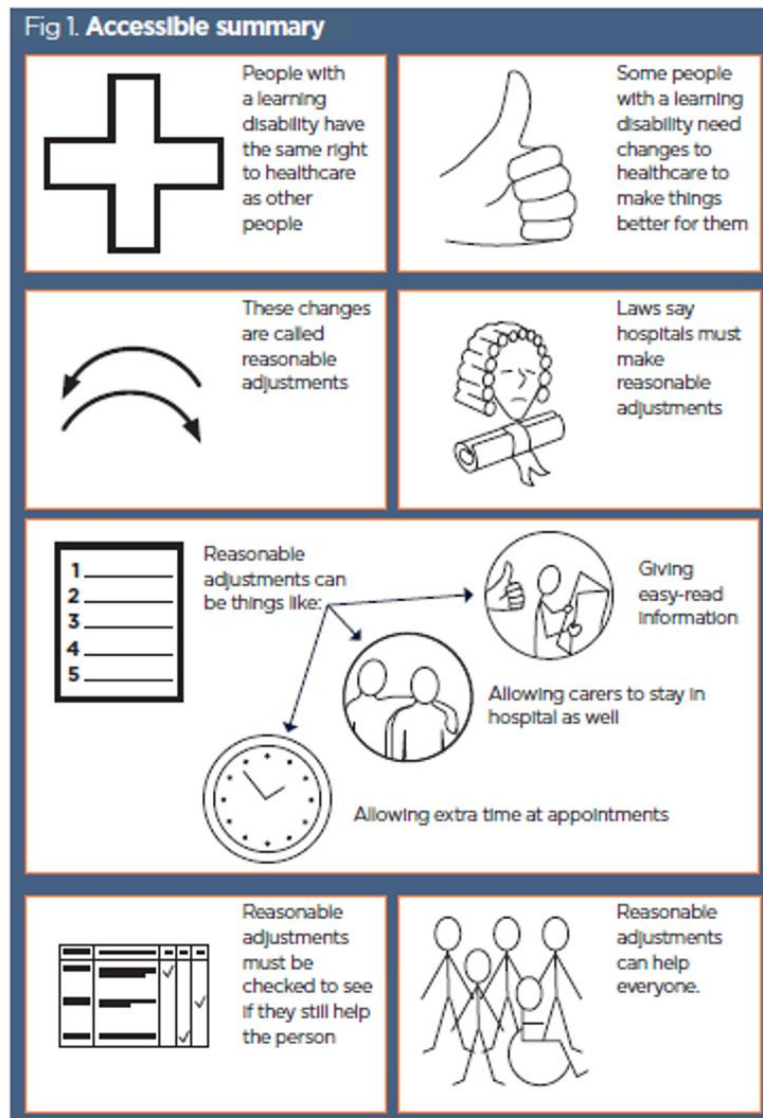


Figure 7: Example poster for reasonable adjustment strategies (Phillips, 2019, p39)

I. Issues and strategies

Consideration of the legislation, policy, frameworks and literature outlined above suggests that issues and strategies associated with improving the health of people with disabilities can be categorised into five key groupings: **prevention and wellbeing**, **organisational management**, **reasonable adjustments**, **service infrastructure and workforce**, **tailored service models**, and **other access issues** (such as financial barriers to appropriate care).

Prevention and wellbeing

i. Policy and program settings

Issue/s:

Numerous studies have shown that people with disabilities are less likely to:

- Engage in physical activity
- Receive messaging about population-wide health promotion strategies
- Participate in public screening and early intervention services than the broader population (Krahn et al. 2006 & 2017).

As a result of this low level of engagement with health-promoting activity and prevention-oriented health services, people with disabilities are much more likely than the general population to develop lifestyle-related chronic illness and to have those illnesses diagnosed and treated at a later stage (Trollor et al., 2016; Salomon & Trollor, 2019). They are also more likely to have other potentially preventable and/or treatable conditions, such as cancer, diagnosed at a stage where a good health outcome is significantly less likely (NSW Ombudsman, 2018).

Strategies for improvement:

Improving outcomes through better access to prevention and health promoting strategies can be achieved by:

- Implementing a range of strategies to promote participation in healthy activities, including implementing suitable reasonable adjustment strategies for access to those activities and programs that provide targeted skill development and mentoring and/or peer-based supports to build confidence
- Ensuring that communication about health promotion strategies includes portrayal of diversity and is available in a range of forms and communication channels so that the messaging will be received effectively by people of all abilities
- Outreach programs for screening services
- Strengthening primary care relationships by improving access to stable and accessible primary care services and trusted providers (Selick et al., 2018).

In recognition of the proven need to support proactive prevention, early diagnosis and active management of the health of people with intellectual disabilities, there are specific attendance items listed on the Commonwealth Medicare Benefits Schedule (MBS Item Numbers 701, 703, 705 & 707 – <http://www9.health.gov.au/mbs/fullDisplay.cfm?type=item&q=705&qt=item>). Studies have shown that such regular checks can improve health outcomes (Lennox et al., 2007) and specific tools have been developed to support this approach in general practice. The most widely used tool in Australia

is the Comprehensive Health Assessment Program (CHAP) tool developed by an Australian GP academic at the University of Queensland, Professor Nick Lennox. This assessment tool has been extensively implemented and peer-reviewed and is available for a small fee from the university (<https://gcidd.centre.uq.edu.au/resources/chap>).

ii. Health system literacy development

Issue/s:

People with disabilities are known to have lower levels of awareness of the existence of health services, the roles of those services and how to access those services (ACSQHC, 2013). They are also less likely to have a comprehensive understanding of how to take a proactive approach to their own health management and the supports they need in the health system to build and maintain good health (Krahn et al., 2006; Krahn et al., 2016). A lower level of health literacy can also leave more scope for safety issues during the course of health care service provision (ACSQHC, 2013).

Strategies for improvement:

Good access to easy-to-understand information material about priority health issues and what to do to stay healthy and get the right health services has been found to be effective (ACSQHC, 2013). Availability of this form of information is particularly effective when combined with a more personalised approach involving support and assistance with service navigation. The Tasmanian Government has developed a *Communication and Health Literacy Action Plan* (Department of Health & Human Services, 2018) that provides guidance and online resources for staff and the broader community on increasing the health literacy of all Tasmanians. The key principles identified in the Action Plan are:

- clients have a right to information: it is the responsibility of government to communicate effectively
- clients have a right to be involved in decision-making about their health and wellbeing
- improving health literacy is a shared responsibility, especially across the health and education sectors
- improving communication and health literacy requires small contributions from many
- consistency of messages in important and supported by evidence-informed practice.

Organisational management

iii. Management goals and accountability

Issue/s:

Despite broader legislative and international agreement requirements about the rights of people with disability and the need for 'reasonable accommodation' (DDA, 1992; UNCRPD, 2006) to promote equity of access to the same services and information that is available to the general population, studies continue to reveal that access to health care is not achieved equitably by all people who live with disabilities (Naaldenberg et al., 2015). There are currently few systems in place in Australia to systematically monitor whether adequate accommodations have been made to ensure good access to care and to quality of care (NSW Ombudsman, 2018). The absence of such monitoring systems being in place mean that it can be virtually impossible for even highly motivated managers to demonstrate their organisation's performance in this area.

Strategies for improvement:

The first step in improving practice in relation to access and quality of care is to identify and document the actions and outcomes that are relevant to monitor (O’Hara, 2008). The next step is to implement a monitoring system, such as an audit and review process, to check performance against the established targets. Typically, this audit approach appears to be implemented as part of a local quality improvement activity but in some settings this performance information is utilised to monitor performance at a broader organisational level (Tuffrey-Wijne et al., 2013).

The schematic prepared by Tuffrey-Wijne and her team, in Figure 9 on the following page, provides an overview of the factors that contribute to barriers and enablers of safe health care for people with disabilities. In turn, this provides guidance for those actions that would warrant a combination of investment to develop better skills and responses as well as careful performance goal-setting and monitoring.

For population groups who will need reasonable adjustment support for a successful planned hospitalisation, such as people who live with disability, integration of care can also commence prior to hospitalisation, resulting in a full circle of integrated care from pre-admission to discharge and re-integration to community care (US Agency for Healthcare Research and Quality, 2013).

The established principles of integrated care align well with the current *ACT Health Quality Strategy 2018-2028* (Quality Strategy) and its three identified strategic priorities:

Strategic Priority 1: Person-centred – Improve the experience of care

Strategic Priority 2: Patient Safety – Proactively seek a reduction in patient harm

Strategic Priority 3: Effective Care – Best evidence for every person, every time.

Figure 8 below provides further information about the issues identified for active attention and management.

