AUSTRALIANS WITH DISABILITY: CHANGING ATTITUDES TO THEIR RIGHTS, ABILITIES AND LIFESTYLE
Prepared for Focus ACT

BACKGROUND

Australia is the lucky country, where most Australians have the opportunity to dream without limit. Yet our largest minority, people with disability, is not afforded the basic rights others take for granted, let alone the relative luxury of leading a good life. That is, approximately 4 million Australians living with disability are at risk of or are currently being treated unfairly. This is explicitly highlighted in the Productivity Commission’s report (see below).

This should resonate with every Australian, because anyone could find themselves living with disability at some point in their lives.

A cultural change within our society is required to facilitate reform in the disability sector. This involves increasing awareness, educating widely and shifting attitudes to move towards genuine community involvement.

HISTORICAL ATTITUDES

Beliefs about people with disability
Attitudes and cultural representations that go back to Greece and Rome are still threaded throughout our society. Societal views towards people with a disability over the centuries were further driven by the development of negative associations – they were considered ‘evil’, ‘to be pitied’, ‘unproductive’, ‘dependent’, ‘a drain on society’.

People with disability have been ignored, hidden, cursed and treated as unwanted. When made visible, they have been the subject of exhibitions and objects of ridicule. Society dealt with the ‘problem’ of people with disability by placing them in institutions or prisons and by sterilising women and girls.

Despite these widely held attitudes, there was often acceptance and inclusion at the family and local level. This continues into the modern day, with informal supports being the principal contributor of care and support.

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1 Globally, disability affects hundreds of millions of families. Currently around 15 per cent of the total world’s population, or roughly 1 billion people, live with a disability. This figure is increasing through population growth, medical advances and the ageing process, says the World Health Organization. In most of the OECD countries, females have higher rates of disability than males. Having a disability places a person in the world’s largest minority group.
Institutionalisation: once the preferred model of support
It was common practice to label people with intellectual disability as ‘mentally retarded’ or ‘mentally handicapped’ and place them in institutions, or in segregated schools or workplaces, where they had few rights.

In the 1880s, institutions providing accommodation for people with intellectual disability and psychiatric disability opened across Australia. People with disability lived in these facilities separated from their families and communities, sometimes for their whole lives.

In 1913, the introduction of intelligence testing saw increasing numbers of people being diagnosed as ‘sub-normal’. Eugenic-based fears about the ‘threat’ posed by the ‘feeble-minded’ led to calls for complete segregation.

As recently as 40 years ago, people with severe disability were still largely invisible to the community. Typically they died young, were supported under extreme hardship by their families, or spent their life in institutions with names such as Blind, Deaf and Dumb Asylum, Home for the Incurables, Destitute Asylum, or Kew Idiot Asylum.

CHANGING ATTITUDES

The Disability Rights Movement
In 1908, the Australian Government introduced the Invalid Pension, which provided some independence to people with disability as well as acknowledging them, to some extent, as recognised members of society.

After the First World War and the return of many soldiers with impairments, the government funded rehabilitation programs. With the increased numbers of people with disability they couldn’t all be institutionalised – this demographic change acted as a step towards disability as a better-recognised condition.

The consequences of the Second World War had a similar impact and strengthened the belief that people with disability have a right to lead decent lives. The Commonwealth Rehabilitation Service (CRS) was established and volunteer organisations extended their services to people with disability.

Between the 1930s and 1960s, approximately 70,000 Australians were paralysed by polio. Most people recovered with varying levels of disability, many going on to lead active lives. Parents of children affected

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2 At the beginning of World War II, the Nazi Party tried to eliminate this ‘threat’ by its policy of ‘racial hygiene’ that saw the killing of at least 200,000 people with physical or mental handicap.
4 http://amhistory.si.edu/polio/howpolio/disability.htm
by polio, some with the help of philanthropists, started many of the organisations that are still providing supports to family members today.\textsuperscript{5}

Family members began the movement to close institutions and return people to the community. They wanted their sons and daughters, brothers and sisters who lived in institutions to have a better life, to learn in school, have friends, and to be welcome in their community. Their message was that disability is a social and civil rights issue, not simply a medical problem.

Up until the late 1970s, the views of people with disability were mainly filtered through the voices of disability service providers, professionals working in the area of disability and family members.

The disability rights movement was also active at the international level. At the time, the key international disability organisation, Rehabilitation International, had a policy that while people with disability could attend its periodic international conference as observers they were not permitted to speak. People with disability strongly protested against this policy at the 1980 Rehabilitation International conference in Winnipeg, Canada, where a decision was made to establish a new international organisation of and for people with disability. That organisation was Disabled Peoples International (DPI), which now has members in over 160 countries throughout the world, including Australia.

