



ACT
Government

ACT Health

Future Directions of Disability Health in the ACT – An Abridged Version

A part of the
development of
the ACT Disability
Health Strategy



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Future Directions of Disability Health in the ACT – Discussion Paper

Introduction

Purpose

This document provides an abridged version of the report entitled *Future Directions of Disability Health in the ACT: Phase One of the ACT Disability Health Strategy* (referred to as the Scoping Paper).

A copy of the full version, including references, of the Scoping Paper can be found [here](#).

Background

In late June 2021, ACT Health Directorate commissioned Human Capital Alliance International to undertake a scoping study as part of Phase One of the ACT Disability Health Strategy Project. The aim of the study was to review disability health related local, national, and international legislation, policy, literature, and research that would inform the development of the ACT Disability Health Strategy and its First Action Plan (from here, collectively referred to as the ACT DHS).

In September 2021 and based on their findings, Human Capital Alliance International delivered the Scoping Paper.

Overview of the health system in the ACT

The schematic at Figure 1 on the following page provides an overview of the health system of the ACT and identifies the key types of health services or initiatives that currently exist. 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'.

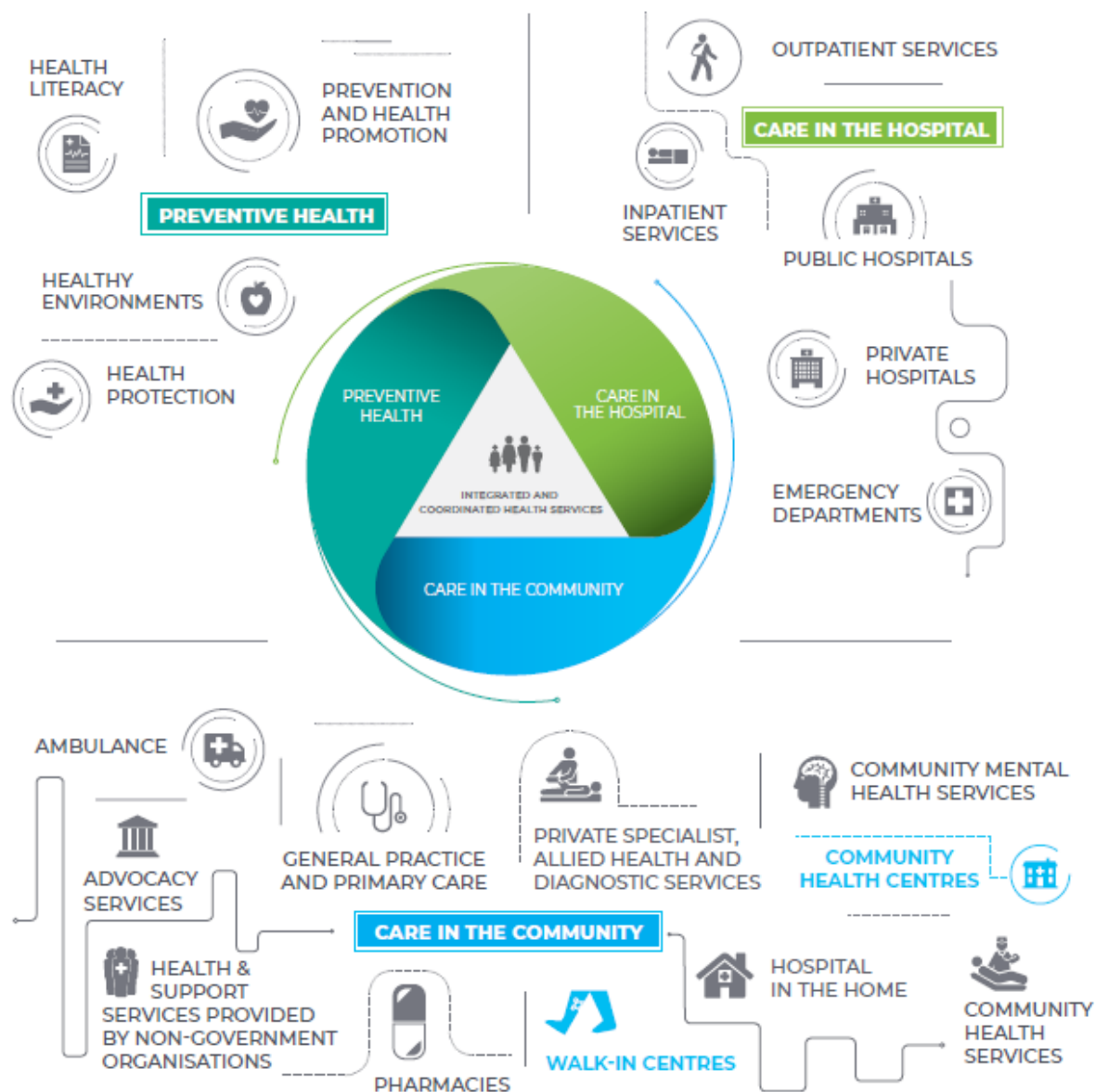


Figure 1: Schematic of the health system in the ACT (Source: ACT Government, *Accessible, Accountable, Sustainable: A Framework for the ACT Public Health System 2020–2030*, p.2)

Key legislation, policy, and research

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 disability and their families. Legal rights against discrimination are protected by both national and jurisdiction-based legislation, as outlined from the ACT perspective at Figure 2 on the next page.



Figure 2: Schematic of relevant legislation, regulation and standards

Policy

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 on the next page provides a summary of the most influential current and planned policy documents that will inform development of the ACT DHS. Naturally, since people with disability 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 ACT DHS in order to align and amplify relevant opportunities for improvement.

