Choice and control

Strengthening human rights, power and inclusion for people with disability

April 2017
About ACTCOSS

ACTCOSS acknowledges Canberra has been built on the land of the Ngunnawal people. We pay respects to their Elders and recognise the strength and resilience of Aboriginal and Torres Strait Islander peoples. We celebrate Aboriginal and Torres Strait Islander cultures and ongoing contribution to the ACT community.

The ACT Council of Social Service Inc. (ACTCOSS) is the peak representative body for not-for-profit community organisations, people living with disadvantage and low-income citizens of the Territory.

ACTCOSS is a member of the nationwide COSS network, made up of each of the state and territory Councils and the national body, the Australian Council of Social Service (ACOSS).

ACTCOSS’ vision is to live in a fair and equitable community that respects and values diversity, human rights and sustainability and promotes justice, equity, reconciliation and social inclusion.

The membership of the Council includes the majority of community based service providers in the social welfare area, a range of community associations and networks, self-help and consumer groups and interested individuals.

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Executive summary

Choice and control for people with disability has its foundations in a human rights framework, in the United Nations Convention on the Rights of Persons with Disability (UNCRPD) and the National Disability Strategy (NDS). In recent years government disability policy has narrowed to a focus on choice and control expressed as a choice of a provider in a specialist disability services market. Not only does this approach risk replicating existing market failures, this greatly limits the expression of choice and control across economic, political and social domains. It risks diverting focus and effort from promoting the choice and control of people with disability in other critical areas including employment, legal systems and political life.

Advocacy and information is key to people being able to exercise choice and control in a market and to tempering market failure in areas where the market is thin. Advocacy and information are not purchasable commodities within the market. Current supply of advocacy cannot meet demand and ongoing funding for independent advocacy is not assured.

We need to review and amend the processes of the National Disability Insurance Agency (NDIA) that are not empowering, and avoid developing areas of market failure in specialist disability services through monopoly behaviours, cartels and supplier driven markets which, because of ongoing power imbalances in a marketised approach to provision, remain unresponsive to consumers.

Focusing primarily on a marketised service delivery system also distracts government, business and the community from addressing significant and entrenched market failure in areas like housing, health, transport, education, communications and the provision of other goods and services for people with disability. In addition to developing an individualised, marketised service system, these areas of market failure warrant concerted effort, interventions and investment to address barriers and provide access points where people living with disability seek broader and deeper engagement in economic, social and political life.
Key concerns

If choice and control continue to be solely assessed and progressed in a market framework, people with disability will have limits on their power. They will be constrained as consumers with uneven power because of market failure, rather than liberated to enjoy their full rights as citizens across economic, social and political domains. The risks to individuals of continuing to limit choice and control is well documented.

*Shut out: The Experience of People with Disabilities and their Families in Australia*, the 2009 NDS consultation report, documented many impacts of having limited choice and control. These included:

- concern over the practice of relinquishing children with disabilities to state care as a last resort to ensure access to services
- the over-representation of people with disabilities in the criminal justice system, and the specific needs of people with disabilities to enable full participation in the legal system
- abuse of children with disabilities in institutional settings including respite services
- lack of access to voting facilities to protect the right to a secret ballot
- gender-based discrimination and violence against women with disabilities

Advocacy for Inclusion conducted research on the experience of control and choice for people with disability in the ACT. Below is the experience of one of the participants in the research:

They started running my life from the outside in and not from my point of view. It was the total opposite … people should ask me ‘what would you like to have done today?’ and the absence of that question is like a saw in your heart because it is not healthy, not happy, you’re sort of regimented. And you never invited that regimentation it’s just put upon you.

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2 Advocacy for Inclusion, *Ask me. I make my own decisions: Report on the findings of a study into the experience of control and choice of people with disabilities in the ACT*, 2013, p.22.
Implementing choice and control within a human rights framework

Meagher and Goodwin describe choice and control within a human rights framework:

It’s concept of the individual is a person with rights to autonomy and participation in their personal, social and political worlds, and choice is one means through which each person can enact self-determination. The perspective within this frame is person centred: choice is a means of expressing and maintaining identity, dignity and autonomy.

Self-determination or control over one’s own life is the goal, and choice enables this.

Choice in a human rights framework leads to self-determination and control over all aspects of one’s life, not only in the purchasing of services. It encompasses the variety of outcomes described in the United Nations Convention on the Rights of Persons with Disabilities and National Disability Strategy.

