Enabling Health

Taking action to improve the health of people with a disability

EVIDENCE-BASED HEALTH PROMOTION RESOURCE

www.vichealth.vic.gov.au

VicHealth

Acknowledgements

Acknowledgement of history

We acknowledge the journey of the many Victorians with a disability whose experience and wisdom informs this report. In particular, we acknowledge those who resided at St Nicholson Hospital, the site on which VicHealth now operates and where this resource was centrally coordinated and written.

Acknowledgement of country

We acknowledge the Traditional Owners of the land on which this report was produced, the Kulin Nation. We also acknowledge and pay respect to the wisdom of Elders past and present.

Cover artwork

The artwork on the cover of this publication is by Anthony Romagnano. Anthony's work can be commissioned through the Arts Project, a Melbourne-based non-profit organisation supporting artists with intellectual disabilities. For further information see www.artsproject.org.au.

Terminology

VicHealth also acknowledges that many people with a disability have numerous and often compounding disabilities. However, for consistency the term 'people with a disability' has been used throughout this resource.

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ENABLING HEALTH

Introduction and how to use this resource

Introduction and how to use this resource

Introduction

Approximately one in five Australians has a disability. Disability may occur at any time in a person's life or be present from birth. Some disabilities are obvious; others are invisible. Despite the high prevalence of disability, Australian evidence regarding the health of people with a disability is sparse.

The limited existing Australian and international evidence base does show that the health of people with a disability is worse than that of their peers without a disability across a range of health outcomes such as obesity, diabetes, oral health and mental health (WHO & World Bank Group 2011).

Much of this difference is socially determined, rather than due to particular characteristics of the disability itself (Emerson et al. 2011). For example, people with a disability are more likely to live in poverty, have poor quality or insecure housing, have low levels of workforce participation and education, and be socially excluded or marginalised. They may also face violence and discrimination related to their disability and have difficulty accessing appropriate health care (WHO & World Bank Group 2011). This means that much of the difference in health is preventable.

Enabling Health is about contributing to a better future for people with a disability. This evidence-based health promotion resource provides information and guidance on action to improve the health of Australians with a disability.

It is significant because while we know that the overall health of people with a disability is much worse than that of the general population, people with a disability have generally not been prioritised in the same way as other population groups experiencing inequity.

There is a clear role for public health and health promotion agencies to consider the health and wellbeing of this population group explicitly. This resource provides a framework and evidence base from which to do this, bringing together the findings of a scientific literature review with stories of promising health promotion practice from across Australia and internationally.

Enabling Health is about contributing to a better future for people with a disability.

Importantly, the resource challenges the notion that people with a disability should naturally have worse health than their peers without a disability. It does this by identifying the underlying drivers of the poor health of people with a disability and providing guidance to address them. Its purpose is to provide the best available information to guide service and program planning and policy development.

The resource is designed for people who work in community and health services, across the disability sector, within health promotion agencies and in local and state government. It will also be useful to others who are working to improve the health of people with a disability.

It is important to note that this resource comes during a period of significant policy change affecting the lives of people with a disability. The Federal Government's National Disability Insurance Scheme (NDIS) is a landmark reform that when fully enacted will provide much needed support and care for the daily needs of Australians with a disability. However, it will not create a society that reduces health inequity by increasing inclusion and supporting greater social and economic participation of Australians with a disability. We hope that this resource will make a start at providing evidence to support this broader change.

How to use this resource

This resource has been designed for a diverse audience. It has therefore been divided up into key sections so that readers can quickly find the sections that are most relevant to them. Note that people with a disability are not a homogeneous group and are actually highly diverse with varied skills, abilities and needs.

Enabling Health presents the best available information on actions that can be taken to address the socially produced causes of ill health experienced by people with a disability. People are encouraged to utilise the framework in the implementation and evaluation of their own activities and to share their findings and experiences to continue to build the evidence base for action.

The resource is structured as follows:

Section 1: The introduction, background and key concepts section describes the foundations that have been used to develop the information provided in this resource. This includes the methodology for the literature review, health status of people with a disability, health inequities and an overview of health promotion. The legislative and policy context sections provide a summary of current state and federal policies and Acts.

The history section puts disability within Australia into context and should be read by those new to the disability or health promotion sector.

Section 2: The *Enabling Health* framework provides a succinct overview of the key contributors to the health and wellbeing of Australians with a disability. It can be used to assess priorities and guide practice or as an advocacy or partnership tool. The diagrammatic version of the framework is available in this section.

Section 3: This section outlines the results of a review of evidence on interventions that are likely to work to improve the socially determined causes of ill health experienced by people with a disability:

Key social and economic determinants

- Access to employment, education, housing and transport
- Freedom from discrimination
- Freedom from violence, neglect and abuse
- Social connection and community participation

Contributing factors

- Health behaviours (including alcohol, tobacco, physical activity and nutrition)
- Access to the health system

Promising stories related to the key determinants and contributing factors are provided as case studies throughout the resource.

Defining disability: the social model

Disability is a complex, contested, evolving concept. Definitions of disability are important because they can directly affect the lives of people with a disability through, for example, eligibility criteria for programs and benefits, policies and legislation.

The United Nations (UN) Convention on the Rights of Persons with Disabilities, which Australia ratified in 2008, describes disability as resulting 'from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others' (UN General Assembly 2007).

This definition distinguishes the impairment or health condition (e.g. paraplegia) from the restrictions on participation in society (e.g. unemployment due to discriminatory recruitment practices). These restrictions are not an inevitable consequence of the impairment; they are a result of unfair and avoidable barriers that this resource aims to address. VicHealth adopts the UN definition of disability, commonly understood as *the social model of disability.*

Background and key concepts

Central to the development of this resource was the input and advice of the broader disability sector, including key advocacy organisations and a diverse range of individuals with and without a disability.

The *Enabling Health* framework and resource have been guided by existing policy frameworks and promising approaches, such as:

- the UN Convention on the Rights of Persons with Disabilities, which Australia ratified in 2008
- *Fair Foundations* – the VicHealth framework for health equity
- relevant national and state policies.

The central guiding principle throughout the development of the resource was simply 'nothing about us without us'.

THE HEALTH STATUS OF PEOPLE WITH A DISABILITY

In August 2012, VicHealth published a report titled *Disability and health inequalities in Australia: research summary.* As well as defining disability within a social model of health, the report provided an overview of information regarding the health of people with a disability using available population health data.

The purpose of the report was to collate the best available information on the health status of people with a disability, and therefore raise the profile of the health inequities experienced by people with a disability in Australia. The report painted a sombre picture of a significant proportion of the Australian population who experience poor health across a range of outcomes, including self-reported health, mental health, chronic illness and life expectancy. It was also developed to explore the underlying drivers or determinants of the poor health of people with a disability. Some of the findings of the report are described below. We would suggest that the report is essential reading for understanding the context for developing *Enabling Health*.

Visit www.vichealth.vic.gov.au/disability-health-inequalities to access the full report in either an audio, Easy English, PDF or word version.

In reporting the health status of people with a disability, it is recognised that there are many different ways to classify disability (VicHealth 2012) and that people with a disability are not a homogeneous group. Common to all people with a disability is their differential experience of the social determinants of health compared to their peers without a disability.

One in every five complaints to the Victorian Equal Opportunity and Human Rights Commission is from people with a disability, making this the highest area of complaint. They cover areas such as employment, education, housing, transport and access to health services (VEOHRC 2011). Discrimination against people with a disability occurs across individual, institutional and systemic levels.

HEALTH INEQUITIES AND THE SOCIAL DETERMINANTS OF HEALTH

The World Health Organization (WHO) defines health inequities as differences in health status between population groups that are socially produced, systematic in their distribution across the population, avoidable and unfair (WHO 2014a).

Many of the differences in health status between people with a disability and people without a disability in Australia are not a result of medical conditions or impairments (e.g. paraplegia), but are a consequence of societal barriers (both attitudinal and environmental) that hinder the full and effective participation of people with a disability in community life.

These barriers to participation in society are demonstrated through population-based data that describes the limited access to the social determinants of health (the social and economic conditions in which people are born, grow, live, work, play and age that influence their health (WHO 2008)) experienced by people with a disability compared to people without a disability. For example:

- in relative terms, Australians with a disability only earn around 70 per cent of those without a disability. This is the lowest of all the 27 OECD countries
- in Australia, people with a disability are half as likely to be employed as people without a disability compared to the OECD average of 60 per cent

- people with a disability are less likely to have completed Year 12 (or equivalent)
- the majority of complaints made to the Australian Human Rights Commission are about discrimination on the basis of disability
- adults with a disability are one and a half times more likely to be victims of violence than those without a disability
- 90 per cent of women with intellectual disabilities have been sexually abused.

People with a disability are among the most socially and economically disadvantaged people in Australia. This disadvantage is a major contributor to poor health and is preventable. Given that we as a society create and maintain the barriers to participation that result in such disadvantage, we can also remove them.