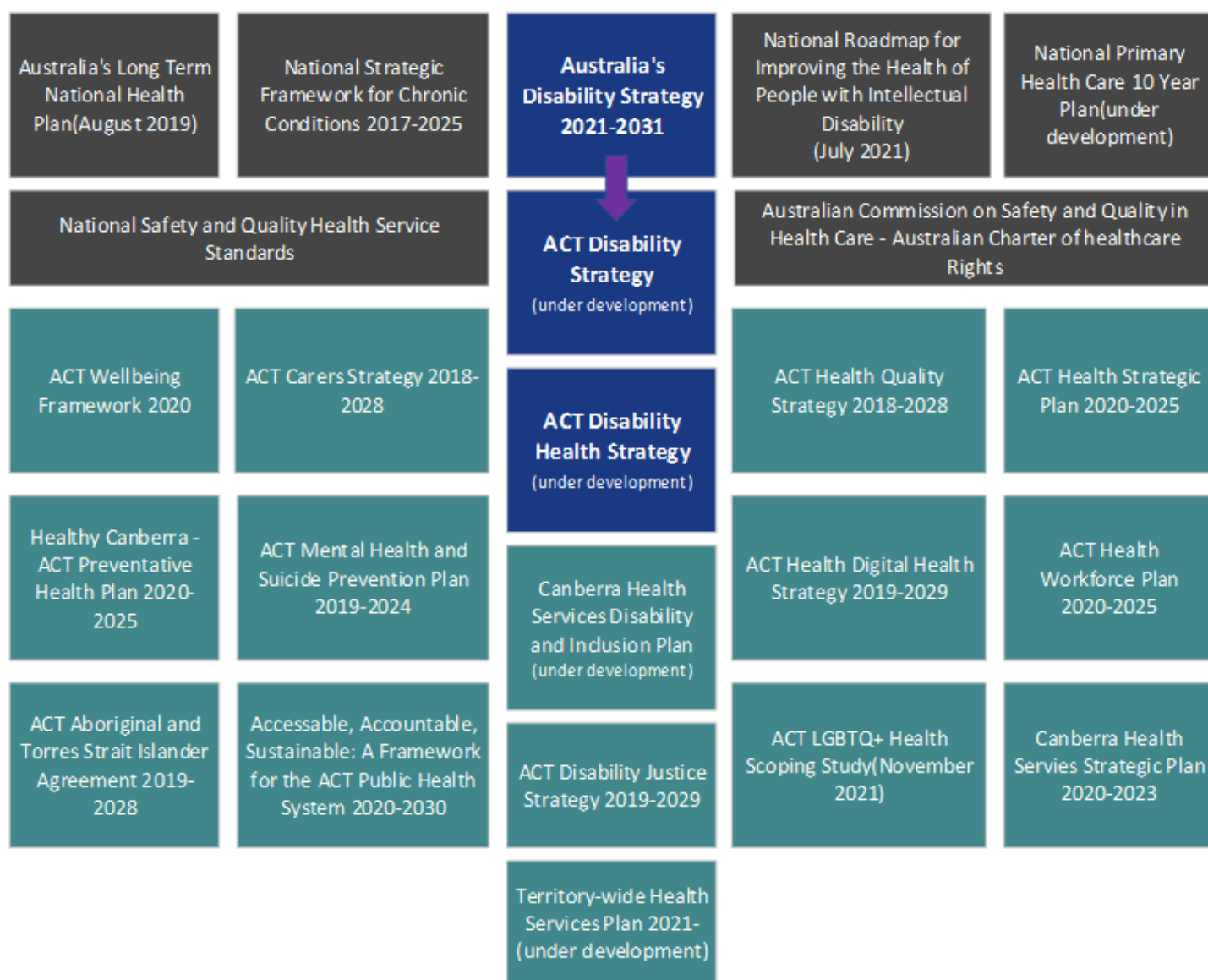


Figure 3: Overview of the national disability health policy and strategic planning documents

ACT research

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 DHS.

Some key examples of relevant ACT reports are as follows:

- ACT Council of Social Services (ACTCOSS), 2019, *Imagining Better: Reflections on access, choice and control in ACT health services for people with disability* (Imagining Better)
- Women's Health Matters, 2022, *"I have to ask to be included..." The views of ACT women with disability about their health and health needs, access to services, supports and information; and the barriers to maintaining their health*
- Health Care Consumers' Association, 2018, *A model for patient navigation in the ACT for people with chronic and complex conditions*
- Canberra Health Services, 2021, Canberra Health Services Disability Needs Assessment (DRAFT) (embargoed)
- ACT Health Directorate, 2021, ACT LGBTQI+ Health Scoping Study
- ACT Community Services Directorate, 2020, *ACT COVID-19 Disability Strategy and ACT COVID-19 Disability Action Plan*
- ACT Office for Disability, 2019, *Towards Disability Justice for the ACT: Summary of research and consultations*

Key principles

United Nations Convention of the Rights of Persons with Disabilities

The *United Nations Convention on the Rights of Persons with Disabilities* (CRPD), 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 disability 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 of willing and disability-confident service providers.

‘Nothing About Us Without Us’

The widely adopted motto ‘Nothing About Us Without Us’ highlights that quality health care people with disability relies on the principle of participation. This principle should underpin all efforts to improve outcomes for this community.

The New Zealand Government Office for Disability Issues 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 disability from the outset.

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 habilitation, 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 bio-ethics 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 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 and well-being, including sport, recreation, arts and 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.

Social model of disability and health

The term 'social model of disability' arose out of a UK-based movement called the Integration Alliance in the late 1980s and initially focussed on integrating children with disability 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 disability and Figure 4 provides a comparison between the two models.

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. 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.

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.

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.