Advocacy for Inclusion includes a broad range of recommendations related to implementing different dimensions of control and choice, in its report Ask me. I make my own decisions: Report on the findings of a study into the experience of control and choice of people with disabilities in the ACT. These include:

- Control and choice over day-to-day decisions. For example, ‘Easy English human rights resources should be made widely available to people with disabilities to inform and remind them of their human rights’. This should include accessible formats like braille.
- Control and choice over big decisions. For example, ‘explore “risk enablement” as an alternative to traditional risk management approaches in order to maximise the quality of life, wellbeing and control and choice of people with disabilities.’ Also, replace substitute decision making with supported decision making.
- Skills in control and choice. For example, ‘make decision making tools widely available to people with disabilities to guide and remind them about decision making processes’ and ‘make human rights resources and training widely available in appropriate formats for people with disabilities’.

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4 Advocacy for Inclusion, op. cit., p.6.
5 ibid., p.7.
6 ibid., p.7.
• Supporting control and choice. For example, ‘supporting self-advocacy courses for support people to learn how to support people with disabilities to self-advocate and exercise control and choice’\(^7\)

• Choice and control over supports. For example, ‘human rights training and resources should be made widely available to disability organisations and support workers, since human rights are fundamental underpinnings of the NDIS’\(^8\)

• Being assertive, negotiating, making complaints. For example, ‘services and resources that support people with disabilities to make complaints and negotiate with their service providers must be made widely available to them’, including ‘access to independent advocacy services’\(^9\)

Limiting choice and control to a choice of provider in a market, prevents people with disability having the full spectrum of real and meaningful choice in their lives, and therefore their ability to have control over their own life. Choice and control in a human rights framework would facilitate people with disability enjoying full citizenship, with equal rights to exercise choice and control over: their legal rights; economic security and financial affairs; health and wellbeing; supports; where and with whom they live; political and public life; personal mobility; and, communication and expressing themselves.

Committing to assess and progress choice and control within a human rights framework views people with disability as full citizens with equal rights, rather than only as consumers of disability goods and services. This shift would address the risks raised in this paper, contribute greatly to meaningful and ongoing inclusion of people with disability, and strengthen the economic, social and political life of Australia.

\(^7\) ibid., p.8.
\(^8\) ibid., p.6.
\(^9\) ibid., p.8.
Recommendations

1. Review and amend the NDIS Legislation, all NDIA operations, policies and processes so they enhance rather than reduce choice and control for people with disability

2. Bolster the ACT’s commitment to implement the NDS, ‘Involve’, with tangible commitments under the National Disability Strategy, including measures on disability access, housing, jobs, information access, rights protection, civic participation opportunities and leadership development programs

3. Implement a whole of government architecture for the development and implementation of disability policy in the ACT post 2017 with sufficient leverage, resourcing and line of sight to central agency directorates to deliver whole of government outcomes across the 6 thematic areas of the NDS

4. Sufficient resourcing of Information, Linkages and Capacity Building (ILC) to account for areas where markets are thin and unlikely to be fully effective even if they do develop. To prevent market failure, make a significant investment to grow community mainstream inclusion with the changing Local Area Coordination (LAC) role, and to deliver choice and control in a human rights context not just a market context

5. Increase resources to information provision, skills development and advocacy beyond current ILC guidelines so that people with disability can exercise power, informed choice and real control in all parts of the market for goods and services and in legal, political and social domains

6. Resource systemic advocacy so that areas of market failure can be monitored and tackled

7. Develop a disability housing reform agenda which specifically includes: access and affordability strategies for people with disability as a priority; components to educate community housing providers, private developers and landlords on disability inclusion and universal design; and, support to incentivise private investment to deliver increased accessible and affordable housing stock.
Discussion

One of the key objectives of the National Disability Insurance Scheme (NDIS), the landmark social policy reform of this generation, is to ‘enable people with disability to exercise choice and control in pursuit of their goals and the planning and delivery of their supports’. However, there is a growing disconnect between this objective of the NDIS and the experience for some individuals in entering and being a participant in the scheme.

This paper aims to demonstrate:

- The escalating failure of the NDIS to enable choice and control through the way it’s operated and its reliance solely on a market framework
- The limits of choice and control within a market approach, which on its own is unable to address or leads to market failures in the areas of housing, employment, education, transport, physical environment, legislation, political and legal rights, health and information
- The broader definition of choice and control within a human rights framework, with its foundations in the UN Convention on the Rights of Persons with Disability and Australia’s National Disability Strategy
- The need to assess and progress choice and control within a human rights framework as a priority, in addition to implementing a marketised framework for disability service provision.

ACTCOSS does not believe disempowering processes and marketisation should be the main focus for facilitating and achieving progress in choice and control. Instead, a human rights framework should drive infrastructure development, policy reform, service system design, implementation and evaluation of progress and outcomes. If human rights do not underpin progress for people with disability exercising choice and control over the services and supports they utilise, we will continue to see market failure in service provision. This will add to the many market failures that already impede people with disability’s exercise of choice and control in every domain of their lives.

