The Canberra Disability Review

People With Disabilities ACT Inc

Original writing and voices on disability for Canberra

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Choice and control...

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Acknowledgement of Country

We acknowledge the traditional custodians of this land, the Ngunnawal people. The PWD ACT offices, where we publish and distribute The Canberra Disability Review, is on the traditional land of these people.

Welcome to this third edition of *The Canberra Disability Review* where we take a fresh and critical look at choice, control and markets in disability services.

It's now seven years since the National Disability and Carers Council released the Shut out Report which cast a critical eye over the many ways that governments, community and the marketplace had failed to step up for people with a disability.

It's also more than five years since the NDIS moved from concept to government intent as a result of the hard efforts of a group of advocates, politicians, public servants, service providers and dedicated people. Its three years since rollout began in the ACT.

It's a good moment to stand back and ask whether the market is really starting to respond and deliver more choice and control for people with a disability or whether we are witnessing an unravelling market failure for people with disability in the specialist service sector similar to the market failure that is occurring in the mainstream world.

In short if people with disability are 1 in 5 Australians and older people are the fastest growing group in the Canberra population then why isn't the community knocking down our doors to provide accessible tourism, transport, infrastructure, housing, allied health services and education. Why can we still wheel down the streets in Weston, Dickson and the courts in Phillip and Belconnen and see entire streets where every shop has a step? Why are there dentists with steps? Why is the Canberra private hospital one of the least accessible places in the entire city? Why are we waiting to 2022 to make all the buses accessible in our city when tourism is the biggest growing area of our economy and the grey nomads are the biggest growing group of tourists? If markets responded rationally, reasonably and automatically to demand, then the invisible hand would have fixed them decades ago.

Maybe then, choice and control needs to be seen in a human rights framework. That's why the Canberra Disability Review is pleased to partner with the ACT Council of Social Service in this edition through the launch of their Choice and Control paper that takes a critical but constructive look at markets in disability services and asks whether they alone can achieve human rights outcomes for people with a disability.

We've therefore taken a different approach in this edition looking at the meaning of choice and control, the claims made for markets and reality checking them with the actual experience of people with disability on the ground. Contents include reviews of the Choice and Control paper, vox pops from consumers, a reality check on the Shut Out report and a cheeky game which invites you to consider how your experience of choice and control maps with the UN Convention on the Rights of Persons with Disability, the National Disability Strategy and the NDIS Act passed in 2013.

None of us are just consumers and see our lives as being an endless set of purchasing problems. We look at these issues inside and outside the NDIS to ask whether we are really getting the choice and control we were promised – whether as purchasers, users, clients, citizens, students, travellers, partners, voters, or simply human beings.

Craig Wallace
Editor

This edition accompanies the release of an important Report: Choice and Control – Strengthening Human Rights, Power and Inclusion for People with Disability by the ACT Council of Social Service.

We invited four reviewers – covering disability rights and advocacy, carer perspectives and the views of people with a psychosocial disability – to provide perspectives on the paper and to ask whether markets really hold the key to delivering choice in human services.

When the market doesn't work

When I read the ACTCOSS Discussion Paper on 'Choice and Control' it spoke to me because it says many of the things that I had been thinking for some time. I needed someone to say it so I knew I was not alone and ACTCOSS has said it, clearly and powerfully. The application of market principles to the relationship between disability service providers and ourselves as people with disabilities is not working.

There is no market equilibrium and no optimum solution. I still don't know which button to push on the market contraption to make it work for me. Also, its just got a whole lot worse. You see the buttons I used to know have gone and there is a flat touch screen in its place, the instructions are in print with pictures. Even if I can safely find my way from the bus stop to the building, I can't find the counter because the large building has no wayfinding system for people like me who are blind.

The Paper reminded me of what I should have remembered from when I studied economics for two years. The NDIS cannot achieve its aims of achieving inclusion in society for people with disabilities by the application of the market principles of supply and demand to the provision of services for people with disabilities and the acquisition of those services by people with disabilities. This is because there is a fundamental disconnect between the operational principles of the classical market and the daily lives of people with disabilities. The ACTCOSS Paper says it better than I can say it in this short opinion piece. The issue which the ACTCOSS Paper deals with very well is that in the markets in which people with disabilities operate there is no equality of bargaining power between buyers and sellers. As people with disabilities we have less money, less knowledge and less buying power than service providers and policy makers. All too often we are not seen as valued customers. The inaccessibility of the physical technological and social environments keeps us in our houses and out of the offices, shops and playing fields. Our invisibility compounds our disempowered situation. In so many instances we are just not thought of as market participants. A recent example is the introduction of EFTPOS terminals called "Alberts" which have touch screens. I am thinking of my friend who told me that because five of the twenty shops in the small town in which he lives has these Albert terminals he cannot do business in 25% of the shops in his town. And yes, there is a sixth Albert coming for him.