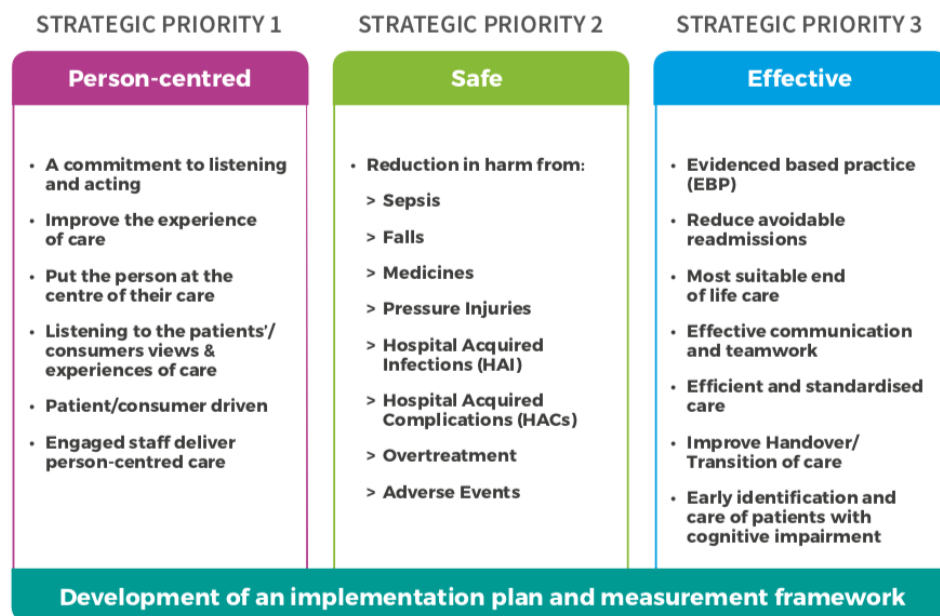
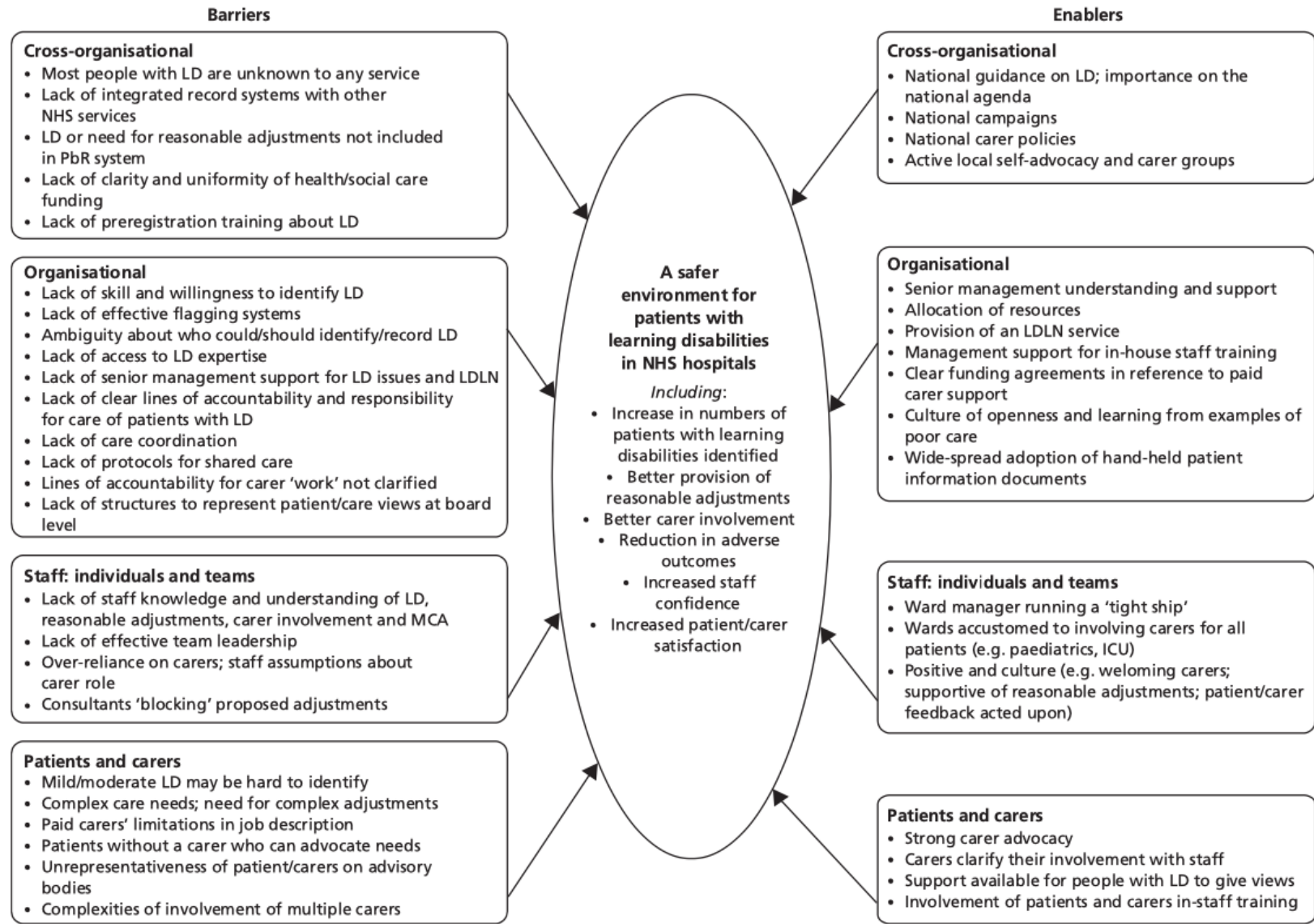


Figure 8: ACT Strategic Priorities for Quality and priority issues for action and ongoing review



14 Empirical framework showing the factors that affect the promotion of a safer environment for patients with learning disabilities. LD, learning disabilities.

Figure 9: Overview of organisational barriers and enablers for reasonable adjustment (Tuffrey-Wijne et al. 2013)

These priorities are embedded within a broader framework for driving quality and better outcomes, as elaborated in Figure 10 below that outlines the Quality Strategy drivers.



Figure 10: Quality Strategy driver diagram, ACT Health Quality Strategy 2018-2028

iv. Data and monitoring processes

Issue/s:

There are currently few systems in place in Australia (and in the ACT) to systematically monitor whether adequate accommodations have been made to ensure good access to care and to quality of care (Trollor et al., 2016). The absence of such monitoring systems being in place mean that it can be virtually impossible for even highly motivated managers to demonstrate their organisation’s performance in this area.

While the availability and use of electronic health records hold a lot of potential for improving access to critical information that can support personalised health care, including in crisis situations, some safeguards and cautions are warranted. Information held on these records may be out of date or incomplete and may not provide a suitable basis for decision-making (Zegers et al., 2009).

Strategies for improvement:

In the UK, the 2008 Independent Inquiry into access to Healthcare for People with Learning Disabilities and subsequent introduction of the *Equality Act 2010*, there has been an increasing emphasis on the need for collection of data on the care of people with disabilities, including flagging mechanisms, and effective monitoring systems (Tuffrey-Wijne et al., 2015).

The NSW Policy Directive on People with Disabilities in Hospital (2017) sets out the following guidance for Local Health Districts to improve their capacity to monitor and address their performance for this population:

- Access by people with disability to health services (including hospitals) — how many seen; in what services; for what reasons
- Adherence to adjustments to meet the needs of people with disability — including audits of identified support needs/adjustments required and the adjustments made (and type of adjustment)
- Rates and trends over time for emergency department presentations, including:
 - Pathways to and from emergency department
 - Rates of ambulatory care sensitive presentations to emergency department for people with disability, disaggregated by disability type.
- Rates and trends over time for admitted patient data for people with disability, disaggregated by disability type and admission facility, including:
 - Admission pathways
 - Diagnoses
 - Potentially avoidable admissions
 - Length of stay
 - Separation mode
 - 30-day readmission rates.
- Rates and trends over time for ambulatory care for people with disability, disaggregated by disability type and ambulatory care setting
- Error rates for people with and without disability, disaggregated by disability type
- Use of restraints (with examination of the identified support needs and the support provided)
- Inclusion in chronic disease management and other out-of-hospital programs
- Inclusion in preventative health programs.

Flagging of clinical records for the purpose of creating alerts for various priority issues can be a useful tool, particularly in relation to safety issues. Although flagging is an increasingly common tool in acute care facilities in particular, caution is warranted. Given the well-documented high risk of adverse events, such as choking or aspiration pneumonia, for some patient populations, it is critical that risks are dealt with openly and relevant person-specific strategies put in place that are well understood by health care providers and the patient and their support network. In other words, the way that flagging is applied should promote engagement with the person, their support network and their current needs for reasonable adjustment rather than as a static flag that remains in a person's health care record from admission to admission

A flagging system that merely operationalises decision-making on the part of health care staff without the active and current input from the person with disability and their carer/family, including the use of appropriately adjusted consent procedures, introduces the risk of adverse outcomes. Implementation of a flagging system therefore should only be implemented with the consent of the person with disability, in consultation with their nominated support person if needed (ACI, 2015). Ideally, flagging should operationalise the need for discussion of reasonable adjustment needs at each point in the care journey (e.g. ambulance transport, Accident and Emergency Department, hospital ward, rehabilitation activities, health improvement strategies, and transfer to community health care/general practice care).

Reliance on information held in electronic (or even hard copy) clinical records should be accompanied by active communication with the consumer and their carer/next of kin and potentially the person's usual primary care professional/s to ensure that the information contained in the record is correct (Zegers et al., 2009).

The national My Health Record e-health tool holds potential for integrating information across numerous care settings and is unique in its capacity to create transparency for consumers and their care support networks about clinical information and planning. This potential, though, is still to be fully activated by both health care providers and consumers. For example, information can as yet only be uploaded in text form by consumers whereas the most useful information to support safe health care might be in the form of images that, for example, can support communication with that consumer.

Another unique option offered by this tool is the capacity for consumers and carers to submit information about their care history and care needs. This option may become a useful support for the negotiation of reasonable adjustments as part of care planning or emergency treatment. However, the current online environment for recording such information is very basic and may not support all the relevant information needed, such as use of symbols for communication strategies.

The ACT public health system Digital Health Record (DHR) Project is underway. Due to COVID, some components have been fast tracked, including the establishment of an ACT digital patient portal – MyDHR.

An emerging adjunct to these population-wide health record options is the use of mobile technology applications ('apps') for consumers, carers and health care providers to record and update key information that will support effective and personalised health care. One example of this approach is the 'ASK' diary and app developed by the Queensland Centre for Intellectual and Developmental Disability in association with the University of Queensland³.

Under the ACT Health Directorate's *Digital Health Strategy 2019-2029*⁴, investment in ACT public health system's future digital health environment will be guided by a set of architectural principles to ensure a consistent and structured approach to the delivery of digital health capabilities. The strategy identifies four priority areas for investment:

- Digital Clinical Systems
- Diagnostic and medication services
- Digital corporate and operational systems
- Collaboration and communications.

Additionally, the strategy identifies six guiding principles which are elaborated in Figure 11 below.

³ <https://qcidd.centre.uq.edu.au/resources/ask-health-diary-and-app>

⁴ <https://www.health.act.gov.au/digital/strategy/strategic-response>







Principle	Meaning
 People first	Puts people receiving healthcare first in terms of maximising the quality and safety of care they receive from an organisation and its partners.
 Use integrated solution suites	Makes maximum use of integrated solution suites to ensure the delivery of integrated clinical, operational and business systems that avoid the siloing of information that exists today. Best of breed solutions will only be considered where a compelling case can be made for their implementation—with consideration of the integration impacts along with the more obvious functional, technical, cost and risk considerations.
 Single source of truth for critical information	Delivers a single digital source of truth for critical clinical information such as medications, conditions, allergies, and alerts. This information is used to support clinical decision making across various care settings, drive electronic decision support and other automated care delivery tools, and enable high impact research through integrated data sets. A single source of truth should be available to all members of the care team, whether they are employed by or students with ACT Government publicly funded health service organisations or are community based clinicians such as GPs, nurses and allied health professionals, to support the quality and safety of healthcare delivery.
 Shared enterprise services	Minimises the diversity of solutions, medical technologies, supporting platforms and technologies across the organisation by adopting an enterprise approach to their delivery and usage. This will provide access to higher economies of scale as well as reducing operational spend through enabling shared support resourcing and making staff transfers easier.
 Leverage existing investments	Leverages existing solutions where the solution: <ul style="list-style-type: none"> • aligns with and contributes towards realising the future vision for the digital health environment • does not present risk for the organisation, from either a functional or technical perspective • will not introduce additional unsustainable integration complexity.
 Support integrated workflows	Integrates clinical workflows to minimise the number of separate solutions that staff are required to use to support integrated clinical workflows in order to diminish clinical safety risks and workforce inefficiencies. This will also streamline on-boarding of new staff and training effort.