A human rights based approach to improving choice and control, as described in the UN Convention on the Rights of Persons with Disability and Australia’s own

National Disability Strategy\textsuperscript{12}, would ensure equal rights for people with disability to:

- Recognition as persons before the law, to enjoy legal capacity on an equal basis, and to support to exercise their legal capacity
- Economic security to enable choice and control over their lives
- Choice and control as fundamental to health and wellbeing
- Choice and control over their own supports
- Control over their own financial affairs
- Choice of where and with who they live
- Participate in political and public life, freely expressing their will
- Choose their own form of personal mobility
- Express themselves through communication of their choice.

Within a human rights framework, people with disability are citizens with equal rights rather than just consumers with unequal power. Choice and control need to be exercised in ways that enable freedom and power, not just participation in a market.

More needs to be done through implementation of the NDIS to ensure people with disability are able to interact as citizens with equal rights and to redress the existing power imbalance which is diminishing genuine choice and control in the market for goods and services, and in access to core infrastructure.

Not only does choice and control need to be assessed and progressed within a human rights framework, there needs to be:

- A thorough analysis, review and amendment of all NDIS policies and processes to ensure they improve rather than impede choice and control
- Stronger leadership and resources to implement the National Disability Strategy, beyond implementation of the NDIS, to expand the freedom and power people with disability can exercise over their lives.

Reality check: How is choice and control for people with disability being experienced now?

Disempowering processes reduce choice and control within the NDIS

There are mixed experiences of choice and control within the NDIS. Some people are experiencing greater levels of choice and control, while others are exercising the same or less. The National Disability Insurance Agency’s ability to fulfil the purpose of the NDIS is fast losing credibility, through its disempowering processes that restrict rather than enhance people with disability’s exercise of choice and control over their supports. Examples include:

- Limiting person centred planning with the advent of the ‘my first plan’ stage, during which planning processes exclude or severely restrict the development of an individual’s vision and goals for their life, frequently reducing the process to only a half hour conversation on the phone and keeping service levels as they’ve always been for the first year
- Rationing and reduction of services following the formal review of an annual NDIS plan
- Information about the participant, through the development of their plan, being primarily controlled by the agency, with no opportunity for the participant to be consulted about the plan before it is finalised to ensure it properly reflects their goals and needs
- Information being inaccessible and compromising choice and control including because of confusing formats of plans, material not being written in plain English, inability to access plans because of technology decisions taken by the NDIA, unreliably of access to the participant portal and inability to exercise control over the information held about them

The unrealistic planning timeframes have caused many of these poor processes. These include the NDIA being required to complete as many new plans in the first six months since the official launch of the scheme, as in the entire three year trial phase. These pressures will only increase, with the NDIA needing to approve 850 plans per day and review 1100 plans per day in 2018-19, and review 2000 plans per day in 2019-20.  

Bruce Bonyhady, previous chair of the NDIA board, describes these pressures leading to plan quality issues and that, ‘Consideration should be given to

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including quality as well as quantity measures in the monitoring of bilateral targets.\textsuperscript{14} He also states:

Many plans have been extended and plan reviews have been deferred and Local Area Coordinators have not been able to engage in essential work on community inclusion. This is not sustainable and so administrative cost targets should be reviewed periodically, based on the emerging evidence during the transition period.\textsuperscript{15}

The prioritising of quantitative over qualitative outcomes in the administration of the NDIS will need to change if it is to realise its objectives regarding improved choice and control.

The NDIS independent evaluation \textit{Intermediate Report} of September 2016 included findings that since becoming NDIS participants, one third of participants are exercising the same choice and control and 15\% are exercising less choice and control.\textsuperscript{16} Those who are exercising less choice and control over their supports since becoming NDIS participants include people:

- with psychosocial disability
- with vulnerable families
- unable to navigate what services are available
- less able to articulate their support needs
- living in non-metropolitan areas, with fewer services.\textsuperscript{17}

It also found that those whose exercise of choice and control had decreased, are more likely to experience a decrease, than an increase, in the number of supports they’ve received.\textsuperscript{18} Lastly, it finds that choice and control is restricted because of the limitations in the number or capacity of services.\textsuperscript{19}

There needs to be a review of the NDIS Legislation and all NDIA operations, and amendments to policies and processes in response to the findings of this review, to ensure the outcome of the key NDIS objective to ‘enable people with disability

\begin{footnotesize}
\begin{itemize}
\item \textsuperscript{14} ibid., p.4.
\item \textsuperscript{15} ibid., p.6.
\item \textsuperscript{17} ibid.
\item \textsuperscript{18} ibid.
\item \textsuperscript{19} ibid.
\end{itemize}
\end{footnotesize}
to exercise choice and control in pursuit of their goals and the planning and delivery of their supports\textsuperscript{20}, is effectively implemented.