VicHealth is committed to promoting the health and wellbeing of all Victorians. To ensure an equitable approach, VicHealth has adapted and applied the work of the World Health Organization Commission on the Social Determinants of Health to the Australian context, and produced an action-oriented framework to guide health promotion. This framework, titled *Fair foundations: the VicHealth framework for health equity* was utilised during the development of this resource. The framework can be accessed at www.vichealth.vic.gov.au/fairfoundations

HEALTH PROMOTION

WHO defines health promotion as the 'process of enabling people to increase control over and improve their health' (WHO 2014b).

Health promotion is a fundamental part of any action to improve the health of people with a disability. This is characterised as the process of empowering people and communities to exercise control over the determinants that affect their health and lives.

This is particularly critical to Australians with a disability as past exclusionary practices and marginalisation resulted in a lack of self-determination and autonomy. Therefore, the process of supporting people with a disability to make decisions or contribute to making decisions that affect their life is central to the *Enabling Health* framework.

People with a disability are among the most socially and economically disadvantaged people in Australia.

EVIDENCE AND METHODOLOGY

'Evidence' means different things to different people. Within public health, different forms of evidence are available to guide action. Evidence from scientific research is highly regarded, with systematic reviews considered the conventional gold standard. However, systematic reviews are generally only available in areas of interest that have been extensively studied, and are very limited in relation to interventions to reduce health inequities experienced by people with a disability. This type of scientific research also doesn't capture the lived experience of people with a disability.

Within this context, this resource draws on evidence from both scientific research and 'grey literature'. Grey literature is informally published material such as reports or case studies, often developed by people working on the ground. Evidence is regarded as reliable information that is likely to affect positive change to reduce the health inequities that exist between Australians living with and without a disability.

The methodology for the evidence review in this resource included a review of scientific research evidence, and identification and documentation of practice-based knowledge and experiences in the form of stories.

A review of scientific evidence

A comprehensive search strategy was developed to identify evidence of effective interventions across the priority areas described in the framework. Relevant systematic reviews and primary studies were examined by using a standard review approach.

Peer-reviewed and 'grey', or informally published, literature released in English between 2000 and 2012 were sourced from a range of databases. These included scientific databases (Web of Science, Embasse, Cinahl, Pubmed, OVID/Medline, PsycINFO, Proquest). Internet searches using Google, Google Scholar, WHO and UN websites, and clearinghouses were performed. Hand-searching of key journals was also conducted (*Disability and Society*, *Health Promotion International*, *Journal of Intellectual Disability Research*, *Journal of Intellectual and Developmental Disability*, *Journal of Health Promotion*) to ensure key studies had been identified.

Abstracts were screened according to the inclusion criteria. Systematic reviews and primary studies with clear research methods and data on effective interventions were prioritised. However, the small sample size meant that other sources were included in the review.

For abstracts that met the inclusion criteria, full papers were retrieved. Those papers were summarised into a data extraction table to capture further details, including the focus of the study, the study design and methods, key outcomes measured and key learnings from the study. These were shared with the technical reference group and feedback was sought to ensure that the latest expert knowledge was also captured.

A detailed description of the review methods is available as Appendix 1. The full data extraction tables are available as Appendix 2. For an overview of the gaps in knowledge, refer to Appendix 3. All appendices are available online at www.vichealth.vic.gov.au/enabling-health

Identification and collection of good practice case studies

The review involved the collection of stories from people and organisations working to address the areas of the framework relating to the health of people with a disability. These stories were chosen according to the following criteria:

- The stories were relevant to the areas of the framework impacting on the health of people with a disability.
- The context was sufficiently similar that they might be applied in Australia.
- They stories were consistent with the principles identified in the framework.
- Storytellers were happy to share their stories.
- The stories challenged misconceptions about people with a disability and:
- were positive and inspiring
  - motivated workers and organisations to see that they can make a difference
  - demonstrated a process that has worked.

The stories act as case studies, profiling these programs and/or services that show promising practice in preventing disadvantage and poorer health outcomes experienced by people with a disability.

Four stories collected from Australia, Ireland and the UK have been included in the resource.

A note about the case studies

Clearly, there are many dedicated people working to advance the lives of people with a disability in Victoria and Australia, who have been doing so for many years. The stories told here represent a small selection of many promising stories that have not yet had the opportunity to be told to a wider audience. We have also included some stories from outside Australia to broaden thinking about what is possible, although noting that work undertaken in other countries has occurred within a different social and political environment.

The value of including some stories is to enrich and try to gather in one place the best of what we know about effective interventions and different ways of delivering services and providing opportunities for people with a disability. Readers are encouraged to seek out stories from their local area. We hope that by the time this resource is reviewed, there will be many more stories to be told.

A short history of disability in Australia

"His Excellency, commiserating the unhappy condition of persons labouring under the affliction of mental derangement, has been pleased to order an Asylum to be prepared for their reception at Castle Hill, whither they have been accordingly removed from their former place of confinement, which was in the town gaol at Parramatta, and every provision that humanity could suggest has been made for their accommodation and comfort."

SYDNEY GAZETTE, 1 JUNE 1811

The landing of the First Fleet at Botany Bay brought not only settlers and convicts, but also an inherited ideology from Britain in the 1800s, where disability was denied a place within society. People with a disability found no place in the harsh conditions of the new land, where racism and patriarchy provided the foundation for social policy and (in) action. The imprisonment and exclusion from society of people labelled as 'lunatics', 'idiots', 'invalid' or 'insane'[1] began immediately, with people housed on the Hulks (the ships that had transported the convicts to Australia) until permanent accommodation in the form of jails and institutions could be built. While many convicts were able to gain their freedom within the new colony, people with a disability were not. If someone was deemed physically or mentally unable to live independently, then they would serve out their sentences in jails or institutions.

Throughout Australian history, people with a disability have been viewed either with empathy ('the deserving poor' who needed protection from society) or with disdain ('undeserving or deviant' from whom society needed protection). Routine institutionalisation of people with a disability continued for more than a century, with many doctors encouraging the admission of infants into these facilities. Throughout the 1800s, people were also increasingly admitted into psychiatric institutions.

As the Eugenics Movement took hold in the early 1900s, people with a disability were labelled as a menace to society and separated from the very definition of humanity. As a result, people with a disability were routinely sterilised, and continued to be deemed unfit for participation in general society for fear of contamination. As well as stripping residents of their rights to participate in the community, to have a voice in public discourse and to contribute to the economy, many institutions also denied residents dignity in life (with reports of people confined to cages, exposed to unsanitary conditions, physically restrained and restricted) and in death (with reports of mass graves).

Disability policy was influenced by the return of veterans after the First and Second World Wars. Rehabilitation policies and increased income support were offered to soldiers who had acquired a physical or mental disability as a result of their efforts. The majority of care for people with a disability continued to be provided within the family, though formal rehabilitation services providing vocational assistance and allied health were established at this time.

From the 1950s through to the 1970s, widespread social reforms swept through Australia. Liberation struggles for women and Indigenous Australians rose in the public consciousness, and the Whitlam Government enacted 'the Program' of reform in areas such as health, housing and education. However, people with a disability remained largely overlooked. A vote for a national disability insurance scheme was scheduled in Federal Parliament for 12 November 1975, but was never held as Whitlam was dismissed just the day before.

[1] These terms, which we now find so confronting, were used to refer to people with a mental illness, intellectual disability and some physical disabilities. They were part of the formal and colloquial language of the time. The terms were adopted in legislation such as the *Lunacy Act* 1845 (England).

The UN declared 1981 to be the International Year of Disabled Persons (IYDP). The celebration of IYDP across Australia in literally hundreds of events organised by local, state and the Federal Government and by civil society organisations brought together people with disability on a scale and with a focus that had not previously occurred (People with Disability 2013).

The 1981 IYDP has been described as a watershed for people with a disability in Australia, as the need for greater community participation was promoted. The decade that followed saw movement towards de-institutionalisation, community-based services and social (rather than medical) models of care. Self-help and consumer groups formed and legislative reforms were forthcoming.

Rather than heralding a new era of community inclusion and participation, the process of de-institutionalisation introduced fresh challenges for people with a disability in Australia. Many were moved from one form of segregation to another on the margins of society; for example, from institutions to hostels or large group homes. People were placed into communities that were ill equipped, under resourced and inaccessible physically, socially and economically. This exposed many people with a disability to further abuse, exploitation, inappropriate living arrangements and homelessness. Note that the process of de-institutionalisation is not yet complete in Australia, with almost 5000 Australians with a disability still living within institutions.

During the 1990s, the *Disability Discrimination Act 1992* (Cwlth) was passed with an emphasis on the rights of Australians with a disability in areas such as housing, education and the provision of goods and services.

Current disability support arrangements are inequitable, underfunded, fragmented and inefficient and give people with disability little choice (Pricewaterhouse Cooper 2011).

Australia became one of the original signatories to the UN Convention on the Rights of Persons with Disabilities in 2008, effectively pledging a commitment to improving human rights outcomes for Australians with a disability. Despite this formal commitment, Australians with a disability continue to live impoverished lives compared to the rest of the population. Australians with a disability are more likely to be imprisoned, institutionalised, assaulted, in receipt of welfare, restrained, sterilised and aborted. In contrast, people without a disability are more likely to be found in places of higher education, living in their own homes and in paid positions of power (including positions within the disability sector).