Where the NDIS misses the mark in that it treats us as consumers of disability services and only addresses part of our problem. What the NDIS needs to do is treat us as people and as citizens with human rights. The ACTCOSS Paper makes this point wonderfully.

Despite all I have said to date, I remain optimistic about both the NDIS and the future direction of disability services. The solutions to the problems highlighted in the paper are at hand. The tools we need are strong disabled peoples organisations which give their members information, knowledge, peer support and advocacy assistance. Advocacy backed by peer support is what we need.

So as I stand at the door of the big building trying to find the counter with the market contraption with the touch screen and the visual instructions I don't despair. I get with other people with disabilities and advocate for the installation of a wayfinding system to direct me to the counter, for a market contraption with keys or buttons I can feel and instructions in a format I can read. But if that market contraption is an Albert EFTPOS terminal inaccessible to me, I have a DPO to support me and my friends in our advocacy for a market contraption which works.

Robert Altamore, PWD ACT Executive Officer, www.pwdact.org.au

Choice and Control – does a market deliver?

The opportunity to have a greater say, indeed to make decisions about your care that are respected and acted upon, is a core aspiration of people with disability. Indeed, it should be more than an aspiration, it should be a right

that can be taken for granted. We need to think carefully however, about whether a market environment is the mechanism that will ensure access to this right. The ACTCOSS paper 'Choice and Control: Strengthening Citizenship (or Human Rights) Power and Inclusion' identifies a range of concerns with the NDIS and its market.

Economic theory about the power of markets is diverse. But there are some underlying principles that must be met for markets to be effective.

These are:

1. Flow of information about prices and quality is readily available, easy to understand and accessible
2. Consumers and providers both make rational decisions when purchasing and providing services
3. Entry and exit from service is easy
4. There are a large number of providers selling similar services – ie a mature market
5. Actions of individual providers have little or no effect on the market[1]

Reflecting on these principles in the context of the NDIS quickly demonstrates that they are not currently all met in the context of disability service provision. Indeed it may not be possible for them all to be met in the long term either. NDIS information is complex, ever changing, and not readily accessible. As consumers we don't always make rational decisions – particularly when it comes to complex care needs. The NDIS management options, service agreement and online service booking processes do not make entry or exit easy. The ACT market of providers may have grown but it is still thin in many areas (just ask anyone waiting for an OT assessment for assistive technology). In a small market, the actions of large providers certainly impact others in the space and indeed lead to reduced choice for participants.

In addition of course, while prices are set the NDIS environment will never be able to act as a true market. Clearly, this is an imperfect market and the theoretical benefits of markets may not flow to participants. What then needs to be done? What safeguards can be put in place, not only to protect participants, but also to protect their right to exercise choice and control in an imperfect market? In addition it is imperative that we keep working with the NDIS, the government and others to identify and address policy, process and systems that act as disincentives or barriers to an effective market that benefits participants' choice and control. The ACTCOSS paper recommendations are a good place to start.

1 From Justin Symion, Fallacies of the free market

As advocates, ADACAS has extensive experience working with NDIS participants to resolve issues with their access, plan, plan implementation and providers. We are very conscious of the many ways in which some people are denied choice and control both in the NDIS processes, and in the market for services. Advocacy has been effective in supporting participants to exercise these rights, however funding for advocacy itself is uncertain. A crucial safeguard in a market environment is support for consumers in that market to be empowered, informed, and active decision makers. For many, independent advocacy is the key to that empowerment.

Fiona May, Chief Executive Officer, ADACAS, www.adacas.org.au

Captured by a political narrative?

Choice and Control are very important concepts to explore in the context of disability and ACTCOSS must be commended for a very worthwhile effort to lift the conversation out of the current political discourse and bring it back to core principles and understandings. As ACTCOSS points out, Choice and Control should be seen as elements of a Human Rights framework stemming in particular from the UN Convention on the Rights of Persons with Disability (UNCRPD) and borne out in an Australian context in the National Disability Strategy (NDS).