**Implementation of Information, Linkages and Capacity Building program indicates the inclusion goal is unlikely to be achieved**

The purpose of the NDIS Information, Linkages and Capacity Building program is to enable greater access to the social and economic life of the community for people with disability, their families and carers.\textsuperscript{21} It is therefore a key component to build on areas of policy action under the NDS.\textsuperscript{22}

ILC is a core foundation of the NDIS. The ILC policy framework states:

> ILC is a key component of the NDIS insurance model and will contribute to the sustainability of the NDIS by building the capacity of the community, people with disability, their families and carers which in turn will reduce the need for funding of supports for people with disability through Individualised Funding Packages.\textsuperscript{23}

The ILC will contribute to the long term sustainability of the NDIS by supporting people to access and encouraging the provision of more inclusive mainstream services, a more accessible market and more accessible infrastructure.\textsuperscript{24} ILC will need to support potentially nearly 500,000 people with disability who need assistance with activities of daily living at least weekly, but won’t be eligible as NDIS participants.\textsuperscript{25} This will only occur if they are supported into a more inclusive mainstream system, to prevent their needs increasing and leading to a requirement for individual plans.\textsuperscript{26}

The ILC is trying to achieve this with insufficient funding. The majority of ILC funding is going to Local Area Coordination ($550m compared to $132m for the rest of ILC). The NDIA previously stated that LACs are the largest single investment by the NDIA in delivering ILC outcomes. The LAC’s role is to:

\hspace{1cm}


\textsuperscript{22} ibid., p.5.

\textsuperscript{23} ibid., p.2.


\textsuperscript{26} R Naufal, op. cit.
• Link people with disability to the NDIS, providing assistance with the NIDS Planning process and planning implementation

• Link people with disability to information and support in the community, connecting to and building informal/natural supports

• Work with the local community to make sure it is more welcoming and inclusive.27

The LAC role has further evolved to now undertake planning, including reviews, for 70% of NDIS participants. Processing such a large number of individuals for planning will mean the community inclusion aspects of LACs are highly unlikely to occur. This was demonstrated during the ACT Trial, where planning and LAC was combined, with only planning occurring and not the other LAC roles.

With the majority of ILC funding going to LAC, and planning being the main channel through which LACs deliver ILC outcomes, inclusion objectives are both deprioritised and under-resourced.

Other ILC funded services could partially fill this gap, however, funding guidelines exclude other ILC services duplicating the role of LAC.28 Therefore, growing community and mainstream inclusion, on which the NDIS sustainability relies, will effectively not occur.

ILC funding is also almost exclusively being framed as project funding which means there are challenges in driving organisation and operational reform, building continuity and sustainability of programs and growing capacity over time.

As Bruce Bonyhady, former chair of the NDIA board says, though, ‘Currently only $132 million (excluding LAC support) has been has been allocated to the ILC. This is not sufficient and means that one of the key foundations on which the NDIS is being built is weak.’29

If the ILC does not enable greater access for people with disability to the social and economic life of the community, the opportunity to grow people with disability’s exercise of choice and control in these domains is compromised and the sustainability of the NDIS put at risk.

28 R Naufal, op. cit.
29 B Bonyhady, op. cit., p.6.
Limits of choice and control within a market framework

Despite the UNCRPD and NDS forming the policy foundation for the development of the NDIS, the Productivity Commission’s *Disability Care and Support Report 2011* and the *National Disability Insurance Scheme Act 2013* (Cwth) (NDIS Act) focused on choice of provider in a specialist disability services market as the primary mechanism through which improved choice and control for people with disability would be achieved.

The 2011 *Disability Care and Support Report* described the disability support system as underfunded, unfair, fragmented and inefficient. It said people with disability were offered little choice and no certainty of access to appropriate supports.\(^{30}\) In response to this, it had its focus on enabling choice and control through recommending self-directed packages of support, with choice of provider.

Meagher and Goodwin in their book *Markets, Rights and Power in Australian Social Policy* describe increasing choice as a common justification for marketisation in Australian social policy:

> Choice has clearly become a very powerful concept in policy discourse. In almost all areas of Australian social policy increasing choice for people using services has become an important justification for marketisation.\(^ {31}\)

> In practice, choice of provider has been the typical offering, on the assumption that individuals will find a provider that suits them from the more diverse array that market reforms are assumed to present to them.\(^ {32}\)

With a huge historical deficit in the supply of support services for people with disability, choice and control was severely limited. The price levels offered to service providers in NDIS managed individualised packages, have not so far encouraged a significant widening of choice of product or provider in the service market.