**International Year of Disabled Persons:**

The year 1981 became a turning point for people with disability speaking up for themselves. DPI held its first World Assembly in Singapore in the context of the United Nations’ International Year of Disabled Persons (IYDP) with its theme *Breaking Down the Barriers*.

While, individuals and groups did advocate for the rights of people with disability before the IYDP, that action was mostly based around a medical diagnostic group or specific issue. The concept of ‘systemic oppression’ became the motive for the development of a social movement. Disability became more than a diagnosis, to be dealt with by medical professionals. People with disability began to think of themselves more as a public issue rather than a private problem. They discovered the social nature of their condition and became united in claiming self-determination and self-representation to overcome their social oppression as a group. People with intellectual disability began to advocate for their own rights to live as full citizens, and created the ‘self advocacy movement’.

**International Day of People with Disability (IDPwD)**\textsuperscript{6}

The United Nations (UN) recognised the need to foster attitude change at the international level. In 1992, the UN decreed that the International Day of People with Disability (IDPwD) be held on 3 December each year.

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\textsuperscript{5} Thousands of people now aged in their 40s, 50s, 60s and older are experiencing what is called Post Polio Syndrome or Late Effects Polio, which are a set of unexpected new symptoms occurring some 15 to 40 years after the initial infection.

Day aims to promote an understanding of people with disability and encourage support for their dignity, rights and wellbeing.

The Australian Government has been supporting IDPwD (I-Day) since 1996 and provides funds to promote and raise awareness of the day around Australia. While IDPwD attracts some media attention, increased community acceptance has not been measured.

The National Disability Awards are also held each year as part of the I-Day celebrations. The Awards aim to honour and recognise the outstanding achievements of individuals and organisations that have improved the lives of people with disability and thereby contributed to increased recognition of equality and human rights for all Australians.

Through the Focus Supported Living Foundation, the people Focus supports are assisted to attend and be part of the I-Day celebrations each year.

Self-determination gathers strength in Australia
From 1981, disability activism and advocacy sustained a focus on several important cornerstones of disability self-determination:

- A general move away from institutional-type services to community based services
- Relocation of people with physical disability from hostels and nursing homes into community housing
- Enlightened mental health legislation in various states
- The establishment of ‘public advocates’ and guardianship boards in most states
- The introduction with bipartisan support of the Disability Services Act 1986 (DSA) and the Disability Discrimination Act 1992 (DDA)

United Nations Formalises the Rights of Persons with Disability
In May 2008, the United Nations Convention on the Rights of Persons with Disabilities (CRPD) came into force. This followed decades of work by the United Nations to bring about the changes desired by people with disability themselves and their families.

The Convention is intended as a human rights instrument with an explicit, social development dimension. It adopts a broad categorisation of people with disability and reaffirms that all people with all types of disability must enjoy all human rights and fundamental freedoms. It clarifies and qualifies how all categories of rights apply to people with disability and identifies areas where adaptations have to be made to effectively exercise their rights and areas where their rights have been violated, and where protection of rights must be reinforced.

The Convention changed viewing people with disability as ‘objects’ of charity, medical treatment and social protection to viewing them as ‘subjects’ with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society.

Australia was involved in the drafting of the Convention and was one of the first countries to sign and then ratify it. By doing so, the Convention made a significant contribution to the advancement of the disability rights movement in Australia.

**The Move to Deinstitutionalisation**

It is neither acceptable nor appropriate for people with intellectual disability to continue living in hospitals and other harsh institutional environments. Many people in these environments have little access to the community; others have none at all. Nor are people provided with educational or vocational opportunities. This lack of opportunity to access the community and to learn and develop is unfair, and results in a severely inequitable situation that directly contravenes Australia’s human rights obligations and fails to meet contemporary models of support and moral standards.

Furthermore, in many cases it does not make good economic sense to care for people in acute hospital beds, when the same person could be receiving more appropriate support in a community-based setting at a significantly reduced cost.\(^8\)

The experience of the past few decades has shown that no one needs to be separated from communities because of a disability. Institutions cannot develop the potential of individuals to learn, participate and contribute to their communities. They isolate people from family, friends, and communities. And increasingly, they create high-risk environments for abuse and neglect.

Living among family, friends and neighbours provides the environment for people’s abilities to develop and creates communities where everyone is welcome. Even those who require extra support or specialised care have a better quality of life when they receive care and support in their home and community, rather than in an institution.