In late 2009, the Australian Government asked the Productivity Commission to undertake a public inquiry into the care and support of people with a disability. A major recommendation of the Commission was a complete overhaul of the system through the establishment of a National Disability Insurance Scheme (NDIS). This recommendation has attracted significant national media coverage, as well as political, academic, advocacy and industry attention. A commitment to a trial of a NDIS has been achieved, with DisabilityCare launch sites established in July 2013 in South Australia, Tasmania, the ACT, the Hunter region in New South Wales and the Barwon area in Victoria.

Dr Rachel Carling-Jenkins, PhD

Legislative and policy context

Over recent months and years, Australia has undertaken a transformational change in relation to policy affecting the lives of people with a disability. This section provides a brief overview of key legislation and current government policy from both Commonwealth and state-based agencies. It should be noted that the policy environment, in particular, is constantly changing and evolving.

VicHealth acknowledges that a range of other non-health government policies will affect the health and wellbeing of Australians with a disability, given that the drivers of health are often situated in the broader social and economic environment.

LEGISLATION

There is a strong legislative context at various levels supporting the rights of people with a disability. Those of most relevance include the following.

UN Convention on the Rights of Persons with Disabilities

The Convention details the rights of people with a disability and sets out a code of implementation. The Convention came into effect May 2008 and has been ratified by Australia. This means Australia has agreed to develop and implement policies, laws and administrative measures to secure the rights recognised in the Convention and abolish laws, regulations, customs and practices that constitute discrimination.

World Report on Disability

The *World Report on Disability 2011*, the first of its kind, was compiled partly to facilitate implementation of the UN Convention on the Rights of Persons with Disabilities. It provides scientific information, definitions of disability and comparable information on the incidence, distribution and trends relating to disability.

Victorian Disability Act 2006

The *Disability Act (2006)* commenced on 1 July 2007. The Act provides for a:

- stronger whole-of-government, whole-of-community response to the rights and needs of people with a disability
- framework for the provision of high-quality services and support for people with a disability.

Particular regulations have been developed to support the Act in the areas of residents' funds, residential charges, restrictive interventions and supervised treatment.

NATIONAL POLICY

There are four main national disability policies:

- National Disability Strategy 2012–2020
- National Disability Insurance Scheme
- Council of Australia Governments (COAG): National Disability Agreement
- National Carer Recognition Framework.

National Disability Strategy 2012–2020

The National Disability Strategy is a COAG initiative formalising all governments' commitment to a more inclusive Australia, where all people regardless of ability can reach their full potential and participate as equal citizens in society. The Strategy recognises the necessity of actions across the whole community to help 'create a society that is inclusive and enabling, providing equality and the opportunity for each person to fulfil their potential'.

The Strategy identifies six areas of policy action:

- Inclusive and accessible communities
- Rights protection, justice and legislation
- Economic security
- Personal and community support
- Learning and skills
- Health and wellbeing.

This is the first explicit national policy intersection between disability and health. The policy action area on health and wellbeing further identifies the following three policy directions:

- The capability of all health service providers to meet the needs of people with a disability.
- Timely, comprehensive and effective prevention and early intervention health services for people with a disability.
- Universal health reforms and initiatives to address the needs of people with a disability, their families and carers.

The Strategy is available at www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/national-disability-strategy-2010-2020

National Disability Insurance Scheme

The Council of Australian Governments (COAG) committed to launch the National Disability Insurance Scheme (NDIS). The first stage of the Scheme rolled out in South Australia, Tasmania, the Barwon area of Victoria and the Hunter area in New South Wales from mid-2013. The ACT and Northern Territory will join the Scheme in July 2014.

The NDIS has the potential to make a significant difference to the lives of people with a disability and their families.

The core principles of the scheme are:

- a lifetime approach – funding is long-term and sustainable
- choice and control – people choose how and when they get support
- social and economic participation – people are supported to participate in, and contribute to, social and economic life
- a focus on early intervention – investing in people to maximise independence.

Further details regarding the National Disability Insurance Scheme are at www.ndis.gov.au

COAG: National Disability Agreement

The Council of Australian Governments (COAG) National Disability Agreement commits the Commonwealth and state governments to strive, through the provision of disability support services, to help people with a disability and their carers achieve an enhanced quality of life and participate as valued members of the community.

The National Disability Agreement identifies three outcome areas:

- People with a disability achieve economic participation and social inclusion.
- People with a disability enjoy choice, wellbeing and the opportunity to live as independently as possible.
- Families and carers are well supported.

Further details are at www.coag.gov.au/node/304

National Carer Recognition Framework

The National Carer Recognition Framework was established in 2010 to acknowledge the role that carers play in the daily lives of people with a disability. This involved establishing the *Carer Recognition Act 2010* so that the needs of carers are considered when developing policies and programs that could affect them or the people they care for. The Framework also involved the development of the National Carer Strategy to ensure that society values and respects carers and to safeguard their rights, choices, opportunities and capabilities to participate in economic, social and community life.

The National Carer Strategy identifies six priority areas of:

- recognition and respect
- information and access
- economic security
- services for carers
- education and training
- health and wellbeing.

Further details are at www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/national-carer-strategy

VICTORIAN POLICY

Victorian Public Health and Wellbeing Plan 2011–2015

The Victorian Public Health and Wellbeing Plan aims to improve the health and wellbeing of all Victorians by engaging communities in prevention, and by strengthening systems for health protection, health promotion and preventive health care across all sectors and all levels of government.

The Plan describes nine strategic directions, one of particular relevance being 'to tailor interventions for priority populations to reduce disparities in health outcomes'. People with an intellectual disability are identified as an 'at risk' population in this plan.

Further details are at www.health.vic.gov.au/prevention/vphwplan

Victorian State Disability Plan 2013–2016

Victoria has had a state disability plan for the past 10 years, and in 2006 the Victorian Office for Disability was established.

In December 2012, the Victorian Government released the Victorian State Disability Plan (2013–2016). The Plan outlines the government's framework for ensuring that people with a disability have an equal chance to participate fully in the Victorian economy and communities.

The framework supports the Victorian Government to:

- uphold the rights of people with a disability
- remove and prevent structural, systemic and attitudinal barriers to participation
- build a welcoming community
- give people with a disability choice and control over their own supports and services
- enable people with a disability, their families and carers to get the right mix of services and supports.

To implement the framework over the next four years, four goals have been developed:

- developing a strong foundation in life
- upholding rights and promoting participation
- accessible information, transport, buildings and places
- a contemporary approach through disability system reform.

Further details are at www.dhs.vic.gov.au/about-the-department/plans,-programs-and-projects/plans-and-strategies/disability-services/victorian-state-disability-plan-2013-2016

Enabling Health framework

The Enabling Health framework

The *Enabling Health* framework captures and represents the ideas of many of the contributors to the health of people with a disability, and was developed in consultation with people with a disability, carers, key advocacy and service delivery agencies and the broader health promotion sector.

The framework is designed to provide guidance on how and where to best address the determinants of health. An overview of the likely intermediate and long-term outcomes of action is also provided. One challenge of presenting all this information in a one-page framework is that it can oversimplify complex and interrelated issues, so the intent of this section is to provide further background.

It is important to note that the framework is a resource that will evolve over time. It can and should be updated as people 'put it to work' through health promotion practice. It is only through practical application that the framework's strengths, weaknesses and benefits (both intentional and unintentional) will be identified.

The rationale for developing such a framework is that it can:

- highlight that the foundations of health and wellbeing are found in social and economic structures that are beyond the control of individuals
- make a complex picture accessible to more people
- develop a logic that is based on evidence and that can be used to guide practice
- provide a summary tool that can assist in assessing priorities (in terms of determinants and contributing factors) as well as in evaluation
- allow people and organisations to see 'where they fit' and how they might contribute to reducing the health inequities experienced by people with a disability.

The framework outlines entry points for action where health promotion activities can address these health inequities. The first is addressing key (social and economic) determinants of health. The second is addressing key contributing factors, which includes both health behaviours and access to the health system.

Key social and economic determinants of health

INCLUSIVE SOCIETY FREE FROM MARGINALISATION

A history of exclusion and marginalisation has had a profoundly negative effect on the health of people with a disability. An inclusive society free from discrimination and marginalisation is therefore identified in the *Enabling Health* framework as an overarching key determinant of health for people with a disability.

SOCIAL AND ECONOMIC DETERMINANTS

The priority areas or key determinants identified reflect those factors acknowledged as critical to the health of people with a disability by both the academic literature and in consultations and discussions with a range of stakeholders.

The priority areas are employment, education, housing, transport, freedom from discrimination, freedom from abuse (including neglect and violence) and social connection/community participation. Section 3 provides a detailed review of the best available evidence to address each of these determinants.

CONTRIBUTING FACTORS

Reducing exposure and vulnerability to key health-damaging factors has been identified as important to improving the health of people with a disability. These factors are tobacco, poor nutrition, alcohol and physical inactivity. Section 3 provides a detailed review of the best available evidence to address each of these factors.

Receiving adequate care within the health system provides both a treatment and a preventative approach to health care. While health promotion does not focus on the health system as a key setting for action, it is acknowledged that reducing inequitable access to the health system by improving approachability, acceptability, availability, affordability and appropriateness will contribute to reducing health inequities. See Section 3 for a detailed review of the best available evidence to address each of these factors.