The quality of choice is also not growing substantially so far. Quality can be undermined within a market framework, according to Meagher and Goodwin:

> There is not much concern within this frame for the contents of choices. The perspective is system-wide: the sum of individual choices drives competition in markets, leading to increased efficiency and quality.

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\(^{31}\) G Meagher & S Goodwin, op. cit., p.18.

\(^{32}\) ibid., p.19.
...Because this frame has a rather empty concept of choice, it does not necessarily align with policies seeking to give people choices over things that mean something to them.\textsuperscript{33}

It is choice within the market being determined by assessing a sum of individual choices, rather than an expansion in individual choices available over things that matter to that individual, that is constraining the effectiveness of the NDIS in delivering genuine improved choice and control. This approach to measuring and assessing growth in choice means there is potential for disability services to become more marketised but to not deliver genuine improvements in choice and control.

Combined with the wider market failure (in provision of affordable, accessible, desirable goods, services and infrastructure) experienced by people with disability, there is a real risk that the marketisation approach adopted by the NDIS will compromise rather than contribute to achievement of the choice and control objectives of the National Disability Strategy.

\textbf{Market failure that limits the progression of choice and control across all outcomes of the NDS}

Beyond specialist disability services, there are areas of clear and identified market failure for people with a disability, preventing progress across all outcomes of the National Disability Strategy, and compromising the ability of people with disability to exercise their human rights.

For instance, the housing market has failed to act adequately under voluntary compliance guidelines to meet the liveable housing standards; access to communications remains patchy and there is limited compliance with the Disability Discrimination Act Standards Framework in the private sector, non-government sector or by governments themselves.

Market failure is twinned with a lack of economic power.

People with disability have relatively low incomes, whether they are receiving income support or paid work. People with disability in Australia experience some of the lowest levels of economic empowerment in the OECD.\textsuperscript{34} The lack of economic empowerment means that people with a disability wield limited economic power in the marketplace to drive what goods, services or infrastructure the market provides. While an NDIS package has the potential to

\textsuperscript{33} ibid., p.19.

increase economic power in the disability supports marketplace, this increase in power cannot realise improved choice and control without also addressing the other barriers to consumer power that are experienced by people with low incomes, such as low consumer skills, low knowledge of consumer rights, or low consumer confidence.

Examples of market failure across all of the outcomes of the NDS are described below.

**NDS Outcome 1: Inclusive and Accessible Communities**

There is demonstrated market failure in provision of goods, services and infrastructure to meet this NDS outcome.

People with disability have flat housing careers that demonstrate lack of choice and control over where and with whom they live:

> The housing careers of households affected by disability are flatter, more focused on the public rental sector, affected by health and disability concerns to a considerable degree, and less likely to be driven by consumption aspirations when compared with the broader population.35

Access to civic infrastructure is also limited. For example, the ACT will not meet the *Disability Discrimination Act 1992* (Cwth) transport standards for buses until 2022.

Conforming to the international standard on website accessibility, Web Content Accessibility Guidelines (WCAG) 2.0 level AA by government and non-government websites, is now mandatory, however, it continues to be poor. The *Web Accessibility National Transition Strategy (NTS) 2012 Progress report*:

> arguably paints an underwhelming portrait of non-compliance. For example, the report shows that at the NTS’s half-way point, compliance with any level of WCAG 2.0 conformance had grown from 5 per cent in 2010 to just to 26 per cent in 2012. As at 2012, some 46 per cent of government websites were reported as non-conforming.36

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The most popular social media tools are not compliant with the WCAG 2.0 standard,\textsuperscript{37} for instance, Facebook is largely inaccessible to blind people.

The built environment does not cater well to people with disability – there is evidence that the construction sector is not responding of its own accord and there has only been very recent work to incorporate the Australian Standards into the Building Code (the equivalent work in the United States began under the Nixon administration in the late 1960s).\textsuperscript{38} \textsuperscript{39}

People with disability face inaccessible communities, services and facilities on a daily basis:

\begin{itemize}
  \item Footpaths are poorly designed
  \item Essential services such as doctors and dentists are located within inaccessible premises
  \item Many public transport networks remain inaccessible
  \item Accessible toilets are often not available in public venues
  \item Information on public services is often inadequate, unreliable, and not provided in accessible and alternate format
  \item There is no text based option to communicate with 000 emergency services
  \item Captioning quotas on both free-to-air and subscription television continue to restrict access to news, information and entertainment for those who rely on captions
  \item There is no audio description provided at all on television in Australia
  \item Information resources are often only available on websites, with many people with disability not having access to the internet due to the nature of their disability or other aspects of social and economic disadvantage.
\end{itemize}

\textbf{NDS Outcome 2: Rights Protection, Justice and Legislation}

The legal capacity of people with disability is often diminished before the law across many legal domains. Inability to access effective justice compounds disadvantages experienced by people with disabilities. ‘People with disability are over-represented in the civil, criminal justice and prison systems as


\textsuperscript{39} National People with Disabilities, op. cit., p.42.
complainants, litigants, defendants and victims. The Human Rights Commission found that:

Access to justice in the criminal justice system for people with disabilities who need communication supports or who have complex and multiple support needs (people with disabilities) is a significant problem in every jurisdiction in Australia. Whether a person with disability is the victim of a crime, accused of a crime or a witness, they are at increased risk of being disrespected and disbelieved and of not enjoying equality before the law.