**Principle of Normalization / Social Role Valorization**

In 1972, Wolf Wolfensberger introduced *The Principle of Normalization in Human Services* as part of the deinstitutionalisation movement of the 1970s. Normalization involves the acceptance of people with disability, with their disability, offering them the same conditions as are offered to other citizens. It involves an awareness of the normal rhythm of life – including the normal rhythm of a day, a week, a year, and the lifecycle itself (eg celebration of holidays; workday and weekends). It involves the

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\(^8\) People with intellectual disability or cognitive impairment residing long-term in health care facilities: Addressing the barriers to deinstitutionalisation, Office of the Public Advocate, Queensland, October 2013
normal conditions of life – housing, schooling, employment, exercise, recreation and freedom of choice previously denied to individuals with severe, profound or significant disability.

Dr. Wolfensberger’s definition was based on a concept of cultural normativeness: ‘Utilization of a means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics that are as culturally normative as possible.’ Thus, for example, ‘medical procedures’ such as shock treatment or restraints, are not just punitive, but also not ‘culturally normative’ in society.

His principle is based upon social and physical integration, which later became popularised, implemented and studied in services in Australia and across much of the world as community integration encompassing areas from work to recreation and living arrangements.

Governments and organisations in Australia in the 1980s relied on the Principle of Normalization to gain an understanding of the changes needed to improve the way supports were provided to people with disability. In 1983, Normalization became known as Social Role Valorization with the shorter definition: People with a devalued status are enabled to be perceived positively and have good lives.

**Shut Out: The Experience of People with Disability and Their Families in Australia**

Many of the large institutions that housed generations of people with disability—out of sight and out of mind—are now closed. Australians with disability are now largely free to live in the community.

Once shut in, many people with disability now find themselves shut out. People with disability may be present in our community, but too few are actually part of it. Many live desperate and lonely lives of exclusion and isolation. The institutions that once housed them may be closed, but the inequity remains. Where once they were physically segregated, many Australians with disability now find themselves socially, culturally and politically isolated. They are ignored, invisible and silent. They struggle to be noticed, they struggle to be seen, they struggle to have their voices heard.

Widespread misconceptions and stereotypes about people with disability persist. These include that they are a ‘danger’, a ‘burden’, and a ‘threat’. It is not uncommon to still hear people express the view that people with disability would be better off in institutions with others of their own kind. There also appears to be a common belief that people with disability are not able to make a significant contribution to the community, and that they are somehow not of equal value as human beings and members of the community.

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10 National People with Disabilities and Carer Council, 2009  
Many people without disability have low expectations of people with disability, believing that they cannot learn or are not able to do anything useful. People with disability are often denied opportunities to experience life, to explore their potential and achieve success, because it is assumed that their potential is limited. It is often stated that people with disability are tolerated in the community, but tolerance is not acceptance and genuine inclusion.

In a society where the values that predominate are power and wealth, physical prowess and beauty, intelligence, competition, autonomy and self-control, many people with disability are marginalised and devalued. It could well be that many people are fearful about engaging with and including people with disability as a result of a lack of knowledge – they are treated as ‘the other’.

Community Living and Citizenship
Although the movement to bring people out of institutions into the community had been gathering momentum over the previous 20 years, the Australian Government’s National Disability Strategy from 2010 set out a 10-year national policy framework aimed at enhancing the quality of life and increasing economic and social participation for people with disability and their carers.

The Commonwealth, along with the States and Territories, has a major investment in disability specific support. However, there remains a significant level of unmet demand for disability services which impacts upon the lives of people with disability, their families and carers. Demographic change and the anticipated decline in the availability of informal care are expected to place further pressure on the existing system over the coming decades.

While Australia’s social security and universal health care systems provide an entitlement to services based on need, there is currently no equivalent entitlement to disability care and support services.

The Australian Government made a commitment to finding the best solutions to improve care and support services for people with disability. An exploration of alternative approaches to funding and delivering disability services with a focus on early intervention and long-term care was needed. In 2010, the Productivity Commission (PC) was requested to undertake an inquiry into a national long-term care and support scheme for people with disability, including an examination of a social insurance model. In 2011, the inquiry reported:

- Most families and individuals cannot adequately prepare for the risk and financial impact of significant disability. The costs of lifetime care can be so substantial that the risks and costs need to be pooled.


12 *Disability Care and Support*, August 2011

The current disability support system is underfunded, unfair, fragmented, and inefficient, and gives people with disability little choice and no certainty of access to appropriate supports. The stresses on the system are growing, with rising costs for all governments.