Figure 11: Digital Health Strategy guiding principles diagram, ACT Health Directorate Digital Health Strategy 2019-2029

Reasonable adjustments

Reasonable adjustment strategies should always be discussed with the consumer and their carer or support person, either before a planned appointment or admission or at the point of first engagement (and then at subsequent transfers of care). This personalised approach ensures that care will be given safely for the consumer and health care providers and support a partnership approach to successful prevention, diagnosis and/or treatment. However, there are some reasonable adjustment strategies that are known to assist a wide range of health care consumers and can therefore be anticipated and catered for in advance, with reception and triage staff members trained and supported to implement these as soon as the need is apparent. This might include, for example:

- a ‘call back’ arrangement with triage staff so that a person with disability and their carer/s do not have to wait their turn seated in the A&E waiting room (and therefore at high risk of not being able to wait successfully),
- availability of a quiet room with relatively low lighting for either waiting or health care consultations, and
- widespread staff awareness of these potential triggers and associated positive management strategies.

v. Consent procedures and decision-making

Issue/s:

People with disabilities have the right, like all citizens, to participate in decision-making and consent procedures about any proposed medical treatments or interventions (UN CRPD, 2006). However, historically this is an issue that has not been straightforward experience for either consumers, their carer/s or health care practitioners. Consistent with the 'medical model' approach outlined above, it has been common in the past for health care workers to act conscientiously upon their belief that it is their responsibility to make a choice about treatment options 'in the best interests of their patient' if that consumer is (or appears to be) unable to understand or express an opinion on their consent to what is proposed. In such instances, it has been common for consent to be sought from the consumer's next of kin, invoking a similar response to situations where the consumer may be unconscious and therefore technically unable to contribute to the process (Iacono et al., 2014). In the absence of reasonable adjustment strategies that facilitate communication between the health care provider and the consumer, there may be little capacity to secure informed consent.

Strategies for improvement:

Effective and inclusive practice in relation to consent-giving processes relies strongly on a combination of:

- reasonable adjustment strategies to maximise the consumer's capacity for direct inclusion in communication about treatment options and their risks and benefits
- the opportunity to participate being offered
- clear and transparent nomination processes for who are the preferred support people to assist in decision-making.

The literature offers numerous examples of guidelines to support effective and inclusive practice in relation to decision-making and consent (for example, see NSW Government, 2016).

Relevant to (and often included in) these consent-giving formats is reference to any legal arrangements that may exist in relation to decision-making and/or any other pre-agreed guidance, such as an Advanced Care Directive.

It is common now in many jurisdictions for a structured format for inclusive consent-giving to be included in a consumer-held personal health information resource, such as a health passport, as outlined above. A useful example of this type of structured informed consent format is included on page 6 of the current New Zealand government health passport A4 template (NZ Health and Disability Commissioner, 2020). This example can be found at [Appendix 5](#).

vi. Inclusion of family/carer network

Issue/s:

The families of people with disabilities, and health care consumers more broadly, have expressed dissatisfaction with the willingness of some health care providers to include them in diagnosis and treatment planning discussions. This is particularly important in situations where the consumer themselves may not have been able to reliably provide the necessary information (ACT Carers Strategy, 2018). Similarly, both consumers themselves and family members have reported a

reluctance on the part of some health care providers to communicate directly with the consumer about their symptoms and needs (ACTCOSS, 2019).

Strategies for improvement:

Formal recognition of the important role that carers can make to the patient journey can assist in building carers' confidence and in emphasising that role to health care providers (ACT Carers Strategy, 2018). Carers can also assist service providers to have direct communication with the person with a disability.

vii. Communication – written and verbal

Issue/s:

It is commonly understood that effective and compassionate communication is the cornerstone for quality health care practice. There could be a range of reasons why people with disabilities may be unable to communicate effectively with health care providers, including speech difficulties, trauma-related reticence, intellectual disability, non-inclusion of family/carers for support, behavioural issues, low literacy and/or English proficiency levels, attitudinal issues on the part of the health care providers involved and commonly a combination of such contributors (Millar et al., 2004; Lennox, N. et al., 1997).

Strategies for improvement:

A vital issue for achieving effective communication with consumers is the support and understanding of health care providers and organisations to identify and overcome barriers to communication with consumers and their support networks (Tuffrey-Wijne et al., 2014). An equally vital element in this process is the availability of and access to clear guidance about the statutory need for reasonable adjustments to be made and what type of strategies can be implemented to support good communication (Chew et al., 2009). Experience in the UK, where the statutory requirements for reasonable adjustment have become more explicit since the introduction of the Equality Act 2010, has shown that professional development support for health care professionals focussing on confidence-building and awareness-raising improves attitudinal barriers to implementing reasonable adjustment strategies (Heslop, 2019).

Useful communication guide examples are at [Appendix 6](#) and [Appendix 7](#), or found at the following sites:

- Hospital Communication Book (Mencap and Learning Disability Partnership Board Surrey, 2008), including communicating effectively with people with developmental disabilities: <http://ddprimarycare.surreyplace.ca/wp-content/uploads/2018/03/Communicating-Effectively.pdf>
- Overcoming communication barriers: Working with patients with intellectual disabilities. (Chew et al., 2009) <https://www.racgp.org.au/afp/200901/200901chew.pdf>

viii. Patient-held information to support safe and equitable care (e.g. health passports)

Issue/s:

For any health care consumer, it can be a challenge to collate and record the information that may be relevant to share with health care providers to support the management of their health care. This is particularly important if they are experiencing complex health conditions and/or have significant

personal or family medical histories that may be relevant, such as severe allergies (ENDA/EAACI, 2016). For all consumers, effective and well-aligned health care relies on awareness and consideration of usual care processes and previous investigations (Mathioudakis, 2016). For people with disabilities, there may be additional information that is relevant to provide to health care providers, such as how they communicate, known risks (such as choking), their nominated support hierarchy etc (Blair et al., 2010).

Without a process for collating this information, it can be a challenge for consumers and their carers/support network to access and share the necessary information in a timely and complete way. Consumer advocates have also pointed to their experience of not being believed by health care providers when reporting significant information and the associated power of evidence in supporting and validating their input (DSS, 2009).

Strategies for improvement:

Organisational endorsement of the use of patient-held health information resources (most commonly in the form of a health passport) is a significant indication of partnership with consumers and their carers and also of the structural inclusion of patient and family-provided information to assist in care and treatment process (Blair et al., 2010). In the ACT, a group of people with disabilities and advocates worked together to review international practice around the development and use of such tools and to subsequently create a patient-held resource that would assist consumers and health care providers to work together to minimise known risks, implement inclusive informed consent processes, support a more personalised approach to the care of people with disabilities in particular, and to improve the integration of care across care boundaries (ACT Office for Disability, 2019). This resource is currently in production and is unique in that it assists people with disabilities, their support network and health care providers to collaborate in care partnership across the primary care/acute care interface.

Effective implementation of health passports relies on goodwill and partnership between health care providers and consumers and their carers as well as the capacity of such tools to assist in promoting safe and effective care and in preventing adverse outcomes.

ix. Physical access and accommodation of sensory issues

Issue/s:

Physical access to all health care facility buildings is now widely accepted as a basic right for all people regardless of disability and these standards are now embedded into national and international standards frameworks for all public infrastructure and into local planning requirements for private business developments (UN CRPD, 2006; DDA 1992; ACT Discrimination Act 1991; Disability [Access to Premises – Buildings] Standards 2010). This does not, however, ensure that physical access issues are comprehensively addressed in all situations (ACTCOSS, 2019) – for example, a health care service may be housed in an older building where doorways are too narrow for some wheelchair equipment.

Apart from physical access issues, people with disabilities may experience a wide range of sensory and/or social issues that may be triggered by standard health care practising arrangements (Seeberger, 2020). For example, waiting for long periods of time (particularly if this is in a crowded

area with restricted movement) may be almost an impossible task for some people, and having a health care interaction in a noisy and brightly lit environment may be distressing for others. Providing alternatives for how services are delivered that avoid such triggers is an example of reasonable adjustment in action (Phillips, 2019).

Strategies for improvement:

The ideal and recommended approach to improving performance in this area is to design infrastructure, equipment and service provision layouts from a universal design perspective in order to anticipate and accommodate most if not all likely user requirements (Center for Universal Design, 1997, n.d. and 2016).

These design principles have been widely adopted internationally and useful examples of universal design in practice can be found in the Center for Universal Design's publication 'Removing Barriers to Health Care' (n.d.)⁵.

There has been considerable progress in Australia and the ACT to address infrastructure access issues due to the incorporation of access standards into building codes, but some services may still be delivered in older and less well adapted facilities. An active audit program that takes a broader approach to access (for example, to consider the availability and suitability of equipment and service areas to meet diverse abilities) and also has the capacity to be regularly informed by consumer feedback would provide useful data for service planning and adaptation.

Service infrastructure and workforce

The importance of accessible physical infrastructure, service equipment and service environments has been outlined above in the section on reasonable adjustment strategies. This set of issues makes up an important component of an organisation's capacity to deliver high quality and accessible health care for (and with) people with disabilities. The health workforce who provide services in those facilities are the other key enabling component of service delivery.

x. Workforce development

Issue/s:

As outlined in the section on legislation and policy frameworks above, in Australia and the majority of developed international jurisdictions, there are both legislative and social imperatives on all service agencies to respond in an appropriately adaptive way to the needs of people with disability in order to achieve equitable access. The attitudes and actions of the health care workforce (professional and ancillary) are critical contributors to the experiences of people with disabilities who need the services provided by that workforce (Heslop et al., 2019). However, the varied needs of people with disabilities can present unfamiliar challenges for health care professionals which, in some cases, can result in adverse outcomes if those challenges are not anticipated and met (Millar et al., 2004). For example, a health care worker who has difficulty communicating with a consumer may not be able to collect the information needed from that person for a correct diagnosis and treatment plan.

⁵https://global.oup.com/us/companion.websites/fdscontent/uscompanion/us/static/companion.websites/9780199358779/pdf/Universal_Design_final.pdf

Strategies for improvement:

Clear organisational guidance and protocols for competencies and practice for all elements of the health care workforce can assist managers to orient their staff toward safe and inclusive care and support further development of skills and competencies in this area of practice (Alliance for Disability in Health Care Education, 2019). Incorporating skills and awareness-raising training about reasonable adjustment practices into professional development programs has been found to be a powerful tool for confidence-building and increased understanding of the risks to consumers of not adapting practice (Symons et al., 2009).

Another widely used strategy (particularly in large organisations like hospitals) is to employ one or a team of staff members with high levels of training and awareness of how to support reasonable adjustment processes (Phillips, 2019). The key role of these specialist positions is most often to assist staff, the consumer and their carer/s as part of the assessment and admission process and to facilitate the use of positive and protective protocols in each care setting as needed. In some cases, the role of these positions incorporates a care journey navigation component whereby they remain as a key contact for the consumer and their carer/s throughout the care journey and potentially through to safe discharge to community-based follow up care (Valaitis et al., 2017).

Studies have shown that reluctance to engage with consumers and families can be the result of a lack of confidence on the part of health care providers, particularly in those situations where communication is a challenge. Health care provider confidence levels have been shown to increase with access to targeted training and development (Hearn & Hearn, 2020).