Ability to exercise control over the key aspects of life – self-determination

Self-determination involves genuine access to choice and decision-making opportunities, which have been historically and systemically denied to many people with a disability. Genuine self-determination is central to the health and wellbeing of all Australians regardless of ability.

People with a disability

The term 'people with a disability' was adopted after an extensive consultation process.

General principles: 'nothing about us without us'

The general principles guiding the development of the *Enabling Health* framework and resource are a combination of the UN Convention on the Rights of Persons with Disabilities and a series of statewide consultations.

Health promotion actions and priority settings

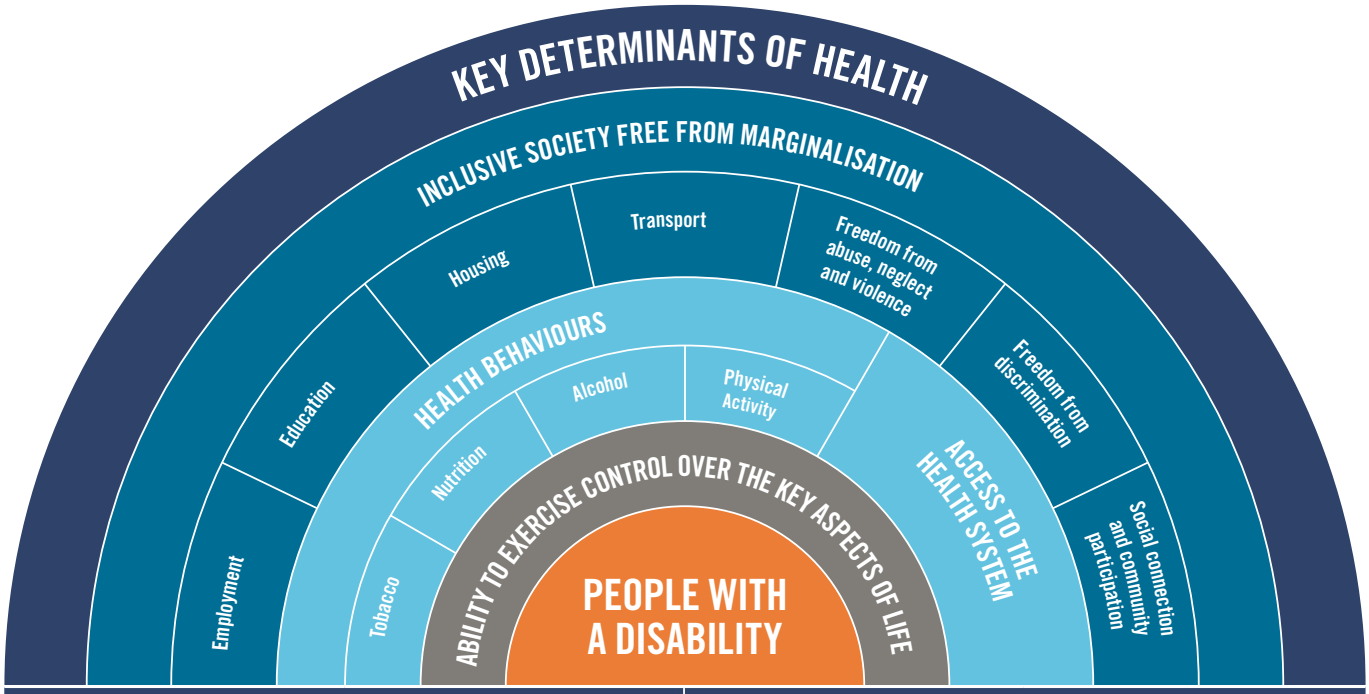
A number of key health promotion actions and priority settings have been identified in the *Enabling Health* framework. These are drawn from seminal health promotion agreements, The Ottawa Charter for Health Promotion and The Bangkok Charter for Health Promotion in a Globalized World, and have been tailored to the specific context of people with a disability.

Health promotion practitioners should be guided by their own community groups and the best practice principles as to the most appropriate structures or settings to work within in any local context.

Intermediate outcomes and long-term benefits

The intermediate outcomes and long-term benefits outlined in the framework are likely to occur as a result of action on the determinants and contributing factors, using the defined health promotion principles and actions.

The Enabling Health framework



GENERAL PRINCIPLES: 'NOTHING ABOUT US WITHOUT US'

- Respect of inherent dignity and individual autonomy, including the independence of people, and their freedom to make their own choices
- Non-discrimination
- Inclusion in society
- Equality of opportunity and accessibility
- Respect for difference and acceptance of people with a disability as part of human diversity and humanity
- Gender equity

HEALTH PROMOTION ACTIONS

- Build healthy public policy across all levels of government
- Create supportive environments
- Strengthen community action
- Secure an infrastructure for health promotion
- Advocate and communicate
- Consolidate and expand partnerships for health
- Re-orient health services
- Develop personal skills

PRIORITY SETTINGS FOR ACTION

Arts	Community	Corporate	Disability sector	Early childhood	Education	Housing	Health
Justice	Local government	Private sector	Sport and recreation	Transport	Technology	Workplace	

INTERMEDIATE OUTCOMES

Individual	Organisational	Community	Societal
• Strong social connection and active participation in community • Access to inclusive and supportive educational opportunities • Access to employment • Access to housing • Reduced experiences of discrimination and violence • Access to appropriate health care	• Policies and procedures that model good, inclusive and enabling practices • Systematic inclusion of people with a disability in policy processes • Committed to sustaining change • People with a disability are employed, appropriately remunerated and supported	• Safe, supportive and inclusive environment • Mutual respect and valuing of diversity • Committed to sustaining change • Meaningful inclusion of people with a disability	• Inclusive and enabling policies, legislation and programs that support the health and wellbeing of people with a disability • Strong leadership • Social norms and practices that support the inclusion of people with a disability in all aspects of society • Reduced inequalities in determinants of health

LONG-TERM BENEFITS

Individual	Organisational	Community	Societal
• Empowerment of individuals • Self-esteem and pride • Alleviation of poverty and socioeconomic inequities • Freedom from discrimination and violence • Improved health and wellbeing • Control/ability to make decisions about determinants of own health • Increased sense of belonging	• Freedom from discrimination and violence • Effective programs that support the participation of all	• Freedom from discrimination • Freedom from violence • Equity of health outcomes • Improved productivity	• An inclusive and enabling society that provides equal opportunity for all people to fulfil their potential • Respect for people with a disability • Equity of life expectancy between people with a disability and all people

ENABLING HEALTH

Action on the key determinants and contributing factors

Action on the key determinants and contributing factors

Evidence-based interventions: introduction to the findings

This section describes results of the evidence review about effective interventions and the key learnings that emerge from this review.

As with all reviews, there are limitations, the most significant being a lack of evidence of effective interventions within Australia. For an overview of knowledge gaps, refer to Appendix 3. While there is a strong body of international research, this literature and findings does not always translate directly into the Australian context due to a wide range of differences in social, political, cultural and healthcare services systems. When international literature is sourced, this is noted.

From the data available, we know that the health of people with a disability is worse than that of the general population. By definition, people with a disability must have a health condition or an impairment, so a degree of difference in health status is inevitable. However, the difference observed extends to areas of health that have no biological connection to the health condition or impairment that is associated with a person's disability.

The majority of data is limited to adults (aged 15 to 64), mostly of Australians with intellectual disabilities, or those with severe or profound disabilities.

BEST-PRACTICE PRINCIPLES

To be effective, health promotion action for people with a disability in Australia must be guided by best-practice principles (refer to the framework on page 17). These principles are particularly important where evidence is weak or inconclusive. All health promotion action that aims to improve health and reduce inequities experienced by people with a disability should be guided by these general principles:

- 'Nothing about us without us'
- Respect of inherent dignity and individual autonomy, including the freedom for people to make their own choices, and the independence of people with a disability
- Non-discrimination
- Inclusion in society
- Equality of opportunity and accessibility
- Respect for difference and acceptance of people with a disability as part of human diversity and humanity
- Gender equity.

Access to economic resources

Four areas that have been identified where people with a disability experience specific economic disadvantage are employment, education, housing and transport.

Employment

In Australia, people with a disability have lower incomes and are more likely to live in poverty than people without a disability. This is driven in part by the lower employment levels of people with a disability and their carers (VicHealth 2012). The income levels of Australians with a disability, compared to those without a disability, are also much worse than observed in most other OECD countries across a number of indicators (Directorate for Employment, Labour and Social Affairs 2009).

Secure, paid employment provides economic, social and health benefits. It is important for social inclusion, autonomy and decision-making. There are a number of employment options for people with a disability, including:

- open or competitive employment (available to all people regardless of disability)
- supported employment (where support is offered to enable participation)
- closed employment (formerly referred to as sheltered employment where employment is offered to large groups of people with a disability, usually for low wages).

