Government of **Western Australia**
Department of **Health**

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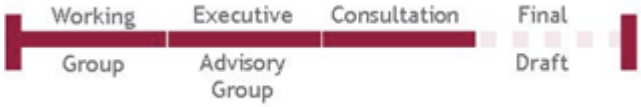
WA Disability Health Framework 2015–2025

Improving the health care of people with disability

Consultation version

This document is considered a draft for discussion, and is in the consultation phase as illustrated in the status bar below



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Contact information

For further information contact Health Strategy and Networks, WA Department of Health on (08) 9222 0200 or healthpolicy@health.wa.gov.au.

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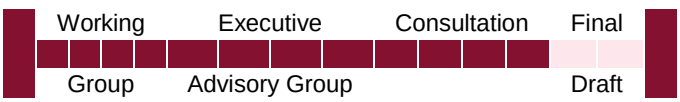

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Executive summary

The *Western Australian Disability Health Framework 2015-2025: improving the health care of people with disability* (the *Framework*) was developed by the Disability Health Network as WA Health's response to the *World Health Organization* (*WHO) Global Disability Action Plan 2014-2021*[1] and the *National Disability Strategy*[2]. It outlines priorities for all areas of the health system, the disability sector and the community to focus their efforts towards improving the health outcomes of people with disability.

This *Framework* is applicable to all public health service providers (permanent, temporary, casual, contract) working with people with disability, their family, carers and communities. It is also appropriate for use by other government departments, private, not-for-profit and non-government organisations working with people with disability, their family, carers and communities.

It has been developed in conjunction with the community, health service providers and disability service organisations in Western Australia (WA) and is underpinned by legislative obligations and local, state and national strategic directions.

The *Framework* adopts the social model, rather than the medical model, to define disability. The social model sees 'disability' as 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.

The vision of the *Framework* is an inclusive Western Australian health system that enables people with disability to enjoy the highest attainable standard of health throughout their life. In order to reach this vision, the *Framework* aims to achieve the following goals:

- foster a broader understanding of the health needs of people with disability and their right to effective services and care
- improve the quality, accessibility, inclusiveness and coordination of services necessary to meet the health needs of people with disability.

The following guiding principles provide a focus for stakeholders when developing policy, implementing services and making decisions regarding the provision of health care for people with disability:

- responsive and flexible
- respect and dignity
- person centred
- collaboration
- continuous improvement.

The *Framework* articulates four system-wide priorities:

1. understanding and recognition
2. health and wellbeing
3. workforce capability
4. inclusive health care.

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The whole community has a role in implementing the *Framework* and action is also required at all levels of organisations and services. For instance:

- health service and organisation executive officers are responsible for implementing systems to ensure the principles and priorities of the *Framework* are embedded in routine practice
- managers and supervisors are responsible for ensuring staff are aware of their roles in relation to the implementation of the *Framework*
- health and disability workers should apply the principles of the *Framework* when providing care to people with disability, their families and carers
- policy and service planners are responsible for considering the implications for policy and service design
- people with disability, their families and carers should aim to understand the key messages and self-advocate to receive the type of care outlined by the *Framework*.

There is a strong rationale for the need to focus on disability including legal obligations, policy linkages, health disparities, a growing interest from people using services to have greater control over the design, planning and delivery of their supports and services and significant social and economic reform with regards to people with disability, their families and carers having a greater say in how they achieve a good life.

Addressing the priority areas and implementing improvement initiatives effectively and sustainably requires understanding a number of system influencers. These can be potential opportunities to use as enablers to change, or they could present as potential barriers to address. They include:

- networking and engagement with stakeholders
- safety and quality in health care
- disability access and inclusions plans
- data and research
- individual, community and organisational capacity.

The Disability Health Network will develop a monitoring and evaluation plan for the *Framework* that recognises the need for a phased approach; early evaluation will focus on the reach and awareness of the *Framework* whilst long-term evaluation efforts will measure the impact of the *Framework* in organisation and services that have adopted it. The Disability Health Network will broadly promote the *Framework*, continually aiming to provide practical advice and examples on how the *Framework* can be translated into practice.

"Disability is a natural part of the human experience"[3]

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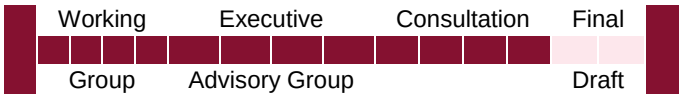
Disability Health Framework snapshot

Vision	An inclusive Western Australian health system that enables people with disability to enjoy the highest attainable standard of health throughout their life.				
Purpose	To provide direction for WA Health and other government and community sector agencies on policy development and service delivery that will achieve improved health outcomes for people with disability.				
Goals/ outcomes	Foster a broader understanding of the health needs of people with disability and their right to effective services and care.		Improve the quality, accessibility, inclusiveness and coordination of services necessary to meet the health needs of people with disability		
Guiding principles	Responsive and flexible	Respect and dignity	Person centred	Collaboration	Continuous improvement
Priority areas	Understanding and recognition	Health and wellbeing	Workforce capability	Responsive health care	
Rationale	Legal obligations and policy	Health disparities	Voice of the consumer, carer and family	Social and economic reform	
System influencers	Networking and stakeholder engagement	Quality and safety standards	Disability Access and Inclusion Plans	Data and research	Individual community and organisational capacity



1. Introduction

1.1 Background

The last three decades have seen significant changes to legislation and disability service provision. This has resulted in more positive outcomes for people with disability with better access to generic services in the community, a more inclusive society and a shift in community attitudes and acceptance.

Despite this, people with disability tend to have a higher prevalence of health problems compared to the general population. There can be different patterns and types of health needs occurring across the life course from childhood, adulthood and into old age. Frequently these health needs are either under-recognised or inadequately managed.