Tailored service models

xi. System coordination/integrated care

Issue/s:

Poor coordination and/or integration of care processes have been widely found to be implicated in poor outcomes of health care occasions of service in the general population, but even more so for people with complex needs and/or poorly established routine health care connections in the community (Thomas et al., 2017). Specific known risks associated with poorly integrated care – that is, transfer of a patient between domains of care, such as discharge from hospital – include: medication errors, poor access to medication, post-operative bleeding, infection, poor access to basic needs such as food, and failed or absent community support arrangements (AHRQ, 2013). These risks have been found to be particularly significant within the first five day period post-discharge from hospital (ARQH, 2014). Similarly, without reliable follow up support and/or easy-to-understand written instructions, it has been shown that patients are less likely to implement rehabilitation and health improvement instructions that are meant to support the final phase of recovery.

Strategies for improvement:

A number of integrated care models have been proven to improve health outcomes (Rennke et al., 2015), largely in the context of discharge from hospital to the community. These models rely on having a small but dedicated team of staff to work with consumers and their support network, clinical hospital staff, and community-based clinical and home support services. The core principles of all of these models are:

- proactive and early commencement of planning for discharge to ensure re-activation of existing support services and to anticipate the need for new temporary or longer-term support
- involvement of the consumer and their support network in planning
- active engagement and communication between hospital and general practice clinical and coordination staff, including arrangement of a follow up GP appointment within five days of discharge
- identification of an accessible and reliable local pharmacy
- provision of consumer-friendly (preferably Easy Read English) to support positive engagement with health improvement recommendations
- planning for arrangements made for meal preparation
- post-discharge checks to ensure that community supports plans have been activated.

A summary of key actions to prevent known risks associated with poorly integrated care (AHRQ, 2014) is provided at [Appendix 8](#).

xii. Patient navigation support

Issue/s:

A widely used UK study by Macredie et al. (2014) offers the following definition of care navigation (also referred to as patient navigation):

‘The assistance offered to patients and carers in navigating through the complex health and social care systems to overcome barriers in accessing quality care and treatment, e.g. financial support, coordinating among providers and settings, arranging for translations etc.’. (p.9)

In its 2018 report on developing a patient navigation for the ACT (Coe & Spiller, 2018), Health Care Consumers’ Association (HCCA) also reflected benefit of this role in relation to supporting people with complex needs. They used the following definitions to orient their work on exploring a relevant model and noted that they considered the needs of people living with disability to be included as complex:

Patient Navigator: While there are many definitions of patient navigator, they share a common goal to anticipate and identify barriers to good patient care and help patients to remove them. In doing so they improve patient outcomes and the overall quality of health care delivery.

Complexity: Complexity is a combination of health needs that can include diagnosis, treatment and rehabilitation, and social needs such as housing, social care and independent living.⁶

The Care Navigator competency framework developed by Health Education England (2016) describes the role and impact of care navigators as follows:

‘From an individual perspective, people who provide care navigation build relationships, problem solve and help locate resources, serving as a link between community, health and social services. They advocate the needs of people, they are enabling and focused on recovery, to strengthen the work of the multidisciplinary team. A key purpose is to ensure patients experience seamless, joined up care and support.’

⁶ National Complex Needs Alliance. ‘Complex Needs’, <http://complexneeds.org.au/complex-needs/>

Coe and Spiller (2018) noted that barriers can usefully be broken down into three categories:

Patient barriers

- Lack of awareness of community based resources
- Financial constraints
- Competing priorities
- Personal circumstances
- Language and culture

Provider barriers

- Lack of clinical support
- Lack of time and knowledge

System barriers

- Complexity of the health care system
- Sub-optimal access to primary or specialty care.

Brisbane Metro South Health's Disability Nurse Navigator service has been established to overcome the access and good health outcomes barriers outlined above:

"There is a real need for more understanding of the challenges people with intellectual disabilities face in accessing health care, both in hospital and in the community. We really try hard as nurse navigators to advocate for our patients to reduce the obstacles they face on a daily basis." (Metro South Health, 2020).

Strategies for improvement:

Based on a synthesis of several studies, researchers at The Commonwealth Fund suggest such a patient navigator model of care should:

- target individuals most likely to benefit
- provide a comprehensive assessment of patients' risks and needs
- use evidence-based care planning and patient monitoring
- promote patient and carer engagement in patients' self-care
- facilitate transitions between hospital and community, and
- provide appropriate care in accordance with patients' goals and priorities.

The HCCA report (Coe and Spiller, 2018) recommends four Key Principles for an effective patient navigation model:

Advocacy

- Promote patient centred care
- Provide personalised and holistic assessment and planning
- Be the single point of contact

Linkage

- Provide links to existing services and resources
- Expedite centrally coordinate care
- Create partnerships with everyone involved in the patients' care
- Include carers and families
- Build professional relationships

Education

- Improve health literacy

- Plan and set goals for self-management

Health system improvement

- Assess and monitor systems for improvement
- Enhance existing services
- Ensure succession planning
- Promote research, assessment and development

The patient navigation model proposed for the ACT by HCCA was summarised visually and is shown in Figure 12 below.

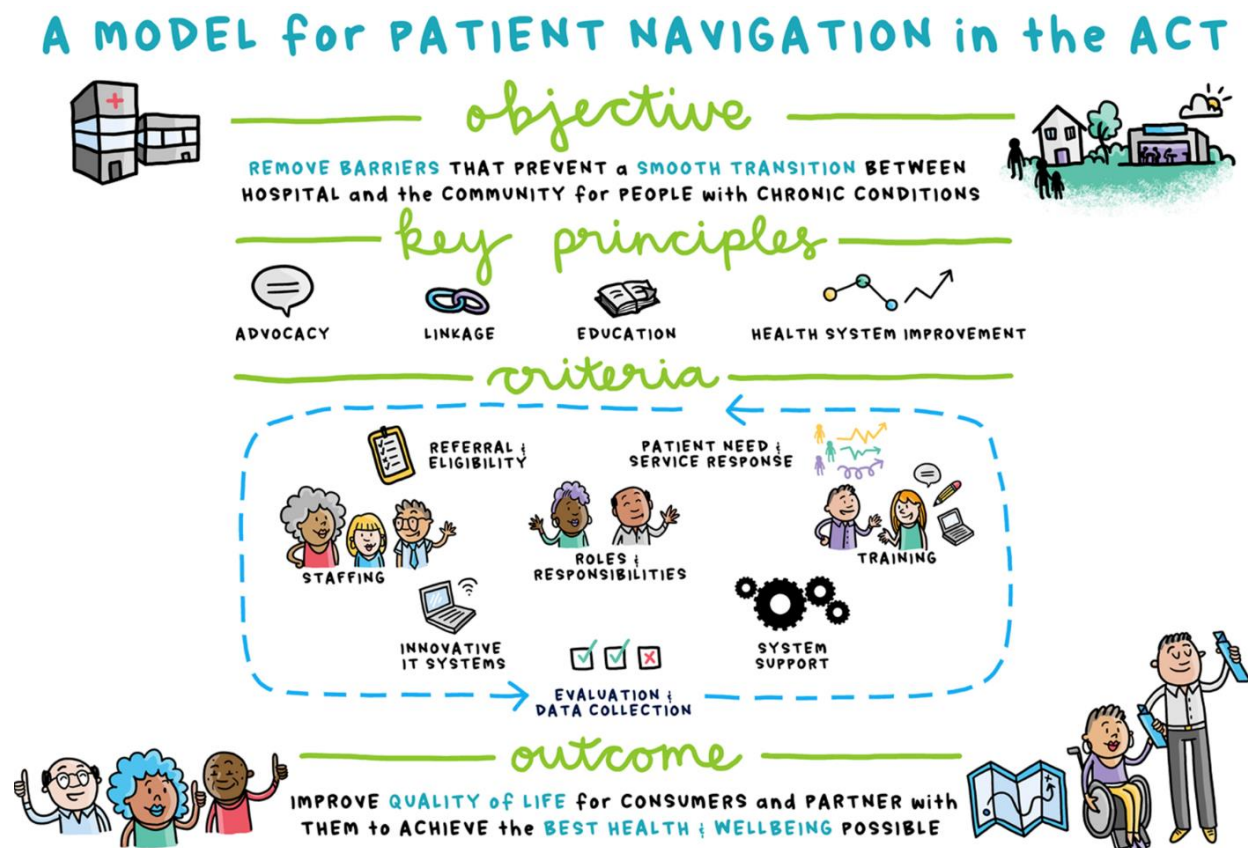


Figure 12: A model for patient navigation in the ACT, A model for patient navigation in the ACT for people with chronic and complex conditions (2018)

The UK Care Navigation Competency Framework (Health Education England, 2016) notes that a person providing care navigation is usually based in a multidisciplinary team, helps identify and signpost people to available services, acting as a link worker. The person who provides care navigation is therefore an important (though alone not sufficient) lynch-pin or enabler to achieving integrated care provision.

This framework has been developed on the basis of a set of key principles, as outlined in [Appendix 9](#). The framework also outlines nine key domains of competency for care navigation. Within each domain there are sub-core competencies described for each tier; essential, enhanced and expert.

1. Effective communication
2. Enabling access to services

3. Personalisation
4. Coordination and integration
5. Building and sustaining professional relationships
6. Knowledge for practice
7. Personal development and learning
8. Handling data and information
9. Professionalism.

The Learning Disability Liaison Nurse (LDLN) role that has been widely implemented in the UK in the past decade (Tuffrey-Wijne et al., 2013) provides support for patients, carers and staff throughout the patient's hospital journey. Referrals to this service come either through the hospital (referrals from hospital staff, or the LDLN actively looking for patients within the hospital) or through the community, by carers and patients contacting the LDLN directly or by community staff making referrals.

Tuffrey-Wijne et al. (2013) point out that this role is often extremely complex and requires significant skills in communication and negotiation. Key aspects of the LDLN role include:

- the provision of expertise around mental capacity assessments and individualized communication
- communicating and liaising with carers, ensuring that the carers' voices were heard and their needs were met
- liaising with other services, in particular primary care services
- co-ordination of care, which included ensuring a wide range of reasonable adjustments were in place.

xiii. Multidisciplinary care models

Issue/s:

Article 26 of the UN Convention on the Rights of Persons with Disabilities describes easy and early access to multidisciplinary 'habilitation and rehabilitation services and programmes' as critical. In health care settings, rehabilitation (that is, 'regaining the skills, abilities, or knowledge that may have been lost or compromised as a result of illness, injury, or acquiring a disability'⁷) is the most relevant. In the Australian setting, rehabilitation services are most often provided on a multidisciplinary basis and widely available through publicly funded health care services. However, studies and consumer advocacy organisations have reported (ACI, 2019) that health care professional judgement and/or organisational policies can have a limiting effect on the priority that might be given for access by people with disabilities to rehabilitation care where such services are in limited supply. This can include value judgements based on the comparative merit of rehabilitation outcomes and the perceived potential for productive gain that could be achieved by 'competing' consumers.