One systematic review of employment programs for people with psychiatric disabilities was located (Crowther et al. 2010). Four primary and evaluation studies that provided insight into Australian programs and services were also included Humpage 2007; Waghorn et al. 2007; Stancliffe 2012; Kober & Eggleton 2005). One review of best practice in the US was also included (Smits 2004), as well as an international study (Wilson-Kovacs et al. 2008). One systematic review examined employment options, and while it identified a lack of research evidence, it did highlight possible elements of successful job placement (Westbrook et al. 2012).

KEY LEARNINGS ABOUT EMPLOYMENT

A study by Kober and Eggleton (2005) found that people engaged in open employment had significantly higher quality of life scores than people in closed employment, particularly those with higher functional work ability.

Providing access to both pre-vocational and supported employment training improves outcomes for people with psychiatric disabilities (Crowther et al. 2010).

Family members who are primary carers of people with a disability also experience higher rates of unemployment as a result of the informal care they provide. Access to respite and flexible employment opportunities will assist primary carers to become more involved in the workforce.

A number of elements make up best practice in career progression for people with a disability. Key factors include:

- investing in public awareness campaigns about the potential contributions of people with a disability
- collaborating and advocating across all of government and across sectors to increase employment opportunities
- acknowledging the psychosocial benefits of work, in addition to the more obvious economic benefits
- involving people with a disability in resolving issues and improving services in employment policy and practice development
- implementing supportive policies within workplaces to build cultures in which diversity is valued
- integrating services, such as employment services, with mental health services
- placing people in appropriate employment
- providing effective supports to both employees and employers in the short and long term
- understanding the positive effects of employment on people with a disability.

(Source: Smits 2004; Wilson-Kovacs 2008; Westbrook et al. 2012; Waghorn et al. 2007)

CASE STUDY

Jobs change lives and attitudes

Go into any supermarket or major retail store in Ireland, and you are likely to see an employee who has a disability.

Ireland is a world leader in the employment of people with a disability in the open labour market, and one of the reasons for its success is its Supported Employment champion, Christy Lynch.

A firm believer that it is more dignified to provide clients with support in the workplace than in a segregated day program, Christy was one of the key players behind the creation of Ireland's first Supported Employment program 25 years ago.

The program went on to be funded by the European Union, spreading the Supported Employment message throughout the EU.

Despite the UN Convention on the Rights of Persons with Disabilities rejecting the use of sheltered workshops for people with a disability, their use is still widespread in many countries, including Australia.

Mr Lynch says the belief that sheltered workshops are the best option for people with some disabilities, because they are unable to work, is both pervasive and wrong.

"I have yet to meet somebody whom we couldn't support," Mr Lynch says.

The only criteria are that the person has a disability and that they want to work. "And if the answer is yes, then it's our problem, not theirs."

In Ireland, Supported Employment is used as an alternative to the traditional model of getting people 'ready' for a specific job before they are employed. Rather, clients are asked what they would like to do, before being matched with an employer and trained in the workplace by a specialised job coach.

"And when you think about that logically, particularly for people with more complex needs or people with intellectual disabilities, people learn skills best in the situation where they need to use them. So, it makes absolute sense," Mr Lynch says.

Mr Lynch says surveys demonstrate there has been an improvement in the broader community's attitude towards people with a disability in Ireland and he believes their greater visibility in the workforce has contributed to that.

"That is the way you change public attitudes. It's a subconscious thing. You would go to a supermarket, you'd see someone with Down syndrome packing your bag or stacking the carts, and in the car park or stocking the shelves. Nobody needs to make a big statement. You don't have to do a lecture on attitudes to disability, because we all value work. It's a very powerful mechanism. You go to a party and ask somebody, 'What's your name?' Next question, 'What do you do?'"

"If you talk to people with disabilities, and you ask them what they want to do, they won't say, 'I want to be in a sheltered workshop for the rest of my life'. They'll say, 'I'd love to get a job. I'd love to have friends. I'd love to have more money in my pockets so I could have my own place'.

"Working allows them to start setting new goals for themselves and to have higher expectations, and we involve parents very closely, which means they also change their expectations. So then, when you come to saying something like, 'Maybe we could look at her getting her own apartment and living in her own place'. It's the next leap, but they've already made a significant leap by getting a job, and you've laid the foundation to do other things that people want to do with their lives.

"Supported employment is the key that opens the door to the rest of someone's life", Mr Lynch says.

Education

Higher levels of education are generally associated with higher levels of workforce participation, greater access to economic resources and better health (VicHealth 2012). On average, people with a disability have lower levels of education than the rest of the population across the range of impairment types (ABS 2004).

Children and adults with a disability remain largely excluded from inclusive, mainstream education options, and are often segregated into 'special' education settings or classes and excluded from continuing their education beyond high school. Children who are given the opportunity to attend mainstream schools (schools that include all children with no criteria for exclusion) have better academic and social outcomes. The social impact on other children has been found to be consistently positive and the impact on their academic performance is either neutral or positive (Jackson 2008).

Research in this area has favoured investigations of the role of inclusive school-based education, with some researchers also looking into the role of vocational training (Boyle et al. 2011; Campbell, Gilmore & Cuskelly 2003). No intervention studies were identified that provided data on Australian university participation. Overwhelmingly, research focused on the individual-level interventions, such as the role of teachers, rather than more broadly on inclusive policies and school practices. This narrow focus limited the key learnings about how to adopt a whole-of-community or whole-of-school approach to improving the education options for students with a disability. A number of Australian research articles were found and have been included (Griffin & Nechvoglod 2008; Sharma, Forlin & Loreman 2008; Boyle et al. 2011; Stancliffe 2012).

Children with a disability who are given the opportunity to attend mainstream schools have better academic and social outcomes.

KEY LEARNINGS ABOUT EDUCATION

Inclusive education strategies will generate more effective outcomes for students with a disability when they focus on:

- implementing broad policies around inclusion in mainstream settings
- debunking myths held within the community that assume children with a disability have a limited capacity to learn
- expanding financial and human resources, with support coming from a federal policy level, not just a local policy level
- understanding the diversity and complexity of accommodating students with diverse needs
- introducing greater equity in the way resources are allocated relating to the needs of individual students
- supporting legislation that promotes inclusive education
- developing educational policies regarding inclusion across all levels – from governments to local schools
- increasing resourcing; for example, inclusive teaching requires support from other teachers
- working in an integrated way with health, education and disability sectors.

(Sources: Ferretti & Eisenman 2010; Fiscell & Kitzman 2009; Griffin & Nechvolglod 2008; Boyle et al. 2011)

Inclusive education relies on a combination of teachers' values and skills. Future strategies need to include:

- promoting positive attitudes towards inclusion in student teachers
- using a combination of classroom instruction and fieldwork experiences in disability to influence the attitudes of student teachers
- enhancing student teacher training in inclusive education techniques
- enhancing professional development training in inclusive education techniques.

(Sources: Boyle et al. 2011; Campbell, Gilmore & Cuskelly 2003; Sharma, Forlin & Loreman 2008)

Factors that improve the successful inclusion of people with a disability into Vocational Education and Training (VET) include:

- implementing more effective transition planning and pathway development for students with a disability, by targeting students while they are still in secondary school
- developing strategic collaborations within and across sectors, such as partnerships between VET providers, disability employment agencies and employers
- developing awareness-raising marketing campaigns about disability within the VET environment as well as the broader community to overcome the attitudinal barriers faced by students transitioning into the workplace
- providing appropriate support to enable effective participation, such as learning supports (Barnett 2004).

(Source: Griffin & Nechvoglod 2008)

Factors that improve the uptake of university offers include:

- employing disability officers within universities (Stancliffe 2012)
- incorporating universal design principles into campus facilities
- offering flexible pathways into and through university degrees
- recognising at a whole-of-university level that people with a disability have a valuable contribution to make, leading to a firm commitment to supporting people with a disability to reach their learning goals
- actively encouraging participation through affirmative action (Powell 2013).

Housing

The link between appropriate housing and health is well established, with appropriate housing described as being affordable, suitable and secure (Mallet et al. 2011). People with a disability are disadvantaged in the housing market and are particularly vulnerable to the effects of living in precarious housing (Office of the Public Advocate 2010).

The majority of people with a disability reside in households rather than in shared accommodation establishments such as residential aged care or residential supported accommodation (AIHW 2008).

While no systematic reviews evaluating housing interventions were identified in the literature review, the following strategies are highlighted in the literature. A major difficulty in identifying interventions is the diverse needs of people with different types and severity of disabilities when it comes to housing options. There is no 'one size fits all' approach (Beer & Faulkner 2009).

KEY LEARNINGS ABOUT HOUSING

There is no consensus on best practice policy interventions, largely because of the diversity of housing needs of people with a disability (see Beer & Faulkner 2009; Bostock et al. 2001). However, key factors that would improve housing outcomes for people across the spectrum of disability types and severity include:

- creating opportunities for people with a disability to participate fully in the housing market
- coordinating housing and disability services to provide more integrated services
- trialling social housing innovations that involve dispersed housing within communities as an alternative to traditional supported accommodation arrangements
- supporting home ownership through government financial initiatives
- acknowledging the views of all stakeholders – including people with a disability, their advocates and families – in housing policy directions.