Across the world, more often than their non-disabled peers, people with disability do not receive the health care they need and have poorer health. People with disability are more than twice as likely to find healthcare providers' skills and facilities inadequate; nearly three times more likely to be denied health care; and four times more likely to be treated badly.[1]

The process of deinstitutionalisation saw the transition away from the medical model with a focus on “illness” toward concepts of health, wellbeing and community participation.

In addition, all health services that were historically provided by the Disability Services Commission ceased or were transferred to health settings. With this, many specialised doctor, nurse and psychiatrist positions were phased out as it was anticipated that generic health services would meet the healthcare needs of people with disability

It is now recognised that many people with disability, particularly intellectual disability, encounter barriers to access generic services. Additionally, the generic health service system cannot always effectively meet the health needs of the people with disability, especially those whose needs are more complex.

Some people with disability access therapy which may be provided by an allied health worker. This may give the impression that those people are receiving a health service. This is not the case and whilst these services are still required, people with disability need to access the types of health services that will improve their health outcomes.

Changes are therefore required to ensure improved access and inclusion and removal of barriers to quality health care so that people with disability can achieve better health outcomes.

1.2. Defining disability

The *Framework* adopts the social model to define disability. However it is recognised that providing one definition for disability is particularly challenging as it varies depending on the purpose of the definition. Many definitions are based on a diagnosis or are used for administrative purposes such as funding criteria or data collection. This leads to an exclusive rather than inclusive paradigm.

The social model of disability[4] 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.

The social model sees ‘disability’ as 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.

A social model perspective does not deny the reality of impairment nor its impact on the individual; it challenges 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 people 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.

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*[5] marks the official paradigm shift in attitudes towards people with disability and approaches to disability concerns.

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.
- **Disability** is the result of the interaction between people living with impairments and barriers in the physical, attitudinal, communication and social environment.

> The United Nations Convention on the Rights of Persons with Disabilities[5] recognises that disability arises from the combination of **impairments** and **barriers** that "hinder...full and effective participation in society on an equal basis with others.". The impairments can include "long-term physical, mental, intellectual or sensory impairments" whilst the barriers can be attitudinal or environmental[6].

2. About the Framework

2.1 What will the Framework do?

The *WA Disability Health Framework 2015-2025: Improving the health care of people with disability* (the *Framework*) provides WA Health's response to the World Health Organization (WHO) Global Disability Action Plan 2014-2021[1] and the National Disability Strategy[2]. It outlines priorities for all areas of the health system, the disability sector and the community to focus their efforts towards improving the health outcomes of people with disability.

The *Framework* intends to:

- identify priority areas for action to be undertaken by WA Health and its partners
- inform policy, service provision and improvement initiatives for WA Health and other government and community sector agencies to improve health outcomes for people with disability.

The *Framework* will facilitate opportunities for:

- meaningful partnerships and collaboration with people with disability, families and carers, WA Health, private and not-for-profit providers and the disability sector
- research and evaluation across the health system for health improvement programs and policies for people with disability.

The *Framework* includes:

- a definition of disability
- priority areas for action
- guiding principles
- drivers and enablers for change.

The *Framework* applies to people of any age living with disability. This includes but is not limited to Aboriginal people and people from culturally and linguistically diverse (CaLD) backgrounds, although it is recognised that targeted and culturally-specific services may be required for these groups.

2.2 Process for developing the Framework

In 2013, a small working group was convened by the Disability Health Network (See Appendix 1 for more information on the Disability Health Network) to plan the scope and vision for the *Framework.* The group considered feedback from a number of key stakeholder consultations including the Clinical Senate debate on disability and health[7]; the Disability Health Consultative Group; Disability Health Network Executive Advisory Group and the Ministerial Advisory Council on Disability[8].

A literature review of current and relevant international, national and interstate policies was then conducted. It became evident that the research consolidated the feedback received during the consultations and hence this information provided a strong base for the formation of the *Framework*.

A draft document was then developed and approved by the Disability Health Network Executive Advisory Group and the Chief Medical Officer of the Department of Health WA before being released for broad consultation in 2015.

The consultation process will include an online survey component as well as face to face sessions with key stakeholders. Communication during the consultation process will be guided by the Disability Health Network Commitment to Inclusive Engagement[9] in order to ensure it is inclusive of people with disability.

The feedback from the consultation will be collated and incorporated into the final version of the Framework. The final Framework will be submitted to the Disability Health Network Executive Advisory Group and the Chief Medical Officer of the Department of Health WA for approval before being released.

3. Vision

The vision of the *Framework* is an inclusive Western Australian health system that enables people with disability to enjoy the highest attainable standard of health throughout their life.

4. Purpose and goals

The purpose of the *Framework* is to provide direction for the WA community including WA Health and other government and community sector agencies on policy development and service delivery to achieve improved health outcomes for people with disability. The goals of the *Framework* are to:

- foster a broader understanding of the health needs of people with disability and their right to effective services and care
- improve the quality, accessibility, inclusiveness and coordination of services necessary to meet the health needs of people with disability.

5. Guiding principles for health care

The following principles provide a focus for government departments and community agencies when developing policy, implementing services and making decisions regarding the provision of health care for people with disability.

Responsive and flexible	Services and strategies will be responsive to the needs of people with disability including those from all cultural and linguistic backgrounds residing in communities across WA, including rural and remote locations.
Respect and dignity	People with disability have the same rights as everyone else – to be respected, to make their own decisions, to feel safe and have opportunities to live a meaningful life.
Person centred	People with disability, their families and carers are supported to make informed decisions about, and to successfully manage, their own health and care. They are able to make informed decisions and choose when to invite others to act on their behalf. This may require partnerships to deliver care responsive to people's individual abilities, preferences, lifestyles and goals[10].
Collaboration	Through collaborating, sharing an understanding of roles and responsibilities, and building partnerships health outcomes for people with disability can be improved more efficiently and sustainably.
Continuous improvement	Programs and services are involved in continuous improvement processes to achieve best-practice. Services delivered meet minimum standards of practice based on best available evidence.