Similarly, it has been reported that a person with a disability may have been injured (for example, experienced a fractured bone) but not be offered standard post-injury rehabilitative treatment because there is little perceived value on the part of the treating professionals in providing such treatment (Adams et al., 2015).

⁷ <https://napacenter.org/difference-between-habilitation-and-rehabilitation/>

Another angle to the issue of referral or otherwise to rehabilitation services involves the phenomenon of ‘diagnostic overshadowing’. In this instance, the focus of a health professional (based in their own assessment of the situation) may be on rehabilitation services to attempt to ‘correct’ the consumer’s underlying disability (Blair, n.d.⁸) In some cases, it has been reported that such services have been prioritised at the expense of proper attention to the health condition that has prompted health care input at that time.

Strategies for improvement:

The UN Convention’s Article 26 outlines the rights of people with disabilities to habilitation and rehabilitation and provides guidance on the critical elements of an effective service for people with disability.

1. States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:
 - a. begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths
 - b. support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.
2. States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services.
3. States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.

The NSW Council on Disability (on behalf of the national branch of that organisation) provided a submission to the Productivity Commission’s inquiry into the health workforce (2005). That submission argued for the benefits of multidisciplinary specialist resources taking the form of an intellectual disability health resource team in each health area. The service sought would be a multidisciplinary team that includes a doctor who specialises in intellectual disability and professionals in other disciplines such as nursing, dietetics, speech pathology, neurology, psychiatry and alcohol and other drugs. Each team would focus on the varying needs and available resources in its local area. The NSW Government provided recurrent funding to support this service model in 2019 and a formative evaluation of that service is about to commence (NSW Health, 2021).

A Patient Journey research project in NSW (ACI, 2015) reported on consumer responses to the availability of this type of multidisciplinary and specialist skilled service:

⁸ <http://www.intellectualdisability.info/changing-values/diagnostic-overshadowing-see-beyond-the-diagnosis>

‘Those who had been referred to specialist health services for people with disabilities were convinced of the benefit to them of the clinical expertise of the team members, and of the integrated care offered. They thought the whole of life approach to care and treatment resulted in health, emotional and social issues being understood and addressed, as well as value given to the significant role of families/carers’ (ACI, 2015, p.29).

Specialised service models have also been developed to support people with cognitive disabilities who also have complex medical and/or psychosocial problems. The Victorian Government has published a guide for service providers to support this type of complex care, which has a strong focus on flexibility of care and support processes (Victorian DHCS, 2020). In the US, a model known as the Flexible Assertive Outreach Team (FACT) approach has been shown to be similarly effective for this population subset (Neijmeijer et al., 2019).

Other access factors

xiv. Financial barriers to care

Issue/s:

It is widely acknowledged that people who live with disabilities are more likely to experience poverty than many other population groups. Although the Australian health care system broadly offers free or low cost access to health care, there can be certain critical aspects of care that are relatively costly to access in some situations. These scenarios include limited or unavailable access to Medicare bulk-billing for GP, allied health, medical specialist, pathology and diagnostic imaging services. Consumer advocates have reported that they may receive free hospital care but be discharged with instructions to receive follow up care from private health care providers, such as medical specialists, diagnostic imaging and/or allied health professionals. For many people with disabilities, this type of referral is likely to lead to no follow up care being received due to the financial barriers experienced by these consumers.

It has been regularly reported that consumers in the ACT have relatively low levels of access to bulk-billed GP services (Suppl. Budget Estimates, 2019) In response, consumers have reported that they are more likely to attend a bulk-billing clinic but that this tends to mean that they do not get to develop a relationship with a particular GP. As discussed in other sections, the absence of an established and effective relationship with a specific GP can have adverse effects and contribute to poorer health outcomes.

Strategies for improvement:

The concept of informed financial consent, though usually associated with interactions between a consumer and a service provider who is offering a service, is also relevant to the process of referral. A referral for specialist or follow up care that is unaffordable for a consumer is in effect a non-referral due to the inability of that consumer to access the proposed service. As a consequence, this type of referral process denies the consumer the opportunity for the benefit of the proposed care. Health care professionals and service unit managers must be careful not to rely on assumptions about what services may be available to consumers and be conscious of financial barriers to care that may exist (ACTCOSS, 2019). These practitioners and service units may need support and resources to support their awareness of the financial implications of various referral options.

Feedback received during the ACTCOSS (2019) Appreciative Inquiry research with ACT consumers living with disabilities indicated the significant financial barriers faced by many consumers in getting access to primary care and allied health services that they needed. That report ('Imagining Better', 2019) recommended that all ACT residents have access to one comprehensive health assessment per annum free of charge.

For approximately 10% of the ACT population of people with disabilities, access to a funding package under the National Disability Insurance Scheme (NDIS) provides some financial relief associated with access to health care (NDIS, 2021). An NDIS funding package may assist, for example, in providing additional support during health care visits and/or assistance with transport to get to appointments. For the remaining population group members, there is no similar financial relief.

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K: Appendices

Appendix 1: UN Convention on the Rights of Persons with Disability - relevant Articles

Article 1: Purpose

The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

Article 2: Definitions

For the purposes of the present Convention:

“Communication” includes languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology;

“Language” includes spoken and signed languages and other forms of non spoken languages;

“Discrimination on the basis of disability” means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation;

“Reasonable accommodation” means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms;

“Universal design” means the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design.

“Universal design” shall not exclude assistive devices for particular groups of persons with disabilities where this is needed.

Article 4: General obligations

1. States Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability. To this end, States Parties undertake:

(a) To adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the present Convention;

- (b) To take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities;
- (c) To take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes;
- (d) To refrain from engaging in any act or practice that is inconsistent with the present Convention and to ensure that public authorities and institutions act in conformity with the present Convention;
- (e) To take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise;
- (f) To undertake or promote research and development of universally designed goods, services, equipment and facilities, as defined in article 2 of the present Convention, which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines;
- (g) To undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost;
- (h) To provide accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities;
- (i) To promote the training of professionals and staff working with persons with disabilities in the rights recognized in the present Convention so as to better provide the assistance and services guaranteed by those rights.

Article 9: Accessibility

1. To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia:
 - (a) Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces;
 - (b) Information, communications and other services, including electronic services and emergency services.

Article 15: Freedom from torture or cruel, inhuman or degrading treatment or punishment

1. No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his or her free consent to medical or scientific experimentation.
2. States Parties shall take all effective legislative, administrative, judicial or other measures to prevent persons with disabilities, on an equal basis with others, from being subjected to torture or cruel, inhuman or degrading treatment or punishment.

Article 17: Protecting the integrity of the person

Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.

Article 25: Health

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

- (a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;
- (b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;
- (c) Provide these health services as close as possible to people's own communities, including in rural areas;
- (d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;
- (e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;
- (f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

Article 26: Habilitation and rehabilitation

1. States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and

programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:

- (a) Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;
 - (b) Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.
2. States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services.
 3. States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.

Appendix 2: European Manifesto on Basic Standards of Health Care For People with Intellectual Disabilities (2004)

Five core standards for improving the health of people with disabilities

This manifesto, prepared by members of the European Association of Intellectual Disability Medicine, summarises the core elements of adequate health care for individuals with ID, and offers guidance on how Europe's nations might address deficiencies in health provision for people with ID.

Five basic standards were formulated:

1. *Optimal availability and accessibility to mainstream health services with primary care physicians playing a central role. This means that people with intellectual disabilities will:*
 - a. Use mainstream health services.
 - b. Receive more time for consultations in the clinic or in home visits, when needed.
 - c. Receive adequate support in communication, when needed.
 - d. Receive a proactive approach to their health needs.
 - e. Have no extra financial, physical or legislative barriers to use mainstream services.
 - f. Be able to participate in screening programmes, in the same way as anybody else.
 - g. Be supported in achieving and maintaining a healthy lifestyle that will prevent illness and encourage positive health outcomes.
 - h. Receive understandable information about health and health promotion (also available to family and carers).
 - i. Receive health care with good co-operation and co-ordination between different professionals.
2. *Health professionals (especially physicians, psychiatrists, dentists, nurses and allied professionals) in mainstream health services will have competencies in intellectual disabilities and therefore in some of the more specific health problems in people with intellectual disabilities. This will require that:*
 - a. Health professionals have a responsibility to achieve competencies in the basic standards of health care for people with intellectual disabilities.
 - b. These competencies include the awareness that not all the health problems of people with intellectual disability are caused by their disability.
 - c. All training programs for health professionals pay attention to intellectual disabilities, including the most common aetiology, some frequent syndromes, aetiology-related health problems, communication, legal and ethical aspects.
 - d. Training in attitude and communicational skills is as important as clinical skills and therefore is part of the training programs.
 - e. Guidelines on specific health issues are available through Internet, CD-ROM or otherwise.
 - f. Health care professionals in mainstream services have easy access to and are able to get advice from specialist colleagues without extra financial, practical or legislative barriers.
3. *Health professionals (physicians, psychiatrists, dentists, nurses and allied professionals) who are specialised in the specific health needs of individuals with intellectual disabilities are available as a back-up to mainstream health services. These professionals can advise, treat specific medical problems or take over (a part of) the medical care for people with intellectual disabilities. This will require that:*
 - a. Training Programmes are available for health professionals who want to gain competencies in health issues of people with intellectual disabilities.

- b. These specialists create and maintain networks with specialised colleagues in and outside of their own profession, in order to improve their knowledge and skills. This can be achieved by personal contacts or by creating (virtual) centres of expertise.
 - c. Research on health issues of people with intellectual disabilities is stimulated in co-operation with academic centres. Academic Chairs in Intellectual Disability Medicine should be created to initiate, stimulate and co-ordinate research projects.
4. *Health care for individuals with intellectual disabilities often needs a multidisciplinary approach.*
- a. Specific health assessments and/or treatments need co-ordination between different health professionals (for example visual and hearing impairment, mental health care, care for people with multiple and complex disabilities, care for the elderly, rehabilitation care).
 - b. Specialist training for nurses and other carers is stimulated. This includes learning how to support and care for people with intellectual disabilities who have for instance sensory impairments, autistic spectrum disorders, epilepsy, mental health problems, behavioural/ forensic problems, physical and complex disabilities, swallowing and feeding problems and age-related problems.
5. *Health care for people with intellectual disabilities needs a pro-active approach.*
- a. Participation in national screening programmes should be encouraged.
 - b. Anticipating health investigations on visual and hearing impairments and other frequent health problems should be evidence based and routinely available.
 - c. General and specific health monitoring programmes are developed and implemented. In the development of Health Indicator Systems special attention is paid to people with intellectual disabilities.
 - d. Responsibility for the development of anticipating investigation programmes and for their implementation must be clarified (primary care physicians, Public Health Doctors or specialised physicians).
 - e. People with intellectual disabilities and their families have a right to aetiological investigations.