People with disability experience low incomes and therefore lack capacity to pursue rights as civil litigants. Even the Disability Discrimination Act system is weighted against people with disability – for example, since King v Jetstar, people who pursue claims through the legal system risk having costs awarded against them.

The right to supported decision making is key to choice and control. The National Disability Strategy recognises as areas for future action the need to ‘review restrictive legislation and practices from a human rights perspective’ and ‘ensure supported decision-making safeguards for those people who need them are in place, including accountability of guardianship and substitute decision makers.’

Equal recognition before the law for people with disability is a core element of choice and control. The Australian Law Reform Commission 2014 Review of equal recognition before the law and legal capacity for people with disability recommended that the:

Reform of Commonwealth, state and territory laws and legal frameworks concerning individual decision-making should be guided by the National Decision-Making Principles and Guidelines … to ensure that:

• supported decision-making is encouraged;
• representative decision-makers are appointed only as a last resort; and
• the will, preferences and rights of persons direct decisions that affect their lives.

In the ACT, ADACAS’ Supported Decision Making Project found that for people experiencing psychosocial and intellectual disability:

each person’s access to and experience of decision making had less to do with their functional capacity and more to do with the values and attitudes of those with whom they interact. There is a positive correlation between recognition of a person’s right to decide and their engagement in decision making.\textsuperscript{44}

More widespread legislative review across Australia needs to occur, with the \textit{ACT Mental Health Act 2015} (ACT) a good example of this. It’s in line with national and international trends in making decision making capacity, rather than risk of harm to self or others, the defining threshold for substitute decision making and involuntary treatment.\textsuperscript{45}

**NDS Outcome 3: Economic Security**

People with disability lack wealth and economic security that would enable them to be purchasers in the marketplace (outside of specialist disability supports). The most recent OECD ranking placed Australia 21st out of 29 OECD countries for employment participation by people with disability.\textsuperscript{46}

In 2012, the Australia Bureau of Statistics reported that labour force participation for people with disability has not changed since 2012, staying at around 53%; this has changed very little in the last 20 years.\textsuperscript{47} Also, in 2012 Australians with disability are still more likely to be unemployed than their peers without disability (9.1% compared to 4.9% of 15-64 year olds).\textsuperscript{48} There were also differences in labour force participation between working-age men and women among those with disability, with women (49.0%) less likely to participate than men (56.6%).\textsuperscript{49}

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\textsuperscript{45} Further information is provided in Appendix 2.


\textsuperscript{48} ibid.

Employment of people with disability in the Australian Public Service has not improved, but continued to decline, from 4.3% in 2001 to 3.5% in 2015.50

The 2016 *Willing to Work* inquiry report from the Australian Human Rights Commission recognised numerous systemic barriers to employment for people with disability, including: lack of practical assistance for employers to support employment of people with disability; negative employer and community attitudes; poor transition to work initiatives for school leavers; negative outcomes from disability employment services which fail to respond to individual needs or deliver long term job retention; segregation of people with disability in ‘sheltered workshops’ (Australian Disability Enterprises); and financial disincentives of entering the workforce such as prohibitive accessible transport costs.51

**NDS Outcome 4: Personal and Community Support**

There is a role for introducing a market into the specialist disability service space where people with disability have until now wielded virtually no market power. However, we should be aware of and guard against systemic issues which have created failure in other markets – there must be a rights-based underpinning, a market umpire and boundaries on uncompetitive behaviour to protect corralling people in spaces and places where they are unable to exercise choice and control. We must also guard against market concentration leading to imbalances in market power (e.g. supermarkets) and constrained choice (e.g. energy retailers).

Not all specialist services can operate within a market framework:

- Some services are boutique and the market will never provide a large enough incentive to offer them (e.g. very specialised one-off pieces of equipment, bespoke services sought by a small number of people, or therapeutic interventions for people with rare diagnostic disabilities)

- Some services involve an irregular supply and demand which make a business model difficult to build and sustain, including peer support groups.

The Government has expected that these issues will be addressed through the ILC. We have outlined the limitations of the ILC earlier in this paper. ACTCOSS does not believe the issues raised above can be addressed through the ILC as currently configured.