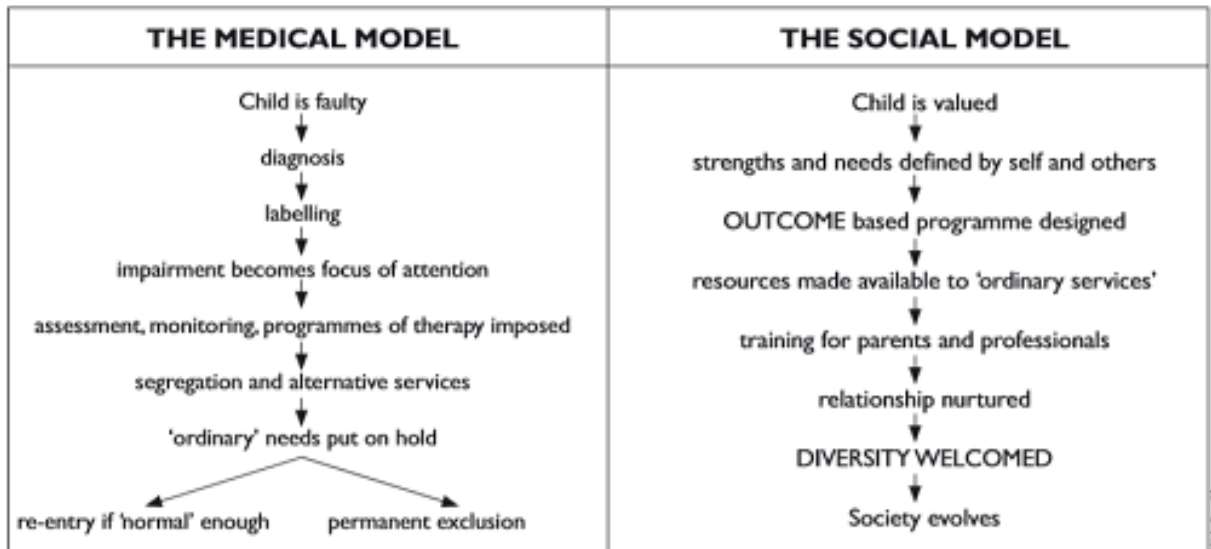


Figure 4: Example comparisons between perspectives from the medical model versus the social model (Source: Mason and Rieser, 1994, *Altogether Better (from special needs to equality in education)*, p.19)

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.

Social determinants of health

The social determinants of health multi-factorial and layered approach to understanding how health status can be influenced has continued to receive increasing support in health policy and practice. The World Health Organization (WHO) 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.

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.

A recent factsheet published by the WHO highlights the public health issues and social determinants associated with improving the health of people with disability 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 disability:

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.

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:

- Equitable Use
- Flexibility in Use
- Simple and Intuitive to Use
- Perceptible Information
- Tolerance for Error
- Low Physical Effort
- Size and Space for Approach and Use

Universal design, which was defined by the Center for Universal Design as 'design that's 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.

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 disability using health care services.

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.

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. Some examples of reasonable adjustments that have been used in practice in the UK include:

- 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 7 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 anesthetic.

The graphic at Figure 5 below, is 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.