(Sources: Bigby 2008; Clement & Bigby 2009; Winkler et al. 2011; Parker & Fisher 2010; Emerson 2004)

Housing strategies will be more effective if they:

- support families who wish to provide accommodation within the family home by providing regular respite services (see VEOHRC 2012)
- expand funding of support options for people with a disability who wish to live independently
- increase coordination between different levels of government around housing policies that would enable people with a disability to access affordable and appropriate housing options.

Governments can play a key role by:

- guiding the development and implementation of universal design principles to new housing developments
- improving access within the private rental market by addressing systemic discrimination
- enforcing legislation and compliance with existing building codes
- developing clear guidelines for the provision of appropriate housing options
- implementing a holistic planning approach tied to transport options and quality support.

Transport

Affordable, reliable and safe transport influences health and wellbeing. Being unable to access transport options limits a number of quality-of-life indicators such as employment, accommodation options, education, health care, spirituality, social connections, and civil and political rights (Currie & Allen 2007; National Council on Disability 2005). While progress has been made towards the goal of all Australian public transport being fully accessible by 2022, it is estimated that in 2009, 1.2 million people with a disability experienced difficulty in using public transport (ABS 2011a). Taxis are a popular form of transport for people with more severe to profound levels of disability, supported by the availability of Mobility Allowances.

One primary study into transport disadvantage and wellbeing was reviewed (Delbosc & Currie 2011). An evaluation of public transport was also included (VEOHRC 2010). No systematic reviews were found. Reviews of transport disadvantage also contributed to the identification of key learnings (Currie & Allen 2007; Stanley, Currie & Stanley 2007; Currie et al. 2010; Stanley et al. 2010).

KEY LEARNINGS ABOUT TRANSPORT

Systemic changes that will begin to address the transport disadvantage experienced by many people with a disability include:

- establishing minimum service levels across all types of public transport and enforcing compliance
- launching an urban planning system that takes into account the geographic location of people with a disability and their need for accessible, reliable and affordable transport options
- including people with a disability in policy decisions pertaining to transport
- increasing awareness of disability among transport providers to improve accessibility for people with a disability.

(Sources: Stanley, Currie & Stanley 2007; VEOHRC 2010; Wilson 2003)

The following factors should be taken into account when redesigning or designing transport options:

- Feelings of vulnerability and safety inhibit use of public transport.
- Costs of travel inhibit public transport use for many people with a disability.
- Physical access to all forms of transport must be considered.
- People with a disability and disability organisations should be involved in an advisory capacity.
- Communication devices, or other relevant technology to support interaction between drivers and passengers with communication impairments, should be installed.

(Sources: Delbosc & Currie 2011; VCOSS 2011; Stancliffe 2012; VEOHRC 2010; Wilson 2003)

It should also be noted that Australia has adopted the *Disability Standards for Accessible Public Transport,* which cover information on public transport services, stations and stops. Full compliance with the standards is mandated for public transport by 2032, with five-yearly intermediate compliance milestones beginning in 2007.

Freedom from discrimination

Evidence suggests that experiencing discrimination can have a negative effect on a person's health. This effect can be both direct (by increasing stress, anxiety and the risk of mental health problems) and indirect (by reducing opportunities for employment, education and social participation) (Kelaher et al. 2008; Otiniano & Gee 2012).

Australian research on community attitudes towards people with a disability shows that negative attitudes are the basis of discrimination and a barrier to social and economic participation (National People with Disabilities and Carer Council 2009; ACT Disability Advisory Council 2004). The evaluated literature identifies approaches to reduce discrimination across individual, institutional and systemic levels.

One international review that evaluated discrimination within healthcare systems for people with intellectual disabilities was identified (Michael & Richardons 2008). Two primary studies from Australia contributed strategies for overcoming the stigma related to disability discrimination (Blignault et al. 2010; Tracy & Iacono 2008).

KEY LEARNINGS ABOUT DISCRIMINATION

Increasing community understanding about the contributions of people with a disability decreases the incidence of indirect and direct forms of discrimination. Examples of approaches to raising awareness within the general public about disability that have been evaluated as effective include:

- culturally appropriate and innovative theatre productions portraying mental illness within an ethnic community (Blignault et al. 2010)
- people with developmental disabilities teaching medical students as part of a communication skills session (Tracy & Iacono 2008).

Discrimination occurs when services fail to provide the reasonable adjustments necessary to accommodate people with a disability. The following recommendations require a coordinated approach from both governments and healthcare systems:

- Reasonable adjustments to services should form part of core standards for healthcare provision, providing accessibility to all people with a disability.
- Health services should be proactive in their approach; for example, by encouraging regular health checks.
- Local health services should work in partnership with people with an intellectual disability and their carers.

(Source: Michael & Richardons 2008)

Effective self-advocacy programs that teach people with a disability the skills to advocate for themselves can:

- raise self-awareness of discrimination, and as a result decrease vulnerability
- provide the confidence and practical tools to people with a disability to help them respond to discrimination.

Freedom from abuse, violence and neglect

People with a disability are more likely to experience violence. Women with intellectual disabilities are particularly vulnerable (VicHealth).

The following reviews were identified in this area:

- two Australian program reviews that focus on people with cognitive impairments, and one that evaluates a violence prevention program (Frawley, Barrett & Dyson 2012; Healey et al. 2008)
- one international primary study (Powers et al. 2009)
- one peer-reviewed literature review (international) addressing service programs and intervention and prevention programs (Lund 2011), which although finding limited evidence for intervention and prevention programs makes considerable recommendations in this space
- one article evaluating sexual assault prevention articles, which makes recommendations for women with intellectual disabilities (Barger et al. 2009).

KEY LEARNINGS ABOUT VIOLENCE

A holistic approach to preventing violence experienced by people with a disability should include:

- cross-sectoral action between disability services, women's service providers and health service providers and health service providers
- legislative reforms aimed at reducing health inequities experienced by people with a disability
- combining tailor-made, evidence-based prevention programs with broader mainstream programs
- approaches that bridge divisions between services and people with a disability to address attitudes, lack of knowledge, incorrect perceptions and physical inaccessibility (Lund 2011).

Health service responses to violence against women with a disability can be strengthened by:

- improving the overall accessibility of services
- implementing effective communication techniques, particularly in the area of alternative communication methods
- training competent staff to increase their knowledge about disability
- investing more time and resources, such as allowing for flexible, longer and multiple appointments
- acknowledging and understanding the role of paid staff, family and friends who may attend appointments
- recognising the role of people with a disability as decision makers
- developing a holistic approach to health by recognising the broader health needs of women beyond a specific impairment
- adopting a broad recognition of rights to good sexual and reproductive health for all, regardless of disability.

CASE STUDY

Peer educators challenge beliefs

A program that assists people to create respectful relationships is challenging the widespread view of people with an intellectual disability being 'vulnerable victims' who are incapable of leading safe sexual lives.

La Trobe University Researcher Dr Patsie Frawley, who led the development of the Living Safer Sexual Lives: Respectful Relationships program, says she encountered major resistance to the idea that people with an intellectual disability could be involved in running a program for their peers about abuse prevention, relationships and sexuality.

"There's a strong myth that people with a disability can only be vulnerable victims, they are not capable of making informed decisions, they are not able to manage their emotions and themselves. This peer education challenges all of that," Dr Frawley says.

"We have to stand back and develop frameworks that enable people with disabilities to be in powerful roles where they can stand up and be seen as people with skills, capabilities and expectations."

The relationships program, which runs over four sessions, is led by a peer educator who uses real stories of people with an intellectual disability to prompt discussion about how to develop and maintain safe sexual relationships. It also educates participants about local support services.

Dr Frawley developed the program with a project team that included two women with an intellectual disability. The team developed and ran peer educator training for more than 20 people with an intellectual disability, and trained 20 co-facilitators who were professionals from community organisations involved in abuse prevention. The peer educators and co-facilitators then went on to run the program in their local areas.

Piloted at five sites in Victoria and Tasmania, Bendigo's Gold City Support Services (GCSS) is one of the three sites currently delivering it.

Yvette Keane, a peer educator at GCSS, says she was keen to become involved as it was clear to her how important it was to have people with a disability running the training.

"It's difficult because some disabled people can't understand what's safe in a relationship and some find it difficult to explain it," Ms Keane says. "We can help share stories and learn from each other."

She says several participants have disclosed abuse and sought help from other services as a result of the program. On a personal level, Ms Keane believes being involved in delivering the program has increased her confidence and improved her opportunities for future work.

GCSS Community Development Officer John Willis says his organisation was keen to support such an 'incredibly important' program.

"In our experience most people have some exposure to sexual health information and self-protection concepts but it doesn't seem to have stuck. What excites us about this program is that they get the chance to talk about it with their peers and hear stories they can relate to.

"It has all sorts of spill overs; it's not just the topic of sexuality or abuse but it's going to those issues of rights and respect. If it's your peer who is delivering this information I think it's heard very differently, and, if they are being paid for delivering it, there's that sense they are respected."

Mr Willis says the program has a strong focus on educating people about their rights and encouraging them to make clear what they do, and do not, want.

"As for knowing a lot more about sexual health and understanding the importance of using condoms, they are now more willing to approach the services, and the services are more open to recognising the needs of people with a disability too.

"It's changed lives," Mr Willis says.