6. Priority areas

People with disability have a right to have their health needs identified early and managed in a responsive manner. Everyone has the same rights; however people with disability are at greater risk of experiencing discrimination and barriers. Although many of the health needs of people with disability are the same as those of the rest of the community the type of impairment, complexity, stage of life, gender and culture may also impact on an individual's health needs.

There is great diversity across the population of people with disability. Differences may include:

- the level of support in daily life, varying from no support where a person is on their own to significant support where the person may have a whole team around them
- living independently in their own homes or with family (perhaps with the aid of a carer or support worker), whilst others may live in group homes or nursing homes with considerable support.
- some may need to spend long periods in hospital as there is no suitable accommodation or support for them to move into the community
- people with disability may have one or more impairments and some may not have capacity to make their own decisions.

Four priority areas have been identified through stakeholder consultations including the Clinical Senate debate on disability and health[7]; the Disability Health Consultative Group; Disability Health Network Executive Advisory Group and the Ministerial Advisory Council on Disability[8]. The four priority areas align with international and national areas for action.

To achieve sustainable change in a large and complex system multiple actions at multiple levels across multiple organisations and the community are required. The four priority areas are:

1. understanding and recognition
2. health and wellbeing
3. workforce capability
4. inclusive health care.

6.1 Priority area one: understanding and recognition

Enabling the provision of services which meet the needs of people with disability requires an understanding and recognition of the specific issues relevant to them. This can be achieved through increased awareness and inclusion in policy. This *Framework* supports action to:

- develop or reform health and disability policy, strategies and plans to be in line with the Convention on the Rights of Persons with Disability[5]
- remove barriers to service delivery (including impediments to physical access, information, communication and coordination) across all healthcare programs including health promotion and other population-based public health initiatives
- improve collection of health data on disability populations, and research on disability-related health disparities and interventions
- include people with disability in the planning, development and implementation of health services that affect them (e.g. Disability Access and Inclusion Plans, design of new infrastructure, policy review).

6.2 Priority area two: health and wellbeing

Good health and wellbeing are essential to leading a good life and for participation in a wide range of activities including social, education and employment. Health promotion activities should reflect the needs of people of all abilities, ages, genders, cultures, linguistic and religious backgrounds in all communities whether they be urban, rural or remote.

The health and wellbeing of carers of people with disability is also important. Carers are reported to have the lowest collective wellbeing index with 59 per cent reporting a decline in physical health and two-thirds a decline in mental and emotional health.[11] The majority of carers are female aged between 45 and 64 years. However this age range will increase as people with disability live longer and continue to live at home and require support.

The *Framework* will support action to:

- build on and link with existing health service and health promotion initiatives including health screening, oral care and chronic disease prevention programs
- focus on supporting people with disability, their families and carers to develop the knowledge, confidence, skills and behaviours to achieve the best possible health
- present health promotion, prevention strategies and healthcare information in a range of formats that is inclusive of people with disability from diverse backgrounds
- promote timely and effective identification, diagnosis and management of co-occurring mental health conditions in people with intellectual disability (e.g. dual disability).

6.3 Priority area three: workforce capability

Workforce capability can be enhanced by people with disability, their families and carers sharing their knowledge of the lived experience.

Specific challenges to the quality of healthcare experiences by people with disability can be overcome by addressing health workers' values and attitudes, knowledge, skills and behaviours[1] as well as enabling participation of people with disability in decisions that directly affect them. Disability support workers also play a key role in supporting health and wellbeing of people with disability. Initiatives to increase workforce capability should include health and disability workers.

The *Framework* will support action to improve workforce capability by:

- integrating education on the health and human rights of people with disabilities into undergraduate and continuing education for all health workers
- including people with disability as providers of education and training where relevant
- building leadership capacity for ensuring disability-inclusive health services
- integrating health and wellbeing education for families and carers of people with disability
- integrating health and wellbeing education into support worker training
- supporting the increase of self-advocacy skills for people with disability to effectively address specific challenges in accessing health services.

[1] Draft Disability Health Workforce Core Capabilities Framework, Western Australian Department of Health (2015).

6.4 Priority area four: inclusive health care

Inclusive health care is a right for people with disability. It requires facilitated approaches to overcome barriers to improve and streamline service delivery and coordination, referral and transition pathways to enable improved health outcomes. This can be achieved through:

- support mechanisms to improve the continuum of care experienced by people with disability across the life course including: discharge planning, multidisciplinary team work, development of referral pathways and service directories
- transition of care including communication and information exchange, identified responsibilities and consistent processes
- valuing input from the person with disability, their families and carers and involving them in the decisions about their health care
- meeting the specific needs of people with disability in all aspects of emergency health care, including injury prevention, emergency response and management
- effectively communicating with people with disability, including those using augmentative or alternative communication methods, their families and carers.

7. Roles and responsibilities

The community along with all health and disability service providers have a role in implementing the *Framework*. This includes all public health service providers (permanent, temporary, casual, contract) working with people with disability, their families, carers and communities. It is also appropriate for use by other government departments including local government, private, not-for-profit and non-government organisations working with people with disability, their family, carers and communities.

In order to achieve the aim of the *Framework*, which is for people with disability in WA to be able to achieve the best possible health and wellbeing outcomes throughout their lives, action is required at all levels.

Other State Government departments and organisations and local government

State Government departments/ organisations and local government are responsible for:

- applying the principles of the *Framework* in the way they plan and provide services to people with disability, their families and carers.

Policy and service planners

All policy and service planners are responsible for:

- consider the *Framework* in all policy and service planning and what implications the *Framework* may have on policy and service design.

Health services and community/disability organisations

Health services and community/disability organisations are responsible for:

- applying the principles of the *Framework* in the way they provide services to people with disability, their families and carers.

The health service and organisation executive officers are responsible for:

- implementing systems to ensure the principles and priorities of the *Framework* are embedded in routine practice
- ensuring systems are in place to monitor compliance with the principles and priorities of the *Framework*
- raising awareness of the key messages of the *Framework* amongst the health service or organisation.