NDS Outcomes 5: Learning and Skills

The mainstream school system is unable to offer an adequate response to the aspirations of students and families for choice and control. Many people with disability are in segregated schools, in which and education outcomes for students with disability are lower generally.52 53 ‘There is clear and consistent evidence that inclusive educational settings can confer substantial short- and long-term benefits for students with and without disabilities.’54 Currently, all schools receive inadequate funding and resources to meet the needs of students with disability. This undermines the ability of schools to implement measures that would underpin inclusion, including: modifying curricula to meet the particular needs of different students; increasing the staff to student ratio; and providing adaptive equipment and technology, accessible transport, universally designed environments and accessible social and extra-curricular activities.

Students with disability are also experiencing disturbing rates of bullying, restraint and seclusion. There are a number of incidents being reported of children with disability being placed in ‘withdrawal spaces’, which effectively amount to seclusion in spaces that are not human rights compliant.55 The ACT is responding to significant issues in this area via the Schools for All initiatives and in revising the School Resource Allocation formulae.

NDS Outcome 6: Health and Wellbeing

People with disability have more limited access to mainstream health services, a comparatively poor health status, and poorer health outcomes, including aspects of health unrelated to their specific disability.56 As the AIHW explains, ‘people with disability are a highly diverse group with significant variations in the extent and nature of their impairments and functional limitations and their health status.’57 Although disability is defined in the context of health, this does not necessarily mean that the person with disability is in poor health.

54 Dr T Hehir & Dr T Grindal, A Summary of the Evidence on Inclusive Education, Alana, 2016, p.2.
In addition to the disability, people with disability have the full range of medical conditions affecting people without disability and require access to the full range of health services. People on low incomes lack access to private insurance. Allied health programs are often inaccessible – from dental care to mammograms to online quit smoking programs. People with disability lack economic power and market access at the most basic levels – even most doctor’s examination tables aren’t height adjustable.

Choice and control within a human rights framework

Choice and control in the UN Convention on the Rights of Persons with Disabilities (UNCRPD)\(^{58}\)

There are a range of references to choice and control in the UNCRPD, including its first principle, ‘Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices and independence of persons.’

Relevant articles include the equal rights of people with disability to:

- ‘Recognition everywhere as persons before the law’, to ‘enjoy legal capacity on an equal basis with others in all aspects of life’, and to ‘support they may require in exercising their legal capacity.’\(^{59}\) Signatories to the UNCRPD are obliged to abolish substitute decision-making regimes and develop supported decision-making alternatives\(^{60}\)

- ‘control their own financial affairs’\(^{61}\)

- ‘live in the community, with choices equal to others’, including where and with whom they live, access to supports, and access to mainstream services and facilities\(^{62}\)

- choose the manner and time of their personal mobility\(^{63}\)

- freedom of expression and opinion, through the communication of their choice\(^{64}\)

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62 ibid., Article 19, p.15.
63 ibid., Article 20, p.15.
‘fully participate in political and public life’, guaranteeing the free expression of their will.65

Australia formally recognised the rights of people with disability by ratifying the UNCRPD in 2008. The six policy areas of the National Disability Strategy, described below, are aligned to the articles of the UNCRPD.

Choice and control in the National Disability Strategy

Following its commitment to the UNCRPD, Australia published the National Disability Strategy in 2011, based on the UNCRPD. Its vision is for an inclusive Australian society that enables people with disability to fulfil their potential as equal citizens.66

There are three explicit references to the phrase ‘choice and control’ in the National Disability Strategy:

- **Outcome 3: Economic Security**
  ‘People with disability, their families and carers have economic security, enabling them to plan for the future and exercise choice and control [emphasis added] over their lives’ 67

- **Outcome 4: Area for Future Action**
  ‘Adopt sustainable funding models and service approaches that give information, choice and control [emphasis added] to people with disability and that are flexible, innovative and effective’ 68

- **Outcome 6: Health and Wellbeing**
  ‘People with disability attain highest possible health and wellbeing outcomes throughout their lives.
  ‘Policy Direction 4- Factors fundamental to wellbeing and health status such as choice and control [emphasis added], social participation and relationships, to be supported in government policy and program design’69

However, there are many other terms that are related to choice and control that are referred to throughout policy documents like the NDS and the UNCRPD that will not be enhanced solely through establishment of marketised arrangements for accessing services.

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64 ibid., Article 21, p.15.
65 ibid., Article 29, p.21.
67 ibid., p.42.
68 ibid., p.52.
69 ibid., p.62.
Outcome 1 Inclusive and Accessible Communities:

People with disability live in accessible and well designed communities with opportunity for full inclusion in social, economic, sporting and cultural life

This requires prioritising investment in accessibility of the built and natural environment, housing, transport and communication and information systems.  