Social connection and community participation

The importance of social connection and community participation as determinants of health is widely documented. This evidence review identified a number of primary studies and program evaluations of social connection and community participation interventions for people with intellectual disabilities (Bigby 2008; Clement & Bigby 2009; Davidson et al. 2008; Burgen & Bigby 2007).

Two international systematic reviews were included that discuss the impact of environmental factors on participation (Verdonschott et al. 2009), and the outcomes of community living post de-institutionalisation (Kozma, Mansell & Beadle-Brown 2009).

KEY LEARNINGS ABOUT SOCIAL CONNECTION AND COMMUNITY PARTICIPATION

Key factors in ensuring genuine inclusion for people with a disability include:

- accessing economic resources, such as transport, housing and open employment
- overcoming behaviours of concern through effective interventions
- engaging service providers to play a more active role in the development of relationships, particularly informal relationships
- avoiding incidences of high staff turnover of disability services staff, which can inhibit continuity of actions in regard to maintaining current social connections (for example, with family)
- ensuring community-based living options are offered.

(Sources: Stancliffe 2012; Hassiotis & Hall 2009; Kozma, Mansell & Beadle-Brown 2009)

Key approaches to overcoming existing barriers to participation include:

- expanding opportunities to interact in the community
- supporting the communication needs of people with a disability through the training in, and use of, supportive technologies
- redesigning support services to include social participation as a key performance indicator.

Disability support staff and allied health professionals (such as case managers) often act as facilitators to community access for people with moderate to severe intellectual disabilities. Key factors that facilitate effective staff practices in organisations include:

- clear policies on social inclusion, including definitions that are aligned to genuine participation models, not just presence or visibility
- consistency across services and within services
- staff training that includes skills in understanding and facilitating inclusion
- clear staff strategies around friendships
- valuing informal relationships (for example, with neighbours) over formal relationships
- maintaining a core staff group, as high turnover in staff has a negative effect
- acknowledging the role of staff as facilitators of friendship support, by planning opportunities, developing skills and so on.

CASE STUDY

Community groups provide connection in retirement

This project links people with intellectual disabilities with groups within the community that share their interests.

For the past three years, Heather, who has an intellectual disability, has been an active member of a local cooking group. She beams when she talks of the friendships she has made and how much she enjoys her weekly activity.

"I love cooking, and they are helping me learn," Heather says. "Spaghetti bolognese is my favourite, and I love cheesecake."

Her small group meet at Olympic Adult Education in West Heidelberg each week to cook and share a meal, but its members freely admit that the opportunity to socialise is more important than the food.

Frank, one of the group's founders, says Heather's contribution is valued, and everyone looks out for her. "She used to have a carer come with her but now she's with us she doesn't need one. We wouldn't know what to do without her."

Heather is just one of the success stories from the Transition to Retirement project, funded by the Australian Research Council and led by a team of researchers from the University of Sydney, La Trobe University and Victoria University in New Zealand.

University of Sydney's Professor of Intellectual Disability, Professor Roger Stancliffe, says the project arose from the recognition that people with intellectual disabilities are living longer, and should be able to take part in the broad range of retirement activities available in the community.

"It's often just a case of making sure the person is not socially isolated in the group," Professor Stancliffe says.

"One particular man enjoys singing and wanted to join a community choir of older people, and several members volunteered to be mentors. One of the difficult things for him was his literacy was not so good, so it was difficult for him to read sheet music, so one mentor wrote out the words in large print and the choir recorded themselves singing the songs so he could listen and practise and be involved.

"Another man joined a community garden and he needed some support in knowing what to do, so they developed a list of activities for him to follow with the assistance of a mentor. It's little things like that."

As part of the pilot, La Trobe University PhD student and social worker Diane Craig worked with five people with moderate intellectual disabilities in Melbourne, including Heather. The participants joined groups as diverse as a Men's Shed, an op shop and a walking group.

"The five people I followed all led lives that were very much segregated from the rest of the community," Ms Craig says. "They lived in group homes and attended day centres and engaged in a broad range of activities that were disability specific. This was the first thing they were doing on their own in a non-disability specific area, and the impact it had on all of them was huge.

"Heather was shopping with her support worker and two people from her group saw her and called out to her by name. You can imagine, her face lit up, and she had the chance to introduce her friends to her support worker.

"It's the sort of things we take for granted. I think those are fantastic outcomes.

"At the start, it requires a lot of support and then it can be reduced. There was a small impact on the group, they had to become involved to help support the person with a disability, but generally within the community, there is a high level of acceptance around the rights of people with a disability to be involved. They were all very open and willing for them to be there," Ms Craig says.

"You get a kind of raised consciousness about the meaning of disability and often comments would be things like it was the first time they had a chance to meet someone with that level of impairment; that they were usually an invisible group in the community."

Health behaviours

ALCOHOL, TOBACCO, PHYSICAL ACTIVITY, NUTRITION

While people with a disability often have a better health profile than the general population in regards to alcohol use, they have worse profiles in regards to physical activity and nutrition (VicHealth 2012). However, the prevalence of some of these risk factors (such as alcohol use or smoking) varies considerably according to the type of impairment or health condition.

Three systematic reviews were identified (Hamilton et al. 2007; Hamilton 2006; Heller et al. 2011). A number of program evaluations focusing on trialling health programs for people with differing types of disabilities were also identified and included. However, each evaluation reached only limited conclusions, due to a diversity of population groups and intervention approaches. The empirical evidence for all has been included (Bazzano et al. 2009; Block et al. 2010; Hughes et al. 2003; Horner-Johnson et al. 2011; Lante et al. 2011; Ravesloot, Seekins & Cahill 2007).[2]

KEY LEARNINGS ABOUT HEALTH BEHAVIOURS

Key factors that contribute to the development of positive health behaviours for people with intellectual disabilities, particularly those living in supported accommodation services, include:

- staff modelling healthy behaviours
- training for staff in health promotion
- physical activity and healthy eating programs
- family modelling of healthy behaviours
- developing tailored prevention programs, specific to individuals with a disability
- developing partnerships between healthcare providers, people with intellectual disabilities and support staff, with a commitment to solving health issues such as obesity together
- developing cost-effective programs to ensure sustainability
- promoting the benefits of exercise in terms of social inclusion; for example, having the opportunity to meet new people (Lante et al. 2011).

(Sources: Heller et al. 2011; Hamilton 2006; Hamilton et al. 2007)

Community-based healthy lifestyle programs contribute to improving the health behaviours of people with different types of disabilities (Abdullah et al. 2004; Bazzano et al. 2009; Hamilton et al. 2007; Hamilton 2006; Horner-Johnson et al. 2011; Ravesloot, Seekins & Cahill 2007). The curriculums for the evaluated programs all used self-determination models. The programs often had the added benefit of providing networking opportunities for people with a disability.

Key factors in the success of such programs include:

- involving people with a disability in the development and delivery of programs
- empowering people with a disability to understand their choices and related health behaviours
- providing access to information (for example, around sexual health)
- providing opportunities to practise healthy lifestyles
- providing opportunities to practise behaviours (for example, exercise sessions)
- using peer mentors throughout the program, and to provide follow-up
- overcoming barriers such as lack of family support, transport, inaccessible environments and financial hardships
- keeping costs low
- using accessible communication strategies to provide information to, for example, people with a visual impairment (Lyndsey et al. 2010)
- using individual goal setting as part of interventions
- facilitating access to community-based services (as opposed to disability-specific services)
- using group-based interventions to decrease social isolation.

[2] While all of these references have similar conclusions, the programs targeted different populations of people with disabilities – from intellectual disability to chronic pain to physical disability.

Access to the health system

Access to the health system includes timely treatment of health problems, the active promotion of healthy behaviours, primary and secondary prevention, and the management of complex conditions. However, the presence of disability can make it difficult for people to engage in self-initiated health promotion practices and the wider health system.

One synthesis of the published literature on access to health care (Levesque, Harris & Russell 2013) conceptualised five dimensions of accessibility: approachability, acceptability, availability, affordability and appropriateness. The table below provides further detail on these dimensions.

One systematic review on access for people with an intellectual disability is included (Krahn, Hammond & Turner 2006). Several program evaluations on health services and health promotion are also included (Lennox et al. 2007; Ziviani et al. 2004; Cooper et al. 2006; Iacono et al. 2011; Tracy & Iacono 2008).

KEY LEARNINGS ABOUT ACCESS TO HEALTH SERVICES

The following key findings contribute to reducing barriers for people with a disability:

- consistency in direct care providers
- holistic attention to healthcare needs
- confidence, skills and efficacy among providers in managing behaviours of concern
- attention to holistic individual health-promoting behaviours
- appropriate access to preventative measures such as health screening
- non-reliance on medication for management of psychiatric issues
- flexibility around the timing of consultation appointments and their duration
- ability of service providers to communicate successfully with people with a disability.