Manager and supervisors are responsible for:

- ensuring staff are aware of their roles in relation to the implementation of the *Framework*
- providing relevant education to staff on the implications of the *Framework* in practice.

Health and disability workers

All health and disability workers are responsible for:

- applying the principles of the *Framework* in the way they provide care to people with disabilities, their families and carers.

People with disability, their families and carers

All people with disability, their families and carers are responsible for:

- having an understanding of the key messages from the *Framework* and their own capacity to respond effectively to their health needs
- self-advocating to receive the type of care outlined by the *Framework*.

8. Rationale for focusing on disability health

8.1 Legislation and policy

8.1.1 Legal obligations

All State Government departments, statutory authorities, corporations and community organisations have obligations under law to respect, protect and fulfil the rights of people with disability in addition to the obligations in the Western Australian Disability Services Act 1993[12].

Other legal obligations include those in the:

- United Nations Convention on the Rights of Persons with Disabilities[5]
- Commonwealth Disability Discrimination Act 1992[13]
- Equal Opportunity Act 1984[14]
- Carers Recognition Act 2004[15]

> Persons with disability have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. All appropriate measures will be taken to ensure access for persons with disabilities to health services.
> Article 25 of the Convention on the Rights of Persons with Disabilities[5]

The Western Australian Disability Services Act 1993[12] provides a foundation for promoting the rights of Western Australians with disability and the delivery of programs and services. It requires that all Western Australian Government departments develop and implement Disability Access and Inclusion Plans (see Appendix 3).

Other associated legislation to be considered includes:

- Guardianship and Administration Act 1990[16]
- Mental Health Act 1996[17]
- Declared Places (Mentally Impaired Accused) Bill 2013[18]
- Code of Practice for the Elimination of Restrictive Practices[19]
- Privacy Act 1988[20]

Some of these legislative obligations are outlined in more detail in the Appendix 2.

8.1.2 Policy linkages

The *Framework* aligns with the WA Health Strategic Intent 2010-2015[21] of "healthier, longer and better quality lives for all Western Australians" where one of the four pillars is about "Caring for those who need it most". Other frameworks and policies that complement and support the *WA Disability Health Framework* include:

- WHO global disability action plan 2014–2021: Better health for all people with disability[1]
  The vision of the action plan is a world in which all people with disabilities and their families live in dignity, with equal rights and opportunities, and are able to achieve their full potential. The overall goal is to contribute to achieving optimal health, functioning, well-being and human rights for all people with disabilities. The *Action Plan* has three objectives:

    - to remove barriers and improve access to health services and programs
    - to strengthen and extend rehabilitation, habilitation, assistive technology, assistance and support services, and community-based rehabilitation
    - to strengthen collection of relevant and internationally comparable data on disability and support research on disability and related services.

- The National Disability Strategy[2] is a ten-year national policy framework for improving life for Australians with disability, their families and carers. It aims to bring about change in all mainstream services and programs as well as community infrastructure by ensuring the principles underpinning the *United Nations Convention on the Rights of Persons with Disabilities*[5] are incorporated into public policy across governments.

- Count Me In: Disability Future Directions[22] developed by the Disability Services Commission sets out a long term strategy designed to guide all Western Australians when responding to people with disability.

- The Western Australian Carers Charter[23] provides clear direction on how carers are to be treated and how carers are to be involved in the delivery of services.

- *The* Policy Framework for Substantive Equality[24] recognises that specific needs of certain groups in the community can only be met by adjusting government policies, procedures and practices.

- WA Health Disability Access and Inclusion Policy[25] outlines WA Health's commitment to ensuring that people with disabilities, their families and carers are able to fully access the range of health services, facilities and information available in the public health system.

- The WA Health Promotion Strategic Framework 2012-2016[26] provides direction for primary prevention of health conditions in WA. It recognises people with disability as a vulnerable population and acknowledges they are a population that has difficulty in gaining access for the provision of health promotion activities.

- Western Australian Strategic Plan for Safety and Quality in Health Care 2013-2017 – Placing patients first[27] articulates the vision and system-wide priorities for safety and quality improvement in WA Health and provides a focus for detailed discussions, planning and action at all levels of the health system.

- *National Oral Health Plan 2015-2024*[28] (in draft) aims to set the national direction and provide a framework for collaborative action in oral health over the next 10 years. The Plan emphasises a population health approach, recognising the importance of the social determinants of health. To this end, Foundation Areas have been established to support action across the whole population. Additionally the needs of those who are disproportionately affected by poor oral health are addressed through priority populations actions. These priority populations are:
    - people who are socially disadvantaged and/or on low incomes
    - Aboriginal and Torres Strait Islander People
    - people living in regional and remote Australia
    - people with additional and/ or specialised healthcare needs (including people with disability, people living with mental illness, people with complex medical needs and frail older people)

Other policies may exist within community and government organisations which also align with the *Framework* to support a whole of State response to the vision of an inclusive health care system.

8.2 Health disparities in people with disability

In 2012, it was estimated that 18.5 per cent of the Australian population had a disability.[29] This number is projected to continue increasing due to the ageing population and increases in chronic health conditions, among other causes.[1]

People with disability have the same general healthcare needs as everyone else, and therefore need access to mainstream healthcare services as well as specialist care when required. There is also a need for a focus on addressing health conditions which are more likely to impact on the health of people with disability, particularly where it may require specialist care.

8.2.1 Health issues for people with disability

People with disability can attain the highest possible health and wellbeing outcomes throughout their lives. Despite the overall improvement in the general population's health, the gap between the health of Australians with disability and those without disability remains large.