There should be a new national scheme — the National Disability Insurance Scheme (NDIS) — that provides insurance cover for all Australians in the event of significant disability. Funding of the scheme should be a core function of government (just like Medicare).

The NDIS would have other roles. It would aim to better link the community and people with disability, including by using not-for-profit organisations. It would also provide information to people, help break down stereotypes, and ensure quality assurance and diffusion of best practice among providers.

A New World: The NDIS and More Choice and Control

The NDIS began in 2013. For the first three years, it is being introduced at trial sites at selected locations (http://www.ndis.gov.au/about-us/our-sites). The full rollout of the Scheme will take place from July 2016/17 to June 2019/20.

The NDIS covers the same types of supports currently provided by specialist providers (but with sufficient funding), gives people more opportunity to choose mainstream services, and encourages innovative approaches to support.

The NDIS:

- Supports people with a permanent and significant disability that affects their ability to take part in everyday activities
- Works with individuals to identify supports they need to live their life. Supports may help them achieve goals in many aspects of their life, including independence, involvement in the community, education, employment and health and wellbeing
- Gives individuals more choice and control over how, when and where their supports are provided, and gives certainty they will receive the support they need over their lifetime and
- Focuses on early intervention where getting early supports can reduce the impact of disability on the family or the child

People eligible for the Scheme have flexible support packages tailored to their individual needs. People can choose their own provider(s), they can

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14 In the ACT from 1 July 2014
ask an intermediary to assemble the best package on their behalf, cash out their funding allocation and direct the funding to areas of need (with appropriate probity controls and support), or choose a combination of these options.

The report *Disability expectations: investing in a better life, a stronger Australia* briefly traces the history of disability entitlement, services and policy, considers the PC’s report, and asks what needs to change if the NDIS is to make a meaningful difference.15

While Focus has always used a person-centred approach to determine the individual supports people need, the NDIS takes this to another level with a separate planning process with each person conducted by plan managers.

Focus is assisting the people it supports to transition to the NDIS as they become eligible in line with the transition schedule set by the ACT Government. Focus is also helping people and their families to understand the NDIS by running pre-planning workshops before the first planning session with a plan manager.

**Legal Attitude to Supported Decision-making**

Under the NDIS, people with disability increasingly will make decisions about the supports they need, how they will be provided and by which service providers. They will have the opportunity to manage the money for their supports. To make informed decisions and choices, some people will need independent support.

An inquiry conducted by the Australian Law Reform Commission (ALRC) ‘Equality, Capacity and Disability in Commonwealth Laws’16 recommended

- Supported decision-making for people with disability is to be encouraged
- Representative decision-makers are appointed only as a last resort
- The will, preferences and rights of people must direct decisions that affect their lives

Further, the ALRC report recommended the reform of relevant Commonwealth, State and Territory laws should be consistent with the following National Decision-making Principles

*Principle 1: The equal right to make decisions*

All adults have an equal right to make decisions that affect their lives and to have those decisions respected.

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Principle 2: Support
Persons who require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives.

Principle 3: Will, preferences and rights
The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.

Principle 4: Safeguards
Laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for people who may require decision-making support, including the prevention of abuse and undue influence.

These principles reflect the paradigm shift signalled in the United Nations Convention on the Rights of Persons with Disabilities (CRPD) to recognise people with disability as persons before the law and their right to make choices for themselves. The emphasis is on the autonomy and independence of people with disability who may require support in making decisions—their will and preferences must drive decisions that they make, and that others make on their behalf.

Supported Decision-making Through Advocacy
From 1986, disability rights advocacy was funded as a program area under the DSA. There are a number of recognised forms of advocacy that aim to assist an individual with disability to make informed choices and decisions.

Self-advocacy is when someone with disability is able to speak up and represent themselves. There are a number of community-based groups providing support and training to enable and empower people with disability, particularly those with intellectual disability, to speak up for themselves.

Individual Advocacy is when an advocate assists a person with disability by taking action on their behalf and in their best interests. This can be:

• Providing information and advice so that the person with disability can advocate for themselves

• Supporting the person with disability to take action on any matter related to discrimination

A relative, friend or professional advocacy service can undertake this type of advocacy. Currently, there are no formal training requirements involved in being an individual advocate. This lack of training is of concern to Focus and other disability service providers. Untrained advocates could, advertently or inadvertently, encourage a person to make decisions based on the advocate’s, rather than the individual’s, opinions and wishes.

17 Such as Advocacy for Inclusion in Canberra www.advocacyforinclusion.org/
Group Advocacy is similar to individual advocacy but involves representing a group of people with disability.