Appendix 3: Recommendations for Future Actions to improve disability health

(Krahn et al., 2006)

Recommendations for Future Actions

I. Promote principles of early identification, inclusion, and self-determination of people with ID in quality health care

- a. Include persons with ID, family members, and caregivers in establishing health agendas, developing practices, and conducting research
- b. Increase the understanding of persons with ID and family members about health treatment options and support their role in decision making.

II. Reduce the occurrence and impact of associated, comorbid, and secondary conditions in people with ID

- a. Ensure regular assessments by knowledgeable health care providers, which include:
 - i. Management of associated conditions (e.g., epilepsy, cerebral palsy, specific conditions related to disorder)
 - ii. Review of medications
 - iii. Diagnosis and intervention for mental health and behavior disorders
 - iv. Adherence to general population guidelines for clinical preventive services to screen and treat comorbid conditions (e.g., cancers, diabetes, hypertension)
 - v. Monitoring of hearing, vision, weight, height, skin, constipation, and oral health
- b. Provide for regular dental care
- c. Provide for specialty care to diagnose and manage genetic, neurological, psychiatric, behavioral, and nutrition conditions and problems
- d. Provide health care coordination for persons with ID who have complex health needs
- e. Conduct research to determine etiologies and syndromes for persons with ID to optimize their current and future health
- f. Conduct research to distinguish preventable secondary conditions from associated conditions and from progression of disorders over the lifespan g. Establish mechanisms to accurately monitor mortality and assess cause of death for persons with ID, particularly those in the community

III. Empower caregivers and family members to meet the health needs of persons with ID in their care

- a. Provide assistance and supports to reduce the burden of care for families
- b. Improve wages, benefits, and required credentials to assure greater continuity in non-family caregivers
- c. Educate and train people with ID and their caregivers to:
 - i. Monitor nutrition, height, weight, and physical activity and to record changes
 - ii. Prevent and treat chronic constipation
 - iii. Improve oral hygiene of persons with ID
 - iv. Monitor functional decline, particularly in older adults with ID
 - v. Communicate with health care professionals
- d. Conduct research to determine effectiveness of training and intervention models with caregivers and family members.

IV. Promote healthy behaviors for persons with ID

- a. Include persons with ID in all health promotion and preventive health practices across the lifespan.

Appendix 4: Equality Act 2010 (UK)

(as summarised in UK report: Equality and Human Rights Commission (2016). *Being Disabled in Britain: A Journey less equal.*)

The Equality Act 2010 prohibits unlawful discrimination, harassment and victimisation on the basis of what are called ‘protected characteristics’ in a wide variety of fields, including employment, education, the exercise of public functions, and the provision of services and associations.

The nine ‘protected characteristics’ are: age; disability; gender reassignment; marriage and civil partnership; pregnancy and maternity; race; religion or belief; sex; sexual orientation.

Prohibited conduct takes a number of forms, although not all are relevant to all protected characteristics. Prohibited conduct includes the following:

- **Direct disability discrimination** – less favourable treatment of a disabled person because of their disability compared with others who are not disabled.
- **Indirect disability discrimination** – where a policy, practice or criterion is applied to everyone (or would be), but in fact puts (or would put) disabled people at a particular disadvantage when compared with others who are not disabled. Indirect disability discrimination can be lawful if objectively justified as a proportionate means of achieving a legitimate aim.
- **Discrimination arising from disability** – less favourable treatment of a disabled person, because of something arising in consequence of the disabled person’s disability, where the less favourable treatment cannot be shown to be a proportionate means of achieving a legitimate aim. Discrimination arising from disability does not occur if the person does not know, and could not reasonably be expected to know, that the disabled person has the disability.
- **Duty to make reasonable adjustments** – discrimination against a disabled person occurs where there is a failure to comply with a duty to make reasonable adjustments. The duty comprises three requirements:
 - Where a provision, criterion or practice puts disabled people at a substantial disadvantage compared with those who are not disabled, take reasonable steps to avoid that disadvantage.
 - Take reasonable steps to remove or alter a physical feature or provide a reasonable means of avoiding such a feature where it puts a disabled person at a substantial disadvantage compared with those who are not disabled.
 - Take reasonable steps to provide an auxiliary aid where a disabled person would, but for the provision of that auxiliary aid, be put at a substantial disadvantage compared with those who are not disabled.
- **Harassment related to disability** – unwanted conduct related to a person’s disability that has the purpose or effect of violating the person’s dignity, or creating an intimidating, hostile, degrading, humiliating or offensive environment for that person.
- **Victimisation** – subjecting someone to a detriment because they have, in good faith, carried out a protected act, such as:
 - making an allegation of discrimination
 - bringing proceedings under the Equality Act 2010
 - giving evidence or information in relation to such proceedings
 - doing anything else in connection with the Equality Act 2010.

The Equality Act 2010 permits proportionate positive action measures that aim to overcome disadvantage connected to a particular protected characteristic. The Equality Act 2010 goes further in

relation to the protected characteristic of disability than it does for other protected characteristics: it is not discrimination to treat a disabled person more favourably than a non- disabled person.

Appendix 5: New Zealand Government's Health Passport - structured informed consent format

(NZ Health and Disability Commissioner, 2020)

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4. Decision-Making

a. I can and would like to make my own decisions, so please ask me first. Yes No

b. I may need assistance to make an informed decision. Yes No

c. If for some reason, I am unable to make a decision at a time when a decision needs to be made the following will apply:

i. I have a legal representative Yes No

My legal representative is: _____

Full Name: _____

Their legal relationship: *(e.g. Welfare Guardian, Enduring Power of Attorney for health and welfare.)*

Telephone: _____ Mobile: _____

Email: _____

ii. I have a list of my wishes for health care in the future: Yes No

Information about my wishes can be found: *(e.g. on my medical records, at home, with my GP who holds my advance directives, I have given verbal directions to my son.)*

(This section applies only if I ticked 'No' to both sections **a** and **b** above. I do not have a legal representative or advance directives. I trust that any decision concerning my care and welfare will be made by appropriate professional/s in my best interests.)

Review your information when daylight saving occurs, or earlier if change occurs.

Appendix 6: Communicating Effectively with People with Developmental Disabilities
(Mencap and Learning Disability Partnership Board Surrey, 2008)

SECTION I: Tools for General Issues in Primary Care

Communicating Effectively with People with Developmental Disabilities (DD)

- People with developmental disabilities (DD) are likely to have communication difficulties.
- It will generally take more time to communicate.
- An assessment of language skills helps to choose the level of language to use. Talking with someone with a mild DD is very different than talking with a person with a moderate or severe DD.
- Many people with DD have stronger receptive (understanding) communication skills than expressive skills. Assume that the person with DD can understand more than he/she can communicate.
- Conversely, the person’s expressive speech may sometimes give an impression of better comprehension than is actually the case, so check the person’s understanding.
- People with DD have a variable, and sometimes limited, ability to interpret their internal cues (e.g., need to urinate, anxiety). They may not be able to give you an accurate picture of their feelings and symptoms. Involving caregivers who know the person well may help you to better understand his/her subjective experiences. However, continue to focus your communication efforts on the person rather than his/her caregiver.
- If you are in a busy area with many distractions, consider moving to a quieter location to minimize environmental distraction.

GOAL	SUGGESTED COMMUNICATION TIPS
<p>ESTABLISHING RAPPORT</p> <p>SPEAK DIRECTLY WITH THE PERSON</p> <p>AVOID TALKING TO AN ADULT AS IF HE/SHE WERE A CHILD</p>	<ul style="list-style-type: none"> • Speak directly to the person with DD, not to his/her caregiver(s). • Ask the person: “Do you want your support worker to stay here for this visit?” • Explain at the outset the purpose and process of the meeting in simple terms. • Ask simple introductory questions (e.g., name, reason for visit). • Gain the person’s attention and eye contact if possible by using his/her name or by touching his/her arm prior to speaking. • Determine how they communicate: “How do you say Yes? No?” “Do you use a device? Can you show me how to use this book/machine?” • If the person uses a communication technique or device, involve a caregiver who is familiar with it. • Show warmth and a positive regard. • Encourage the use of “comforters” (e.g., favourite item the person likes to carry, or a preference for standing and pacing rather than sitting). • Show interest in a precious object the person is holding on to. • Some people (e.g., with autism spectrum disorders [ASD]) prefer to avoid eye contact. This should be respected. • Use positive reinforcement and focus on the person’s abilities rather than disabilities.

Communicating Effectively with People with Developmental Disabilities (DD)

GOAL	SUGGESTED COMMUNICATION TIPS
<p>CHOOSING APPROPRIATE LANGUAGE</p> <p>USE CONCRETE LANGUAGE</p> <p>AVOID SHOUTING</p>	<ul style="list-style-type: none"> • Use plain language. Avoid jargon. • Use short, simple sentences. • Use concrete as opposed to abstract language, for example: <ul style="list-style-type: none"> “Show me”; “Tell me”; “Do this” (with gesture); “Now.” “Come with me”; “I’m going to…” • Use “Put your coat on” instead of “get ready.” • Use “Are you upset? Are you sad? Are you happy?” instead of “What are you feeling?” • The concept of time is abstract and may be difficult to comprehend. Use examples from daily and familiar routines (e.g., breakfast, lunch, dinner, bedtime). • Ask or test whether the person wants you to refer to him or her in the third person (e.g., he, she, or name) rather than the second person (e.g., you).
<p>LISTENING</p> <p>LISTEN TO WHAT THE PERSON SAYS</p> <p>ALLOW ENOUGH TIME</p>	<ul style="list-style-type: none"> • Let the person know when you have understood. • Tell him or her when you do not understand. • Be sensitive to cues and tone of voice. • It may be difficult to read facial expressions or body language because of differences in muscle tone. You may need to check/validate your perceptions. • Tell the person when you do not understand him/her. • Be aware that the visit will likely take more time than usual and that several consultations may be required to complete a full assessment.
<p>EXPLAINING CLEARLY</p> <p>EXPLAIN WHAT WILL HAPPEN BEFORE YOU BEGIN</p> <p>TELL AND SHOW WHAT YOU ARE GOING TO DO AND WHY</p>	<ul style="list-style-type: none"> • Speak slowly. Do not shout. • Pause frequently, so as not to overload the person with words. • Give the person with DD enough time to understand what you have said and to respond. • Rephrase and repeat questions, if necessary, or write them out. • Check understanding. Ask the person: <ul style="list-style-type: none"> “Can you explain what I just said?” “Can you explain what I am going to do and why?” • If you are unsure whether the person has understood, ask, “Can you repeat what I said in your own words?”
<p>COMMUNICATING WITHOUT WORDS</p> <p>USE VISUAL AIDS</p> <p>ACT OR DEMONSTRATE</p>	<ul style="list-style-type: none"> • People with poor language understanding rely on routines and cues from their environments to understand or anticipate what will happen. • Use pictures or simple diagrams and gestures (e.g., basic sign language). • Some people with DD may express themselves only in writing. • Allow them to handle and explore equipment. • Act out actions or procedures. • Use picture language when explaining; find signs in their communication book: <ul style="list-style-type: none"> “It looks like …” (point to objects familiar to the person with DD). • Point to a body part or mime a procedure (e.g., checking ears).