In 2007-08, almost half (46 per cent) of people aged 15–64 with severe or profound disability reported poor or fair health compared with 5 per cent for those without disability.[30]

Table 1: Disability health in Australia (15-64 years) – comparative prevalence rates for some health-related conditions[30]

Health condition/behaviour	Severe/profound disability	Typical adult population
Long-term conditions:		
Diabetes	23%	7%
Arthritis	14%	6%
Osteoporosis	43%	7%
Mental health problems	48% (particularly with intellectual disability)	6%
Childhood onset of mental health issues	14%	7%
Obesity	69%	58%
Low exercise	43%	31%
Daily smoking	31%	18%
Suicidal ideation	42% and 18% attempted	13.3% and 3.2% attempted*

*Age range is 16-84 years[31]

A study of the use of health services by people with a disability by the Australian Institute of Health and Welfare[32] compared with people without disability found that people with severe or profound disability (aged 15-64 years) were:

- 10 times more likely to have check-ups with general practitioners
- 3.5 times more likely to consult specialist doctors
- 5 times more likely to consult specialist doctors and other health professionals like occupational therapists, social workers and welfare workers.

> When controlled for co-morbidity of long-term health conditions, people with three or more conditions with severe or profound disability consulted both specialist doctors and other health professionals compared with 27 per cent of those without disability.[32]

Despite this, people with disabilities continue to encounter a range of barriers when they attempt to access health care including prohibitive costs, limited availability of services, physical barriers and inadequate skills and knowledge of health workers.[33] For example:

- Women with mobility difficulties are often unable to access breast and cervical cancer screening because examination tables are not height-adjustable and mammography equipment only accommodates women who are able to stand.
- People with disability were more than twice as likely to report finding healthcare provider skills inadequate to meet their needs, four times more likely to report being treated badly and nearly three times more likely to report being denied care.

Furthermore, as life span increases, so too does the incidence of disease patterns of the general population such as cancer and coronary heart disease; yet health promotion and prevention activities seldom target people with disability. For example:

- People with intellectual impairments and diabetes are less likely to have their weight checked.
- Adolescents and adults with disability are more likely to be excluded from sex education programs.

There is also a lack of health promotion material in an accessible format, particularly for people with an intellectual disability[33].

8.2.2 Health issues of carers

The health of families and carers also needs to be considered as many people with disability depend on their family as major contributors to their care and support and carers often initiate and facilitate access to health care. Many people with disability who are now living into adulthood are being cared for by elderly parents. It is reported that these carers have 40 per cent more limiting health disorders; depression is almost four times more common among female carers; back problems are particularly prevalent in carers of people with physical disabilities; and stress related illnesses are common.[34]

Along with the people with disability, people in a caring role may experience anxiety or distress during the hospital admission. It is important that communication methods acknowledge this by providing information in different formats, such as supplementing verbal advice with written advice in plain language and alternative formats where required. WA Health has in place a number of policies that assist in this regard including the WA Health Language Services Policy[35] which requires staff to ensure that the communication needs of both the patient and the carer

are assessed and met. This may require the use of interpreters, hearing loops or meetings in a quiet space.

8.3 Voice of the consumer, carer and family

National and Western Australian reforms of planning and funding disability services incorporate a model of giving people with disability more choice and control over their services and supports. Additionally, people with disability, their families, and carers are being given the opportunity to have their voice heard through increasing consultation and community engagement.

> "Nationally and internationally, there is a growing interest from people using services to have greater control over the design, planning and delivery of their supports and services. People also seek more personalised approaches to their supports and services that are tailored to and responsive to their individual requirements. There is also broad acknowledgement that better outcomes for people are achieved when they have genuine choice and the level of control they desire over their supports and services."[36]

In WA, My Way[37] is the next step in the Disability Services Commission's journey towards personalised, individualised disability support services. This program aims to empower people with disability, their families and carers to plan in a way that will give them greater choice and control over the supports and services they wish to access. Nationally, the Commonwealth has introduced the National Disability Insurance Scheme (NDIS), also known as Disability Care Australia.[38] This is a new way of funding individualised support for people with disability that involves more choice and control and a lifetime approach to a person's support needs. Both of these models are being trialled in specific locations from July 2014.

Although these initiatives do not relate directly to funding of health services or provision of health care, they are a mechanism that is recognising the individual needs of the person with disability and empowering them to determine what services they want to support these needs. This is consistent with the direction of healthcare reform towards person-centred care which aims to place the person at the centre of the care they are receiving, recognising them as a 'whole' person and supporting the person and carers to develop their own goals. Furthermore, many health and wellbeing initiatives are now being evaluated from the perspective of the benefit to the consumer.

Recent consultation forums for people with disability on health care and health services has provided valuable information and insight into how people with disability want to be treated when requiring health services and barriers that could be addressed by the health system. In Speaking out about Disability 2013[39], a report on the views of Western Australian children and young people with disability, the key message was that their disability was only one part of their life and they want to be known for who they are, their unique abilities, talents and potential, as a whole person. Lack of appropriate information about disability resulting in misconceptions, misunderstanding and sometimes fear are what children and young people with disability see to be problematic. Young people and children wanted there to be an increased understanding and acceptance of disability.

In relation to the provision of health care, people with disability, their families and carers consistently identify the following as barriers to effective and timely health care:[8, 40, 41]

- poor information flow or disregard for information provided, particularly at transition or transfer of care
- lack of awareness, understanding and knowledge of disability by healthcare providers, including communication skills
- health information resources not provided and distributed in user-friendly ways
- uncoordinated or poorly planned transition of care between health and disability providers or the community
- lack of knowledge on healthcare needs and services available for individuals, carers and disability service providers to be able to advocate.

Issues on flow of information from different perspectives

Hospital staff perspective: "there are several inefficiencies and time wasted due to not having access to current patient information, patient profile summaries and no central database that holds this information … including functional requirements like meal-time management, mobility, seating, communication …"

Consumer and carer perspective: "have to repeat the same information over and over again to several staff, which leads to feelings of frustration and not being listened to".