Citizen Advocacy is when a community member voluntarily enters a relationship with a person with intellectual disability to represent the interests of that person and develops a long-term relationship that offers new experiences and opportunities. Citizen Advocates are recruited, trained and supported through a community-based Citizen Advocacy agency and then matched up to a person with disability.

Systemic Advocacy is about social change. It addresses discrimination affecting a number of people with disability by advocating for change to legislation, policies and practices. Systemic advocacy includes lobbying politicians, campaigning and raising public awareness in order to build an inclusive community.

An example of systemic advocacy is National Disability Services (NDS). Focus is a member of NDS.

The National Disability Advocacy Framework is currently under review.

MORE CHANGE IS NEEDED

Just under 1 in 5 Australians (4.2 million people) reported having a disability in 2012. Of these, 1.4 million people needed help with basic daily activities of self-care, mobility and communication.

Health and Wellbeing of People with Disability

A person’s quality of life includes their health and wellbeing across all physical, mental and social aspects.

Due to a range of factors—only some of which may be directly related to a person’s disability—as a group, people with disability experience significantly poorer health than those without disability. Almost half (46%) of people aged 15–64 with severe or profound disability report poor or fair health compared with 5% for those without disability. Self-reporting of health by people with severe or profound disability showed that only 28% had excellent health and 26% good health.

Similarly, for people aged 15–64 with a specific long-term health condition or injury, a higher proportion of those with severe or profound disability than those without disability had:

- young onset of arthritis before age 25 (14% compared with 6%)

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18 There is no citizen advocacy program in Canberra at the time of writing.
- osteoporosis before age 45 (43% compared with 31%)
- young onset of diabetes before age 25 (23% and 7% respectively)

Higher proportions of people with disability compared with those without were also overweight, smokers, or had suicidal thoughts.

Australians aged 15–64 with severe or profound disability were extensive users of professional health services, with higher rates of consultations with general practitioners, specialists and other health professionals than people without disability.

Service providers can assist people to better manage their health through implementing the Comprehensive Health Assessment program (CHAP). This is a tool designed at the University of Queensland to prompt a comprehensive health assessment for adults with intellectual disability. This may potentially help doctors make better diagnoses, provide appropriate treatment and ultimately ensure an overall better health. The CHAP tool is a two-part questionnaire requiring collaboration between the person with the intellectual disability, their supporter and their GP. On completion, a health action plan should be agreed.

*Focus purchases CHAP licences so that people supported are able to undergo the comprehensive health assessment. The resulting health action plan is taken into account in the way supports are provided.*

To ensure the wellbeing of the people supported is a primary goal of, organisations should not simply ask if they are happy with their supports. Organisations should collect, compile and analyse information to gauge people’s satisfaction with the supports they receive. This will help to assist people with disability to exercise choice and control over their lives, as expected by the NDIS.

One way organisations can assess the personal wellbeing of a person is set out in the Personal Wellbeing Index (PWI)–Intellectual Disability, designed for use with people who have an intellectual disability or other form of cognitive impairment. It has eight items in the adult PWI scale, each one corresponding to a quality of life domain:

- standard of living
- health, life achievement
- personal relationships
- personal safety
- community-connectedness
- future security and
- spirituality-religion

*Focus has conducted satisfaction surveys with the people it supports. It will also develop a more detailed process to better gauge the wellbeing of individuals.*

22 [https://www.som.uq.edu.au/media/217592/CHAP%202010%20brochure.pdf](https://www.som.uq.edu.au/media/217592/CHAP%202010%20brochure.pdf)
Housing for People with Disability
There is a housing crisis looming in Australia for people with disability. Right now there are massive waiting lists for social housing provided by governments. Over 6000 young people with disability (those under 65 years) are inappropriately in aged care. A growing number of aged parents despair about what will happen to their sons and daughters with disability when they pass away or can no longer support them.

The NDIS vision is for people with disability to be active participants in their community and that starts with not being segregated in specialised locations. But, it is next to impossible for anyone with disability to find affordable, accessible housing. It is anticipated that, by 2020, there will be 127,000 NDIS participants without affordable housing. A plan for the housing needs of people with disability is needed now so they can be accommodated once the NDIS rolls out across Australia.\(^\text{24}\)

Because NDIS funds will not be sufficient to meet the housing needs of all participants, the National Disability Insurance Agency (the Agency that administers the NDIS) is seeking long-term collaboration and partnerships with governments, the housing sector, families, disability service providers, churches, social finance and philanthropy. In particular, the Agency is looking to play a catalytic role, looking for scalable and innovative models in which it can co-invest to unlock new housing options for NDIS participants.

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