SECTION I: Tools for General Issues in Primary Care

Resources

The Easy Health Organization in the U.K. has developed downloadable leaflets to help physicians talk with patients in plain language about common conditions: www.easyhealth.org.uk.

The hospital communication book (2008). Developed with the Surrey Learning Disability Partnership Board (U.K.), this is a practical guide to help people who have difficulty communicating due to impairments with learning, sight, hearing, or speech, to get equitable service in hospital. It contains clear pictures that can aid communication with health professionals: www.mencap.org.uk/document.asp?id=1480.

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Appendix 7: Overcoming communication barriers – Working with patients with intellectual disabilities
(Chew et al., 2009)

THEME SUMMER SALAD 

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Overcoming communication barriers

Working with patients with intellectual disabilities

Background

Communication styles and communication difficulties may impact on the ability of general practitioners to provide best possible health care, particularly for patients with intellectual and other developmental disabilities.

Objective

To highlight potential difficulties GPs may face in consultations with adult patients with an intellectual disability and to raise awareness among GPs of the different communication methods used by people with intellectual disabilities. Current recommendations for improving communication with this marginalised group and practical issues in implementing these recommendations are also discussed.

Discussion

People with intellectual disabilities have different communication abilities, using a range of different styles as a group, as well as on an individual basis. They may use speech, augmentative and alternative communication strategies, or visual or behavioural cues to indicate their wants, needs or feelings. Improved collaboration between GPs, patients, and patients' support people, is encouraged to develop an individualised approach to communication with each patient and to promote best possible health outcomes and patient satisfaction.

Some medical practitioners may feel uncomfortable seeing patients with intellectual disabilities. This discomfort often stems from a lack of experience and training in working with people who have communication difficulties. These difficulties may affect interaction in consultations, which then affects the development of rapport and quality of health care provision.^{1,2} There may also be a reliance on patients' support people in obtaining a medical history.^{1,3} Although obtaining a medical history from support people may be necessary for patients with limited communication skills, it is critical that patients are not excluded from the communication exchange.⁴

Communicating with and without speech

Patients with intellectual disabilities often have varying communication abilities and may utilise a number of different verbal and nonverbal strategies.

Those with mild intellectual disabilities are most likely to communicate with speech. Consideration of the patient's ability to understand concepts is needed and explanation must be tailored to individual needs using language and terms that each individual patient understands.

Those with moderate intellectual disabilities may also communicate with speech, but to a limited degree, such as using incomplete sentences. They are also likely to use a range of other methods, referred to as augmentative and alternative communication (AAC) strategies, in addition to, or instead of, speech (Table 1).

Those with severe to profound intellectual disabilities have more limited communication skills and often rely on people around them to optimise their communication opportunities (eg. by using visual cues) and interpret behaviours that may indicate their wants, needs, and



Table 1. Augmentative and alternative communication systems

Formal communication systems	
Aided	
Communication boards and books	Pictures, symbols and/or the alphabet is available for users to communicate specific messages
Electronic devices	Electronic devices of varying complexity are used. Some have a limited number of messages, while others allow users to construct longer messages by typing words or accessing picture symbols. Access may be direct, such as through touching a key, or indirect, such as use of switch access to a scanning system
Unaided	
Key word signing (ie. Makaton vocabulary)	Signs are used to indicate needs and wants, or to formulate messages for other purposes. Skill in using key word signing may vary, and is dependent (to an extent) on motor skills and memory
Informal communication systems	
Facial expression, body language, vocalisations, gestures, eye contact	Informal communication may convey information about general feelings (ie. feeling happy, anxious, angry), or to indicate needs and wants

feelings (eg. vocalisations, facial expressions, body language). It is also common for people with severe intellectual disabilities to have physical and/or sensory impairment which further impacts on their ability to communicate.

Formal augmentative and alternative communication strategies

Augmentative and alternative communication strategies are used by people with all levels of intellectual disabilities (Table 1).^{5,6} Some formal AAC strategies are more straightforward to use and understand, thereby appearing more user friendly to those not familiar with them. For example, electronic devices allow a person to communicate with recorded speech (Figure 1). Communication books (Figure 2) and spelling boards may require some interpretation and co-construction of meaning (ie. the listener working with the individual to determine their message). Key word signs (ie. Makaton vocabulary) may be used by some people to produce single words or short messages. A number of signs are taught to enable those with intellectual disabilities to communicate their wants and needs – for example, signs to indicate that they would like to go out for lunch (Figure 3a–c). Signs that are taught typically depend on their relevance to an individual’s daily routine (each individual may know and use a different range of signs). People accompanying the patient, whether paid carers or family members, may act as interpreters or assist the person in other ways to convey his/her messages. Many people use more than one type of AAC strategy to communicate, such as gestures, signs, and a picture board; choosing which depending on the intended message and their communication partner(s).⁶

Informal communication strategies

People with severe intellectual disabilities may demonstrate limited communication skills and are more likely to communicate with informal communication such as gesturing (ie. facial expressions, eye contact) and by using body movements (ie. shaking hands, pointing, pushing things away). Those with profound intellectual disabilities often lack intentional communication. Instead, they rely on others

Figure 1. Electronic communication device



to interpret their facial expressions and behaviours as indicative of their wants and needs. The absence of formal vocabulary results in increased reliance on support people in medical consultations.

Role of support people

Depending on the severity of intellectual disability and individual communication skills, most of a patient’s medical information may need to be provided by support people, usually a family member or paid support worker. Patients with severe intellectual disabilities are often unable to convey the degree to which they understand the implications of health issues discussed in consultations. As a result, medical decisions may need to be made on some patients’ behalf. In these situations, consent for medical procedures will be needed from a legally designated ‘person responsible’; usually a family member or other appointed person.⁷

Improving communication in consultations

The principles of communication with people with intellectual disabilities are:

- assume competence: people with intellectual disabilities may understand more than they can demonstrate. Even if the person appears unresponsive, he or she may still understand and feel included when spoken to
- communicate directly: interact directly with the patient to obtain as

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THEME: Overcoming communication barriers – working with patients with intellectual disabilities

much information as possible. Assessment of overall functioning of the individual can be made to gauge communication skills and degree of support required in consultations

- tailor communication: the language and communication style can be tailored to individual needs. Suitable words used and the pace of the conversation may be important in ensuring optimal communication
- support communicative efforts: communication can be improved if the medical practitioner is aware of the way the individual communicates and accurately interprets communicative efforts (particularly AAC systems).

Practical recommendations for improving communication with patients with intellectual disabilities are listed in *Table 2*. These recommendations are based on the views of people with intellectual disabilities, their support people, and health and disability professionals.^{5,6,8} Ideally, applying these recommendations will optimise the effectiveness of communication within the consultation.

Inclusive practice

Patients need to be acknowledged and actively involved in consultations. Medical practitioners have been reported to focus consultations on support people and appear to completely ignore patients who have difficulty communicating.⁴ Even if some patients do not have the expressive communication skills required to participate in conversation, actively including them in the consultation conveys respect for the patient – to both the patient and their support person (*Case study 1*). In addition, many people with intellectual disabilities have stronger receptive than expressive communication skills and are likely to understand more than would seem apparent from their expressive ability.⁹ Consistently interacting with patients builds rapport and improves cooperation in the consultation, for example, during physical examinations (*Case study 2*). Strategies to actively include a patient with limited communication skills include:

- doctors introducing themselves and greeting the patient before the consultation. Even if the patient does not respond verbally, nonverbal communication is possible (eg. handshaking, smiling and making eye contact). This is essential to building rapport and is independent of the patient's ability to reciprocate
- while obtaining the patient's medical history from an accompanying support person, the doctor can share eye contact with the patient and address him/her directly to maintain their involvement in the consultation.

Maximising understanding

By adapting to a patient's communication skills, medical practitioners can encourage patient participation in consultations. Comprehension can be enhanced through the use of appropriate language at a pace that is comfortable for the patient. How the patient uses AAC strategies is also an important consideration. Medical practitioners can optimise engagement and communication within consultations through learning how individual patients communicate.⁹ Strategies to aid communication include allowing patients sufficient time to

process their thoughts and respond.⁹ The use of visual cues such as pictures, diagrams, and appropriate body language may also improve understanding.⁹ These suggestions are also applicable to patients who communicate with speech.

Barriers to optimal communication in clinical practice

Using AAC strategies in medical consultations

The use of formal AAC strategies is further complicated by a number of factors:

- for aided AAC strategies, the patient must have access (it is of no use if it has been left at home, or is in the bag hanging from the back of the wheelchair!)
- physical impairment may influence the patient's ability to use some AAC strategies (eg. a painful shoulder may impair the ability to use a communication device)
- the vocabulary required for medical consultations may not be available on the communication aid as AAC strategies are usually

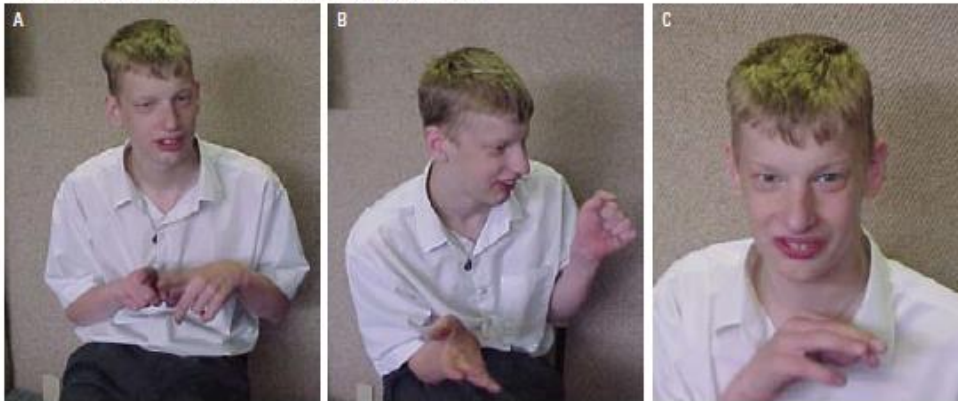
Figure 2. Communication book



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Figure 3A–C. Signing using key words: (A) quick, (B) shop, and (C) lunch



developed to address a person's most frequent communication settings and needs. These might not include the vocabulary required in a health care context (eg. to communicate symptoms such as nausea, or describe pain as sharp, crushing or burning)

- sufficient time must be made available for the patient to both understand what is being said and to formulate his/her messages.