Disability organisation perspective: "care plans on clients provided for hospital admissions are not being utilised by frontline and hospital staff in some wards. For example, a patient requiring thickened fluids to prevent aspiration was not given thickened fluids nor positioned in their wheelchair for meal-times; alternative augmented communication devices are not used on wards with complex communication needs."[40]

8.4 Social and economic reform

Our community is currently experiencing significant social and economic reform with regards to people with disability, their families and carers having a greater say in how they achieve a good life. The Western Australian disability sector has been at the forefront of developing individualised, personalised, self-directed supports and services. This reshaping of support systems reflects a growing realisation that better outcomes are achieved when people with disability, their families and carers have genuine control, decision making and choice over the supports and services they require.

This reform necessarily extends beyond the disability sector, in recognition of the many other systems people use in living their life, including health, education, housing and employment.

Many of the reforms are directed by legislation which provides a powerful vehicle for implementing change across systems. Never the less, the challenge is great as these reforms are occurring in conjunction with many other human service reforms responding to the needs of an ageing population, growing burden of disease and an increasingly fragmented service system.

In WA Health the delivery of high quality, safe and cost-effective services is assessed and funded according to the Annual Performance Management Framework 2014-2015.[42] This is aligned with the national reform to introduce a nationally consistent Activity Based Funding (ABF) model. ABF is in the early stages of implementation so its potential as an enabler is not fully realised, however, in theory there is potential for hospital facilities to recognise people with disability with complex care needs and receive additional funding to meet their requirements effectively.

Activity Based Management (ABM) is the management approach used by WA Health to plan, budget, allocate and manage activity and financial resources to ensure delivery of safe, high quality health services to the WA community.[42] ABF supports ABM to enhance public accountability and drive technical efficiency in the delivery of health services.

Equity and access to quality health care can be further enabled through providing affordable health services; for example, working with local government to provide affordable services that support people in making healthy lifestyle choices.

The National Disability Insurance Scheme (NDIS)[38] has the potential to significantly change the lives of many people with disability, their families and carers by providing them with greater opportunities to make choices about and exert control over the supports they require. This capacity for self-determination will extend to the health system where services will be required to respond in a way that meets individual needs. The sustainability of the Scheme is dependent, in part, on a well-defined interface with the health system to ensure people's needs are met in the best place for them. This interface includes primary care, where great opportunities exist to work with people with disability to promote good health as an important component of a good life.

9. System influencers

Addressing the priority areas and implementing improvement initiatives effectively and sustainably requires understanding a number of system influencers. These can be potential opportunities to use as enablers to change, or they could present as potential barriers to address. Whether they are enablers or barriers will depend on broader contexts outside the scope of this *Framework* such as reform agendas, political landscape and progress of implementation of national or state initiatives.

9.1 Networking and engagement with stakeholders

Improving the quality of life and health outcomes for people with disability along with their families and carers requires innovative solutions to deliver more collaborative and connected services. People with disability either directly or through their representative organisations should be fully consulted and actively involved in all stages of formulating and implementing policies and services that relate to them.

The network approach to health reform is neutral and objective. It provides the opportunity to **connect** all stakeholders across the State and across sectors to **share** ideas and develop solutions to **improve** service delivery across the continuum of care.

Bringing together stakeholders helps to create partnerships and better connect different levels and types of care. This approach places consumers and carers first. It facilitates seamless service delivery across all phases of care and fewer complexities in system navigation for consumers.

The Commitment to Inclusive Engagement[9] was developed by the Disability Health Network as a guide to ensure health care engagement activities that relate to people with disability are inclusive of people with disability, their families and carers. The three principles for inclusive engagement are:

- respect and rights
- inclusion
- transparency.

Through collaborating and sharing an understanding of roles and responsibilities, health outcomes for people with disability can be improved more efficiently and sustainably.

Nothing about us without us![43]

9.2 Safety and quality in health care

The Western Australian Strategic Plan for Safety and Quality in Health Care 2013-2017[27] defines a series of interdependent concepts that have been developed to foster a shared and unified approach to promoting and assuring the delivery of safe, high quality health care in WA.

Safety and quality are augmented by the participation of health services in external accreditation and peer review programs. Safety and quality are driven by:

- identifying and supporting leaders who value safety and quality in health care
- strengthening governance structures and processes to enhance accountability for safety and quality.

The National Safety and Quality Health Service Standards[44] (the Standards) aim to protect the public from harm and to improve the quality of health service provision. Accreditation is recognised as an important driver for safety and quality improvement in health care.

From this policy, Standard 2: Partnering with Consumers states:

> "Leaders of a health service organisation implement systems to support partnering with patients, carers and other consumers to improve the safety and quality of care. Patients, carers, consumers, clinicians and other members of the workforce use the systems for partnering with consumers".[44]

Although Standard 2 provides a crucial opportunity for health services to partner with consumers, the other Standards are equally important when planning and delivering health services for people with disability. The health care needs of people with disability should be considered when health care organisations are working to meet the Standards.

9.3 Disability Access and Inclusion Plans

It is a requirement of the WA Disability Services Act 1993[12] that public authorities develop and implement a Disability Access and Inclusion Plan (DAIP) that outlines the ways in which the authority will ensure that people with disabilities have equal access to its facilities and services (Appendix 3)[12].

WA Health Disability Access and Inclusion Policy[25] states WA Health's commitment to ensuring that people with disabilities, their families and carers are able to fully access the range of health services, facilities and information available in the public health system. The intention of WA Health is to provide people with disabilities with the same opportunities, rights and responsibilities enjoyed by other people in the community. The DAIP is intrinsic in meeting the overall corporate objective of ensuring safety and quality in health services.

To achieve this, WA Health will:

- create and actively promote an environment where information, services and facilities are readily accessible to all people and do not directly or indirectly discriminate against people with disabilities
- consult with people with disabilities, their families and carers and disability-related organisations to ensure that barriers to access and inclusion are addressed appropriately

- work in partnership with community groups and other public authorities to facilitate the inclusion of people with disabilities in consultative forums
- develop DAIPs in accordance with the WA Disability Services Act 1993[12]
- ensure that contracted services for the public are provided in a manner consistent with WA Health DAIPs.