(Source: Krahn, Hammond & Turner 2006)

The five dimensions of accessibility

Dimension	Meaning
Approachability	Refers to people being able to identify that the service exists and that it will have an impact on their health. Information about services and possible treatments are made known. Health literacy fits under this dimension.
Acceptability	Refers to the cultural or social factors influencing the possibility of people utilising the service. A service that is unacceptable could be one that is predominantly delivered by men within a community or society forbidding physical contact between non-married women and men.
Availability	Refers to the built environment and physical space of both the service and the health practitioners. The geographical location of the service and transport options should be considered in this dimension.
Affordability	Refers to the economic capacity of people to pay for health services.
Appropriateness	Denotes a fit between services and client needs, including the timing of appointments, amount of time spent in appointments and quality of service provision.

Healthcare staff play a crucial role both in delivering care directly and in raising awareness of the health needs of people with a disability within healthcare services. Key factors identified that assist healthcare staff to fulfil this role include:

- providing training to trainee healthcare staff that covers the topics of knowledge, confidence and communication (Iacono et al. 2011; Tracy & Iacono 2008)
- providing regular opportunities for professional development for healthcare staff that covers the topics of knowledge, confidence and communication, as well as introducing new areas of evidence-based practice.

Further interventions to reduce health inequities include:

- educating people with a disability about their rights
- coordinating service provision to ensure people with a disability do not 'fall through the cracks'
- employing health advocacy (using the UN Convention on the Rights of Persons with Disabilities where necessary) to promote the health rights of people with a disability, and the obligations of governments to meet the needs of people with a disability in this area (Brolan et al. 2012)
- empowering people with a disability to self-manage with full support of community health organisations
- using universal design principles to ensure physical access, adequate signage and so on
- establishing a relationship with regular GPs
- teaching alternative communication methods to healthcare workers
- training support workers to maintain adequate medical records
- conducting health screening for people with intellectual disabilities (Cooper et al. 2006).

(Sources: Krahn, Hammond & Turner 2006; Ziviani et al. 2004)

COMPREHENSIVE HEALTH ASSESSMENT PROGRAM

Tools can be used to ensure access to a range of health services. One tool that has been developed is the CHAP (Comprehensive Health Assessment program) for people with intellectual disabilities. This tool involves elements of health promotion, disease prevention, case finding (identifying new problems) and implementation of appropriate interventions. It has been widely adopted within services for adults with intellectual disabilities, and forms the basis of annual reviews conducted by GPs.

Key factors contributing to the success of this tool include that it:

- increases GP focus on specific health needs of people with a disability
- reduces barriers to health care by becoming an integral part of primary care provision
- includes accessible information that makes it user friendly
- promotes improvements in communication between people with intellectual disabilities, staff and GPs
- enables GPs to focus on core health issues
- ensures that continuity of health care remains even in the face of high staff turnover
- improves access to health screenings (such as Pap smears)
- increases immunisation update rates
- increases detection of vision and hearing problems.

CASE STUDY

Disability group sets national healthcare standards

A group of people with a disability has set the standard for the care of vulnerable patients in the UK, developing Quality of Health Principles that are to be embedded in all National Health Service (NHS) contracts.

Disability advocacy organisation Changing Lives developed the principles and its CEO, Jayne Leeson, says the fact the government has adopted them sends a powerful message to health providers about its expectations of a 'good quality patient care experience'.

"I think it's very important because it's actually coming from the grass roots, and the fact the principles are to be embedded in NHS contracts means the health services will have to adhere to the standards that have been written by local people with a disability," Ms Leeson says.

The principles set out expectations of care for 'vulnerable' people, including making communication accessible, maintaining privacy and dignity, implementing a system that alerts health professionals to patients' needs for assistance with eating and drinking, and patients' rights to have a support person accompany them to their appointments.

The adoption of the principles follows a major scandal in the UK, when a television exposé revealed shocking abuse of residents with learning disabilities at an assessment and treatment hospital near Bristol. Six staff members were jailed for neglect or ill treatment of patients, with five receiving suspended sentences.

Embedding the Quality of Health Principles into national health contracts was one of the recommendations to come out of the UK Health Department's interim report on the scandal.

Ms Leeson says the principles have already led to concrete changes in her local area, including one hospital funding a specific learning-disability liaison nurse position. The liaison nurse is notified whenever a person with an intellectual disability is admitted, with her role being to ensure they are treated well as a patient.

For example, when a patient on the autism spectrum was afraid of having surgery, the liaison nurse gave him a tour of the theatre prior to his operation and ensured staff put on their gowns at the last moment, Ms Leeson says.

"So there were adjustments made to reduce the impact of the experience on him, and to make the health service fit the person with the disability rather than the other way around."

The liaison nurse also trains other staff members in how to treat patients with an intellectual disability with respect. Working closely with the liaison nurse, a learning disability community nurse has also set up a clinic at the same hospital for people with a learning disability and diabetes, "because their diabetes was being managed dreadfully".

"It's the first specific diabetes clinic for people with an intellectual disability for the region, if not the UK," Ms Leeson says.

However, Ms Leeson cautions that while adopting the principles is a big win, a major cultural shift is also needed across the health service.

"You are getting people with a disability into the health service and people just ignore them. They don't really see the person, just the disability, and they become like a bit of wallpaper."

Traditionally, the auditing procedure followed by health services paid little attention to the patient experience, Ms Leeson says. However, Changing Lives is to meet with the Department of Health to discuss how its strong and inclusive audit process can be rolled out across the wider system to ensure the principles are being implemented, and the experience of patients with a disability is respected.

"All of our audit results lead to an action plan and we go back and make sure things have changed," she says.

Self-determination

Self-determination for people with a disability involves genuine access to choice and decision-making opportunities, which has been historically and systematically denied to many people with a disability. However, as disability supports have shifted away from institutional, segregated services, greater emphasis has been placed on self-determination and inclusion. The National Disability Insurance Scheme, with its emphasis on entitlement and personalisation, should provide more opportunities for people with a disability to be involved in genuine self-determination activities (Foster et al. 2012).

One systematic review that establishes the role of community-based services in ensuring self-determination for people with intellectual disabilities is included (Kozma, Mansell & Beadle-Brown 2009). Another reviewing autonomy in relation to health is included (Wullink et al. 2009), as well as several program evaluations.

KEY LEARNINGS ABOUT SELF-DETERMINATION

Policy and legislative reforms can promote disability-friendly environments that will, in turn, reduce architectural, programmatic and attitudinal barriers that make it difficult for people with a disability to engage in self-initiated health promotion practices (Rimmer & Rowland 2008).

People with a disability need genuine opportunities to exercise self-determination. Key factors that enable people with a disability to practise self-determination include (e.g. Stancliffe 2012):

- enabling people to live more independently
- facilitating the delivery of more individualised services where opportunities for making choices can be routinely provided
- providing opportunities for people with a disability to receive higher education and to transition to genuine work opportunities
- incorporating instruction in self-determination and problem-solving skills within the school curriculum.

Accommodation services for people with intellectual disabilities can contribute to the promotion of self-determination. Key factors to promoting self-determination for people with intellectual disabilities include:

- providing community-based services
- designing small-sized homes
- skilling staff in how to promote choice and empowerment
- promoting the use of active support strategies
- facilitating the creation of a home-like environment.

(Source: Kozma, Mansell & Beadle-Brown 2009)

Self-determination programs can be taught through schools to increase the capacity of people with a disability. Key elements that make up successful self-determination programs for people with a disability include:

- integrating self-determination as part of transition services, such as transitioning from school
- teaching autonomous behaviours such as independence, assessing risk and safety skills
- assessing preferences and building on these to demonstrate ability to make appropriate choices
- teaching self-monitoring and self-evaluation of actions
- encouraging goal setting and action planning
- facilitating self-advocacy skills, including assertiveness and effective communication skills
- promoting self-awareness and self-knowledge
- focusing on functioning autonomously in everyday activities
- tailoring programs to people with intellectual disabilities (Wehmeyer et al. 2013; Sheppard & Unsworth 2011; Wullink et al. 2009).

What you can do next

What you can do next

There are many practical steps you can take to address the health inequities experienced by people with a disability:

- Review action across the key determinants and contributing factors identified in the *Enabling Health* framework (see page 17). Check if action is happening across all, most or some of the key determinants and contributing factors. Consider advocacy or partnering with other organisations to ensure that all or most are being addressed. Even if your organisation's core business is only in one area, you can still make a valuable difference by raising issues regarding other determinants and contributing factors with those who have the capacity to generate change in your local area.
- Check that the general principles are reflected in all your actions.
- Check that you are using many or most of the health promotion actions from the *Enabling Health* framework.
- Consider the immediate and long-term benefits and outcomes of this work as evaluation measures in your health promotion plan.
- Check that the key learnings sections from this resource are relevant to your priority areas and health promotion planning.

Appendices

Available only online at www.vichealth.vic.gov.au/enabling-health

Appendix 1: Detailed description of review methods

Appendix 2: Data extraction tables

Appendix 3: Gaps in knowledge

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Photographs

Front cover image: Model holds Anthony Romagnano's artwork, *Not Titled* 2010, pencil on paper, 38 x 39cm, courtesy the artist and Arts Project Australia. Photo: Joseph Feil, Blue Tree Studio.

Tab pages: Tab 1 Anthony Romagnano at work in the Arts Project studio, Northcote. Tab 2 Robyn Gaile, Coordinator, Disability Advocacy Resource Unit, Melbourne. Tab 3 ©ThinkStock.

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