Table 2. Recommendations for communicating in consultations with patients with intellectual disabilities

<p>Medical practitioners may improve communication by:</p> <ul style="list-style-type: none"> • Speaking directly to patients, regardless of the severity and aetiology of the disability • Using short sentences and clear age appropriate language – treating adult patients as adults and not using child-like or patronising tones • Encouraging patients to be actively involved – either verbally or nonverbally – regardless of communication difficulties • Providing clear explanations and checking regularly that they have effectively communicated key points to the patient (eg. by asking him/her to repeat key points in their own words or answer specific questions about the issues discussed) • Using pictures and diagrams to clarify their explanations • Checking that they have understood what the patient has meant by repeating the key points back to him/her and asking for affirmation or correction • Making good use of the patient's health records to support good information exchange • Ensuring adequate time is available for the consultation • Obtaining information from other sources where necessary – after obtaining appropriate permission <p>For patients who communicate with an AAC system, medical practitioners can:</p> <ul style="list-style-type: none"> • Ensure that the patient has access to his/her AAC system • Find out how the patient's particular AAC system is used

Time constraints within the medical consultation

Many areas of Australia are currently facing shortages of health care professionals, resulting in often multiple pressing demands on doctors' time. Limited time for consultations is one reason patients with intellectual disabilities fail to receive the best possible care.^{1,2} General practitioners estimate that consultations with patients with intellectual disabilities take approximately 19.5 minutes, about 6 minutes more than for other consultations.¹ Many people with intellectual disabilities also have several health related issues including medical, psychological, social, financial, and service related concerns. While these factors further contribute to the consultation time, regular review and double appointment bookings can assist. When people have complex needs the contribution of a number of health professionals may be required.

Case study 1

Judy, 35 years of age, is a woman with autism and a severe intellectual disability. She attends the consultation accompanied by her key worker, Mary. The GP knows Judy does not speak and so directs his attention to Mary who points to a wart on Judy's finger she would like the doctor to remove. The GP takes a history from Mary while Judy sits in a chair humming, seemingly uninterested in the conversation. The GP leaves the room and returns with the liquid nitrogen. He resumes his conversation with Mary as he approaches Judy to treat her wart. Judy looks up as he approaches, yells, jumps from the chair, and shoves him out of the way. She then runs out the door screaming, with Mary in pursuit. When staff try to bring Judy back to the medical clinic she refuses.

Comment

When the patient is overlooked and not actively involved and engaged as much as possible a relationship of trust cannot be established. When a situation engendering fear is experienced it can be very difficult to re-establish a therapeutic relationship.

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Case study 2

John, 28 years of age, has come to see his GP for a health assessment, accompanied by his mother, Anne. John has autism, a moderate intellectual disability and communicates with speech. During the consultation, the GP speaks to John to involve him more actively in the consultation. John, however, responds with only single words and simple phrases and does not seem interested. His GP decides to speak with John's mother about his overall health, and asks John for permission to do so. John does not answer but looks at his magazine while the doctor speaks to his mother.

The GP asks about John's health since the last consultation and hears that John has been well apart from having frequent back and/or neck aches, possibly related to postural problems. The GP then shifts his focus back to John, demonstrating to him several exercises to help with his back pain. During this part of the consultation, John gives his GP his full attention, mimicking the GP's actions, but goes back to looking through his magazine immediately after.

Comment

Demonstrating respect and involving the patient builds trust. Showing the patient what is being recommended can help to engage the patient and supports understanding. A collaborative partnership between doctor, patient and carer optimises health outcomes.

Other barriers

Baseline cognitive deficits, difficulty concentrating and acute problems such as anxiety or depression may compound communication difficulties. Some patients may not want to be actively involved in consultations, preferring their family members or support workers to speak and make decisions on their behalf. Patients with autism spectrum disorders may have difficulty initiating and sustaining conversation; a problem inherent to their disability. Communication in consultations may thus require a balance between:

- involving patients in a way that is practical in terms of the communication skills they use
- obtaining information from other sources (ie. support people, patient health records) to arrive at the right diagnosis and appropriate treatment/management plans
- meeting the expectations of patients and their support people.

Individual expectations

Expectations will vary from one consultation to the next, as each patient, their support people, and the GP, bring different ideas of what is and what is not appropriate behaviour and conversation within consultations. The best strategy is to build collaborative relationships over time, enabling continuity of care between the GP, patient, family members and support workers. Building familiarity allows all parties to become more comfortable with each other, making it easier for those involved to work together in the patient's best interests. Medical practitioners learn over time how best to communicate with any particular patient. Expectations of doctors, patients and support people can be discussed openly, facilitating understanding and providing opportunities for individual expectations to be met while ensuring the best possible health care is provided.

Summary

The effectiveness of applying specific recommendations in clinical practice has yet to be determined. However, specific issues have been raised and may be addressed with an individualised approach. In addition to recommendations made in previous literature, GPs may take the following steps to improve communication and health care provision for patients with intellectual disabilities:

- build knowledge and familiarity with patients, and those supporting them, to learn what their expectations are so these can be addressed appropriately
- develop the ability to include patients in the consultation, verbally and/or nonverbally, regardless of the severity and aetiology of disability
- establish effective collaborative partnerships with a patient's family members and/or support workers and other health professionals involved to obtain relevant health information, and to implement treatment/management recommendations.

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Appendix 8: Components of Re-Engineered Discharge (RED)

From the Project RED Toolkit, US AHRQ et al. (2014)

RED Component	Discharge Educator (DE) Responsibilities
1. Ascertain need for and obtain language assistance.	<ul style="list-style-type: none"> • Find out about preferred languages for oral communication and written materials. • Determine patient and caregivers’ English proficiency • Arrange for language assistance as needed, including translation of written materials.
2. Make appointments for followup medical appointments and post discharge tests/labs.	<ul style="list-style-type: none"> • Determine primary care and specialty follow up needs. • Find a primary care provider (if patient does not have one) based on patient preferences: gender, location, specialty, health plan participation, etc. • Determine need for scheduling future tests. • Make appointments with input from the patient regarding the best time and date for the appointments. • Instruct patient in any preparation required for future tests and confirm understanding. • Discuss importance of clinician appointments and labs/tests. • Inquire about traditional healers and assure that traditional healing and conventional medicine are complementary. • Confirm that the patient knows where to go and has a plan about how to get to appointments; review transportation options and address other barriers to keeping appointments (e.g., lack of day care for children).
3. Plan for the followup of results from lab tests or studies that are pending at discharge.	<ul style="list-style-type: none"> • Identify the lab work and tests with pending results. • Discuss who will be reviewing the results, and when and how the patient will receive this information.
4. Organize post-discharge outpatient services and medical equipment.	<ul style="list-style-type: none"> • Collaborate with the case manager to ensure that durable medical equipment is obtained. • Document all contact information for medical equipment companies and at-home services in the AHCP. • Assess social support available at home. • Collaborate with the medical team and case managers to arrange necessary at-home services.
5. Identify the correct medicines and a plan for the patient to obtain and take them.	<ul style="list-style-type: none"> • Review all medicine lists with patient, including, when possible, the inpatient medicine list, the outpatient medicine list, the outpatient pharmacy list, and what the patient reports taking. • Ascertain what vitamins, herbal medicines, or other dietary supplements the patient takes. • Explain what medicines to take, emphasizing any changes in the regimen.

	<ul style="list-style-type: none"> • Review each medicine’s purpose, how to take each medicine correctly, and important side effects. • Ensure a realistic plan for obtaining medicines is in place. • Assess patient’s concerns about medicine plan.
6. Reconcile the discharge plan with national guidelines.	<ul style="list-style-type: none"> • Compare the treatment plan with National Guidelines Clearinghouse recommendations for patient’s diagnosis and alert the medical team of discrepancies.
7. Teach a written discharge plan the patient can understand.	<ul style="list-style-type: none"> • Create an AHCP, the easy-to-understand discharge plan sent home with patient. • Review and orient patient to all aspects of AHCP. • Encourage patients to ask.
8. Educate the patient about his or her diagnosis.	<ul style="list-style-type: none"> • Research the patient’s medical history and current condition. • Communicate with the inpatient team regarding ongoing plans for discharge. • Meet with the patient, family, and/or other caregivers to provide education and to begin discharge preparation.
9. Assess the degree of the patient’s understanding of the discharge plan.	<ul style="list-style-type: none"> • Ask patients to explain in their own words the details of the plan (the teach-back technique). • May require contacting family members and/or other caregivers who will share in the care-giving responsibilities.
10. Review with the patient what to do if a problem arises.	<ul style="list-style-type: none"> • Instruct on a specific plan of how to contact the primary care provider (PCP) by providing contact numbers, including evenings and weekends. • Instruct on what constitutes an emergency and what to do in cases of emergency.
11. Expedite transmission of the discharge summary to clinicians accepting care of the patient.	<ul style="list-style-type: none"> • Deliver discharge summary and AHCP to clinicians (e.g., PCP, visiting nurses) within 24 hours of discharge.
12. Provide telephone reinforcement of the Discharge Plan.	<ul style="list-style-type: none"> • Call the patient within 3 days of discharge to reinforce the discharge plan and help with problem-solving. • Staff DE Help Line. Answer phone calls from patients, family, and/or other caregivers with questions about the AHCP, hospitalization, and followup plan in order to help patient transition from hospital care to outpatient care setting.

Appendix 9: Principles of patient navigation, Health Education England (2016)

(from the Care Navigation Competency Framework_Final.pdf and adapted from Freeman and Rodriguez (2011) for Patient Navigators in North America⁹.)

1. Navigation is a patient-centric healthcare service delivery model.

Patient navigation has the potential of creating a seamless flow for patients as they journey through the care continuum.

2. The core function of navigation is the elimination of barriers to timely care across all segments of the healthcare continuum.

This function is most effectively carried out through a one-on-one relationship between the navigator and the patient.

3. Patient Navigation should be defined with a clear scope of practice that distinguishes the role and responsibilities of the navigator from that of all other providers.

Navigators should be integrated into the healthcare team in such a way that there is maximum benefit for the individual patient.

4. Delivery of navigation services should be cost-effective and commensurate with the training and skills necessary to navigate an individual through a particular phase of the care continuum.

5. The determination of who should navigate should be primarily decided by the level of skills required at a given phase of navigation.

There is a spectrum of navigation extending from services that may be provided by trained lay navigators to services that require navigators who are professionals, such as nurses and social workers.

6. There is a need in a given system of care to define the point at which navigation begins and the point at which navigation ends. We must keep in mind that for the cancer patient involved, the need is not over until the cancer is resolved.

7. There is a need to navigate patients across disconnected systems of care, such as primary care sites and tertiary care sites Patient navigation can serve as the process that connects disconnected healthcare systems.

Navigation systems require coordination. In larger systems of patient care this coordination is best carried out by assigning a navigation coordinator or champion who is responsible for overseeing all phases of navigation activity within a given healthcare site.

⁹ Freeman HP and Rodriguez R. (2011). History and principles of patient navigation. *Cancer* 117:3539. Available: <http://onlinelibrary.wiley.com/doi/10.1002/cncr.26262/pdf> [Accessed: 22 September 2021].