9.4 Data and research

Good quality data and research on disability are essential for providing the basis for policy and programs and for efficient allocation of resources. There is however, insufficient rigorous and comparable data and research related to disability and healthcare systems nationally and globally.

9.4.1 Data

Collecting and using data is important for obtaining an objective understanding of the population and health status of people with disability and identifying barriers, gaps and priority areas. Effective and usable data also supports measurement of the effectiveness of improvement activities.

Limitations exist when attempting to compare and analyse information across different data sources because of the different definitions of disability used and how the data is collected. Information sources such as the World Health Organisation[45], Australian Bureau of Statistics[46] and the Australian Institute of Health and Welfare[47] all collect data for different purposes, so have different definitions and analysis parameters.

Data collected by WA Health facilities does not consistently capture whether a patient has a disability, and the coding of a disability can vary between health services. For example, WA Country Health Services code intellectual disability as mental health, but in metropolitan health services it is coded as intellectual disability or complex communication difficulty.

Additionally, data collected by the Disability Services Commission relates only to people who are eligible for disability service funding and support. Therefore this excludes populations such as those who acquire a disability after age 65 or those whose level of disability is such that the person has not required or wanted support services.

WA Health has a comprehensive database and data linkage capability; however if data isn't accurately and consistently captured it adds additional barriers to inclusive health care. Although these gaps in existing data and limitations for comparisons mean that a full picture is not possible, it is essential that data is collected and utilised to demonstrate the effectiveness of changes and initiatives implemented.

The WHO Global Disability Action Plan 2014-2021[1] suggests that data needed to strengthen healthcare systems includes the:

- number of people and health status of people with disability
- social and environmental barriers including discrimination
- responsiveness of healthcare systems to people with disability
- use of healthcare services by people with disability
- extent of the need, both met and unmet, for care.

9.4.2 Research

The WHO Global Disability Action Plan 2014-2021[1] outlines a number of priority areas for health-related research such as:

- measurement of disability and its determinants
- identification of barriers to health care
- success factors for health promotion interventions for people with disability
- prevention of secondary conditions
- early detection and referral of health problems through primary health care.

Research on disability should be inclusive of people with disability, and research agendas should be drafted with the active participation of people with disability or their representative organisations.

Supporting and developing capacity in research and quality data collection in WA is critical to ensuring the best possible care is delivered to Western Australians with disability. In particular, it is important to support opportunities to work in collaboration with research providers within and outside of WA Health to ensure research is aligned with the priority areas within the *Framework*.

Additionally, evaluation of services and improvement initiatives, both qualitative and quantitative, is integral to measuring intervention effectiveness and impact as well as fostering involvement in quality improvement processes and contributing to evidence based practice.

9.5 Individual, community and organisational capacity

Improving the health of people with disability requires capacity building at multiple levels. It is the capacity of an organisation to develop and implement inclusive policy and services, the capacity of the community to respond inclusively to needs of people with disability, their families and carers, and equally important the capacity of these people to understand and respond effectively to their health needs. Capacity building can occur in different ways and may focus on areas including:

- leadership to foster a culture of disability-inclusive policy and services
- self-advocacy, self-disclosure and self-determination of people with disability for the best possible health care and outcomes
- workforce education and training
- relationships between the disability sector, health system and not-for-profit community groups
- health literacy of people with disability, their family and carers, disability support services and community groups
- champions of the disability health agenda both in the community and organisational management/executives.

10. Review

The *Framework* will be reviewed at intervals no longer than five years.

Date of last review: N.A

Supersedes: N.A

11. Monitoring and evaluating the Framework

The Disability Health Network will utilise expertise within Health Strategy and Networks and the Disability Health Network's Executive Advisory Group to guide the monitoring and evaluation process of the *Framework*.

Early phases of the evaluation will focus on the reach of the *Framework* in terms of the number and types of organisations that are aware of it. Once those organisations are identified, it will be important to measure their knowledge and level of understanding of the key messages within the *Framework*.

The later phases of the evaluation will aim to measure the extent to which the goals of the *Framework* have been achieved. This will require a partnership approach between the Disability Health Network and the organisations who have adopted the *Framework* in order to determine how the *Framework* has been used to improve systems, processes and practices within the organisation.

A detailed evaluation and monitoring plan will be developed.

12. Making it happen

The final version of the *Framework* will be communicated broadly to all relevant stakeholders across WA. It will be available via the Health Networks website in accessible formats.

The Disability Health Network will encourage health and disability service providers to incorporate the *Framework* into their operations. This will include all public health service providers (permanent, temporary, casual, contract) working with people with disability, their family, carers and communities. It is also appropriate for use by other government departments, private, not-for-profit and non-government organisations working with people with disability, their family, carers and communities.

The Disability Health Network will continually aim to provide practical advice and examples on how the *Framework* can be translated into practice. This will be done in partnership with key stakeholders around the State, using a Networking approach. See Appendix 1 for a description of how Health Networks work.

The Snapshot, which summarises the key messages of the *Framework* into a succinct format, can be used as a practical tool to remind health and disability service providers of the priorities to address from the *Framework* to ensure people with disability in WA are able to achieve the best possible health and wellbeing outcomes throughout their lives.