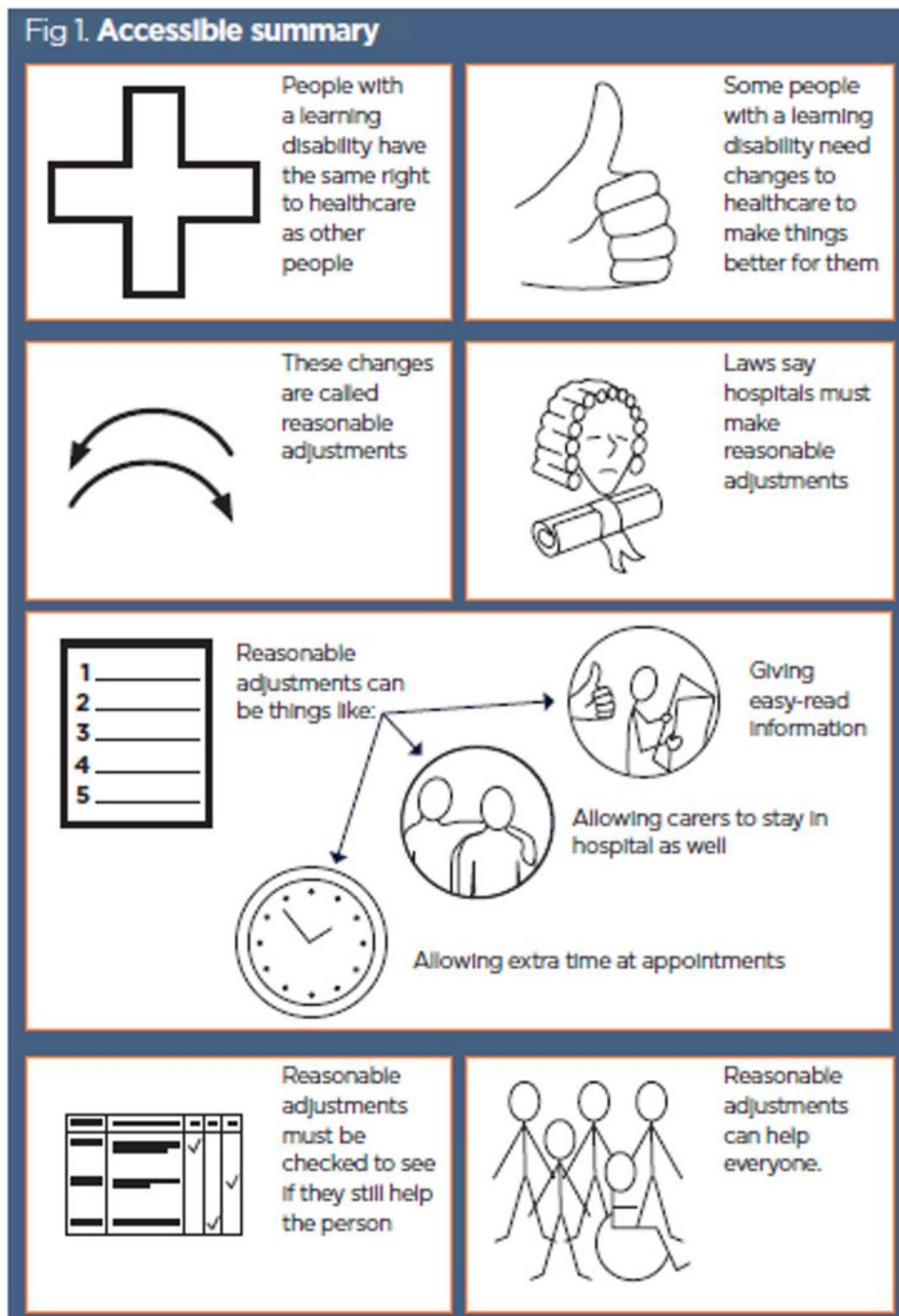


Figure 5: Example poster for reasonable adjustment strategies (Phillips, 2019, *Learning disabilities: making reasonable adjustments in hospital*, p.39)

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.

Key issue areas

Health promotion and prevention

Numerous studies have shown that people with disability 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.

As a result of this low level of engagement with health-promoting activity and prevention-oriented health services, people with disability 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. 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.

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.

Health literacy

People with disability 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. 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. A lower level of health literacy can also leave more scope for safety issues during the course of health care service provision.

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. 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 the *Health Literacy Action Plan 2019-2024* 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.

Health service accountability

Despite broader legislative and international agreement requirements about the rights of people with disability and the need for 'reasonable accommodation' 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 disability. 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. 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.

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.

Data and monitoring processes

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. 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.

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 disability, including flagging mechanisms, and effective monitoring systems.

The NSW Health policy directive on people with disability in hospital 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. 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.

Consent procedures and decision-making

People with disability have the right, like all citizens, to participate in decision-making and consent procedures about any proposed medical treatments or interventions. 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. 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.

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.

Inclusion of family/carer network

The families of people with disability, 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. 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.

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. Carers can also assist service providers to have direct communication with the person with a disability.

Communication – written and verbal

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 disability 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.

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. 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. 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.

Patient-held information

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. For all consumers, effective and well-aligned health care relies on awareness and consideration of usual care processes and previous investigations. For people with disability, 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.

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.

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. In the ACT, a group of people with disability 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 disability in particular, and to improve the integration of care across care boundaries. This resource is currently in production and is unique in that it assists people with disability, 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.

Physical access and accommodation of sensory issues

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. This does not, however, ensure that physical access issues are comprehensively addressed in all situations – 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 disability may experience a wide range of sensory and/or social issues that may be triggered by standard health care practising arrangements. 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.

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.

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.

Workforce development

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 disability who need the services provided by that workforce. However, the varied needs of people with disability 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. 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.

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. 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.

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. 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.

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.

System coordination and integrated care

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. 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. These risks have been found to be particularly significant within the first five day period post-discharge from hospital. 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, 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.

Patient navigation support

A widely used UK study by Macredie 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.

In its 2018 report on developing a patient navigation for the ACT, Health Care Consumers' Association (HCCA) also reflected benefit of this role in relation to supporting people with complex needs; and noted that they considered the needs of people living with disability to be included as complex.

The Care Navigator competency framework developed by Health Education England 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.

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.

Strategies for improvement

The HCCA report 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.