Outcome 2: Rights Protection, Justice and Legislation

People with disability have their rights promoted, upheld and protected

This requires prioritising investment in accessibility of polling places and courtrooms and the right to parent children based on capacity to parent rather than presence of disability.  

Outcome 3: Economic Security

People with disability, their families and carers have economic security, enabling them to plan for the future and exercise choice and control over their lives

Work is the pathway used by most Australians to long-term economic security and wellbeing…Barriers have to be identified and addressed, so that people with disability have opportunities for more control over their lives. 

Employment and the economic security it brings is therefore vital in bringing people with disability self-determination and control over their lives.

‘A secure and affordable place to live is the basis of economic and social participation in the community.’ The right to choose where and with whom they live, also greatly impacts people with disability’s control over their own lives.

Outcome 4: Personal and Community Support

People with disability, their families and carers have access to a range of supports to assist them to live independently and actively engage in their communities

Policy Direction 1 recommends development of a ‘sustainable disability support system which is person-centred and self-directed, maximising opportunities for independence and participation…’ The NDS acknowledged support for more individualised and self-managed funding approaches with a full range of choices within the service system. It referred to evidence showing individual budgets

70 ibid., pp.29-35.
71 ibid., pp.36-41.
72 ibid., pp.42-43.
73 ibid., p.44.
74 ibid., p.48.
75 ibid., p.48.
deliver their primary purpose of giving people more power and control over their own support. This has been the main approach government has taken to implement choice and control. However, this approach does not address gaps in the accessibility, supply or competence of providing disability accessible universal services.

**Outcomes 5: Learning and Skills**

*People with disability achieve their full potential through their participation in an inclusive high quality education system that is responsive to their needs. People with disability have opportunities to continue learning throughout their lives*

Higher education/skill levels lead to higher economic security and participation, which increases ability to exercise choice and control. The UNCRPD article 24 on education states the right for people with disability to access lifelong learning without discrimination and on an equal basis with others. For example, there is a need for ongoing access to capacity building supports through the NDIS to enable lifelong learning, and not decrease over time, which is the current assumption of the NDIA.

**Outcome 6: Health and Wellbeing**

*People with disability attain highest possible health and wellbeing outcomes throughout their lives*

‘The level of control an individual has over his or her own life can make a big difference to the quality of their life and to their health and wellbeing.’ Whether and how people with disability are supported to access mainstream health systems without additional support and adaption is a critical gap in the current investment in service system design and implementation. Current health services do not provide reliable access and only a human rights framework can resolve this current market failure.

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76 ibid., pp.47-52.
77 ibid., pp.53-58.
78 ibid., pp.59-64.
## Appendix 1: Choice and control in the policy and legislative agenda

<table>
<thead>
<tr>
<th>Source</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>UNITED NATIONS CONVENTION ON RIGHTS OF PEOPLE WITH DISABILITY</td>
<td>United Nations 2006&lt;br&gt;This has broad focus on a range of rights to provide greater choice and control.</td>
</tr>
<tr>
<td>NATIONAL DISABILITY STRATEGY</td>
<td>Commonwealth Government 2011&lt;br&gt;This is based on the UNCRPD and has a broad focus on a range of outcomes.</td>
</tr>
<tr>
<td>DISABILITY CARE AND SUPPORT</td>
<td>Productivity Commission 2011&lt;br&gt;This frames choice and control within a narrow focus of recommending self-directed packages of support.</td>
</tr>
<tr>
<td>NATIONAL DISABILITY INSURANCE SCHEME ACT 2013</td>
<td>This also has a narrow focus to enable people with disability to exercise choice and control in pursuit of their goals and planning and delivery of their supports.</td>
</tr>
</tbody>
</table>
Appendix 2: Mental Health Act 2015

The *Mental Health Act 2015* (ACT) is in line with national and international trends in making decision making capacity, rather than risk of harm to self or others, the defining threshold for substitute decision making and involuntary treatment. The Act also incorporates requirements regarding supported decision making. In this way the Act supports choice and control in healthcare and support for people with a psychosocial disability. In particular the Act stipulates that:

- Decision making capacity is assumed unless otherwise determined\(^\text{79}\) and all practically possible steps must be taken to support people with a mental illness or disorder to make their own decisions about their care, treatment and support\(^\text{80}\)

- Decision making capacity is time and decision specific rather than absolute\(^\text{81}\)

- People have the right to withdraw consent for treatment at any time\(^\text{82}\) and the Act establishes Advance Agreements and Advance Care Directions as instruments allowing a person to state their will and preference and give advance consent to treatments and support, should their capacity be impaired in the future.\(^\text{83}\)

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\(^\text{80}\) ibid.

\(^\text{81}\) ibid., p.9.


\(^\text{83}\) ibid., pp. 22-34.
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