Acronyms

Acronym	Full title
ABF	Activity based funding
ABM	Activity based management
CaLD	Culturally and linguistically diverse
DAIP	Disability Access and Inclusion Plan
NDIS	National Disability Insurance Scheme
WA	Western Australia
WHO	World Health Organization

Glossary

Term	Definition
People with disability	This is the contemporary phrase used for people who live with impairment and are affected by barriers that exist in society which cause disability. It will be used in this *Framework* but with full knowledge that the barriers are what the *Framework* aims to remove to improve health outcomes for people living with disability.
Disability	Although the definition used here states that the impairment must be permanent or likely to be permanent, strategies developed to assist people with disability are likely to also assist other vulnerable groups including those who have temporary impairment. Impairment is any continuing condition that restricts everyday activities. The *Disability Services Act 1993*[12] defines 'disability' as meaning a disability: • which is attributable to an intellectual, psychiatric, cognitive, neurological, sensory or physical impairment or a combination of those impairments • which is permanent or likely to be permanent • which may or may not be of a chronic or episodic nature • which results in substantially reduced capacity of the person for communication, social interaction, learning or mobility and a need for continuing support services. With the assistance of appropriate aids and supports, the restrictions

Term	Definition
	experienced by many people with a disability may be overcome.
Carer	A carer is someone who provides unpaid care and support to family members and friends who have disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue, or who are frail aged.
Support worker	A disability support worker provides personal, physical and emotional support to people with disabilities who require assistance with daily living. They provide assistance with showering, dressing and eating, and often facilitate or assist with outings and other social activities. The level of assistance provided will depend on the person's ability and health. Care may also include assistance with self-medication and arranging activities to enhance the individual's physical, emotional and intellectual development.
Disability service organisations	Organisations that provide assistance to people with disability, their families and carers within Western Australia.
Supported accommodation	Supported accommodation is a type of support service available to people with disability. There are various types and settings of the accommodation that can offer different service models (i.e. some offer specialist supported living). Accommodation types include: • group homes • village (aged care) • cluster models • villas / apartments • co-located models • accommodation support for people living in their own or family homes • alternative family placements. It can be provided together with other programs as appropriate to the individual, including local support coordination, behaviour support services and services provided by community support teams.
Self-advocacy	The practice of having people with disability speak for themselves and control their own affairs, rather than having a person without disability automatically assume responsibility for them.
Health literacy	Health literacy is the ability to obtain, read, understand and use healthcare information to make appropriate health decisions and follow instructions for treatment.

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Appendices

Appendix 1: Disability Health Network

The *Framework* has been developed under the auspices of the Western Australian Disability Health Network. The Disability Health Network, launched on 1 November 2012, is built on a partnership between WA Health and the Disability Services Commission. The Disability Health Network was formed in response to the Clinical Senate Debate Clinicians - do you see me?[7]

A health network is a group of interested people and organisations including health professionals, patients, carers, consumers and others, coming together to talk, think, plan and develop health policy and services across the State.

Health Networks in WA were established by the Department of Health WA in 2005 after a major review of health services with the aim of enabling a new focus across all clinical disciplines towards prevention of illness, injury and maintenance of health.

The major functions of Health Networks are to plan and develop:

- evidence based policy and practice
- statewide clinical governance
- transformational leadership and engagement
- strategic partnerships
- evaluation and monitoring systems.

Appendix 2: Relevant legislation and policy linkages

The United Nations Convention on the Rights of Persons with Disabilities[5] *(CRPD)* ratified by Australia on 17 July 2008[48], and the National Disability Strategy[2] *(NDS)* agreed to by the Council of Australian Governments on 13 February 2011 sets out our obligations and commitments to work towards an inclusive society.

The National Disability Strategy[2] is a ten-year national policy framework for improving life for Australians with disability, their families and carers. It sets out six priority areas: inclusive and accessible communities; rights protection, justice and legislation; economic security; personal and community support; learning and skills; and health and wellbeing.

The Carers Recognition Act 2004[15] is aimed at changing the culture of service providers so that the impact on carers is considered when services are assessed, planned, delivered and reviewed. A key part of this Act requires service providers to comply with the Western Australian Carers Charter[23]. The Charter provides clear direction on how carers are to be treated and how carers are to be involved in the delivery of services. Under the legislation, all State Government funded or administered health and disability service providers are required to take all practicable measures to ensure that they comply with the Carers Charter.

In addition, these agencies must involve carers (or people and bodies that represent carers), in any policy or program development, or strategic or operational planning that may affect carers and their roles.

Count Me In: Disability Future Directions[22], developed by the Disability Services Commission, sets out a long-term strategy designed to guide all Western Australians when responding to people with disability. *Count Me In* articulates a vision that "all people live in welcoming communities that facilitate citizenship, friendship, mutual support and a fair go for everyone'[22].

The vision is achieved through three areas of focus:

- economic security and well-designed and accessible communities and homes
- participation and contribution for people with disability in all aspects of life
- the provision of personalised supports and services which are innovative, flexible, and person-centred.

Despite this, there are very few policy documents in WA that indicate the need for health services to be relevant or adapted for people with disability in the same way that policies have begun to recognise the needs of population groups such as Aboriginal people, culturally and linguistically diverse people and people living in rural and remote areas.

Appendix 3: Department of Health WA Disability Access and Inclusion Plans 2010–2015

It is a requirement of the WA Disability Services Act 1993[12] that public authorities develop and implement a Disability Access and Inclusion Plan (DAIP) that outlines the ways in which the authority will ensure that people with disability have equal access to its facilities and services.

The Department of Health is committed to providing equal access for people with disabilities to its information, services and facilities. To achieve this, the Department has developed the DAIP to address the barriers for people with disability wanting to access the Government health services and facilities. DAIPs are developed in consultation with the community and employees of WA Health and are intrinsic in meeting the overall corporate objective of ensuring safety and quality in health services.

WA Health is committed to achieving six desired outcomes listed in Schedule 3 of the WA Disability Services Regulations 2004[49] through the implementation of DAIPs in the various health areas. These outcomes are:

1. People with disabilities have the same opportunities as other people to access the services of, and any events organised by, the relevant public authority.
2. People with disabilities have the same opportunities as other people to access the buildings and other facilities of the relevant public authority.
3. People with disabilities receive information from the relevant public authority in a format that will enable them to access the information as readily as other people are able to access it.
4. People with disabilities receive the same level and quality of service from the staff of the relevant public authority.
5. People with disabilities have the same opportunities as other people to make complaints to the relevant public authority.
6. People with disabilities have the same opportunities as other people to participate in any public consultation by the relevant public authority.

This document can be made available in alternative formats on request for a person with a disability.

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