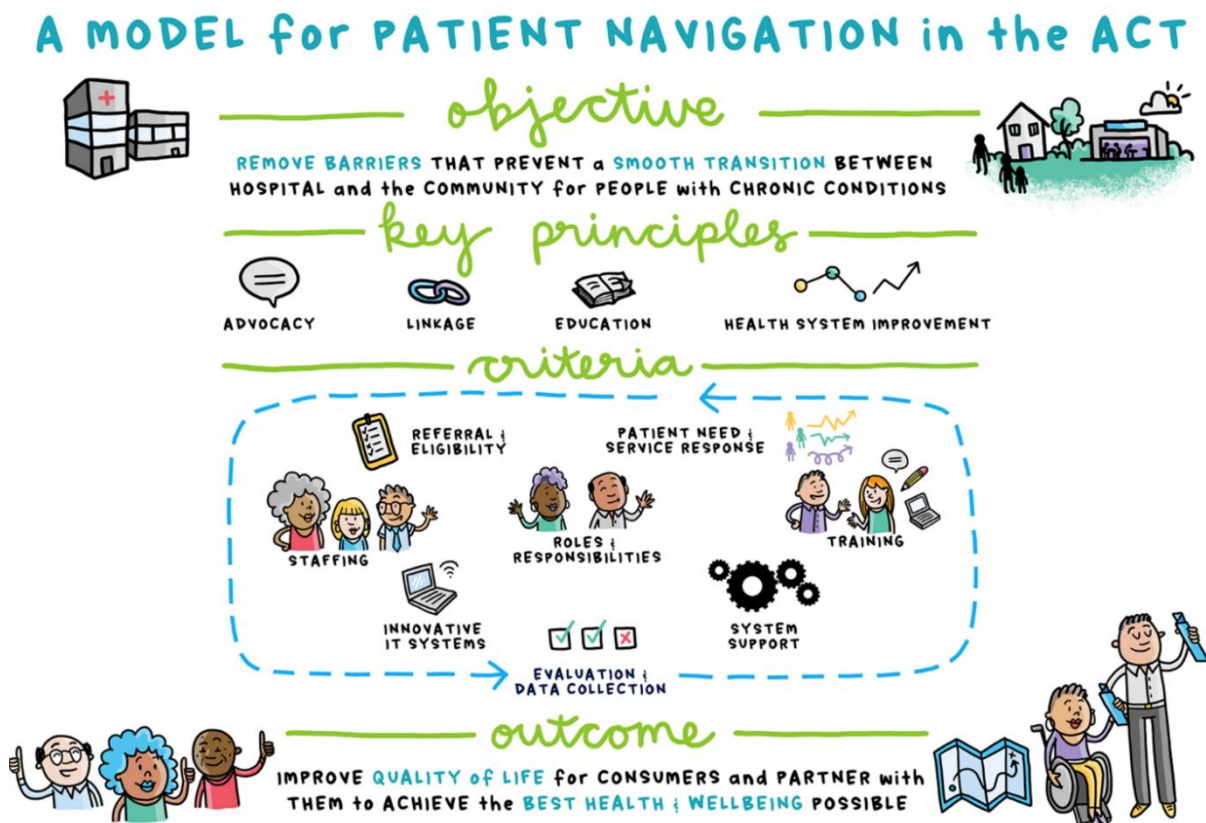


Figure 6: A model for patient navigation in the ACT, A model for patient navigation in the ACT for people with chronic and complex conditions (2018)

The patient navigator role is often extremely complex and requires significant skills in communication and negotiation. Key aspects of the 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.

Multidisciplinary care models

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’) 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 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 disability 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.

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. 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 disability 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 disability 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 disability 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 disability, 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 in 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.

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

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.

Specialised service models have also been developed to support people with cognitive disability 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. 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.

Financial barriers to care

It is widely acknowledged that people who live with disability 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. For many people with disability, referrals to these types of services 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. 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. 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 development of the ACTCOSS Imagining Better report indicated the significant financial barriers faced by many consumers in getting access to primary care and allied health services that they needed. That report 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 disability, access to a funding package under the National Disability Insurance Scheme (NDIS) provides some financial relief associated with access to health care. A 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.