The reality is that in Australia the concepts of Choice and Control have been captured by a political narrative that positions competition, marketization and choice of provider as the answer to all ills. This is a narrative which is rightly skewered by ACTCOSS in this report. There is no question that a bit of competition is largely a good thing for customers, nor that meaningful choice of provider is something people with disability have long wanted, nor indeed that many people with disability have suffered because of the lack of choice in the past. The bone of contention is whether marketization is the best or even a good way to achieve choice and control.

ACTOSS' critique of marketization focuses on disability and the NDIS. It could have been extended to Human Services more broadly. Provision of Human Services really doesn't lend itself well to a market framework based around competition on cost. Vulnerable people are primarily concerned with finding a service which is person-centred, values-driven, safe and accessible. Creating a 'market' of services based around competition on quality would be meaningful to many people, while the notion of lowest cost is simply too far from their experience of the service system to hold much meaning.

It also needs to be pointed out that the NDIS 'market' lacks almost every characteristic of a market. Among other issues, prices are set centrally, which means there is no opportunity for the mechanism of supply and demand to help shape the balance between quality and price. The value of Choice is very much diminished if you only have the choice between a series of 'home brand' products, none of which may actually suit your particular needs or preferences. ACTCOSS note the importance of supported decision making and empowering all people with disability to be active and informed consumers in the market. However, even the most empowered consumer can't choose a product that doesn't exist. As it is, ACTCOSS demonstrates that the 'market' is failing to deliver across all outcomes of the NDS.

The reality is that in the context of Choice and Control in disability and other human services, a market approach simply isn't the panacea it is made out to be by our politicians. ACTCOSS make a

very important contribution to the debate by pointing out that the marketization focus delivers a very narrow version of Choice and Control and only by viewing those concepts within a Human Rights framework can we hope to make genuine Choice and Control possible for people with disability.

Simon Viereck, Executive Officer, Mental Health Community Coalition ACT
www.mhccact.org.au

Choice and Control – a caring perspective

One of the major changes in the national reform agenda on age and disability community care services is the choice and control model that aims to provide increased and more meaningful engagement in economic, social and political life for older people and people with disability, carers and families. The Choice and Control: Strengthening Human Rights, Power and Inclusion for People with Disability paper provides a comprehensive overview and discussion about the genesis of 'choice and control' and delivery of disability services through a market environment versus a human rights environment. It recommends a combination of both to better effect choice and control outcomes.

The 'choice and control' risks and limitations associated with delivery of the National Disability Insurance Scheme (NDIS) in a market environment are evident. Many organisations and individuals have proposed solutions to rectify the challenges people with disability, service providers, and carers and families encounter through their respective engagement with the NDIS, but there is a time factor associated with their implementation and benefits are still to be determined. Community sector concerns about the capacity of the soon-to-be rolled out Information, Linkages and Capacity Building (ILC) Framework to meet its improved choice and control objectives are also evident. A key question is: Will its allocated funding be sufficient to meet the framework's objectives to improve choice and control for NDIS participants, people with disability who are outside the NDIS and carers and families in the framework's, primarily, project based environment?

The paper also identifies that choice and control for people with disability has its foundations in a human rights framework, in the UN Convention on the Rights of Persons with Disability and the National Disability Strategy. Carers ACT's premise is that to truly realise choice and control for people with disability (or those who are aged) is the need for them to be informed and enabled to use this power supported by legislated rights and recognition.

In the context of the paper, it's important to identify that for many people with disability their lives are intrinsically linked to the rights and recognition of unpaid family or friend carers who underpin disability care in the community. It's also important to acknowledge that many people with disability live independently in the community with formal support, and the aims of the NDIS are to increase their rights and capacity to do so.

While most carers identify that their caring is rewarding, many also experience similar reduced opportunities for employment and education, and social and financial disadvantage as people with disability. We know that many carers also have a disability, and some carers are supporting multiple people with disability and this can increase these disadvantages.

The paper considers choice and control across outcomes included in the National Disability Strategy, and carers and families are identified in some – NDS Outcome 3: Economic Security, and NDS Outcome 4: Personal and Community Support. But, too often, carers and caring families are not recognised as a recipient of these outcomes.

The Carer Recognition Act 2010 (Clth) aims to increase national recognition and awareness of the role carers play in providing daily care and support to people with disability, a chronic condition, a mental illness or disorder or who are frail aged. The legislation's Statement for Australia's Carers has ten key principles that establish how carers should be treated and considered by agencies and service providers. The first and second principles state that all carers and children and young people who are carers (respectively) should have the same rights, choices and opportunities as other Australians and children and young people to reach their full potential.

Barriers to the rights of people with disability to fully achieve their objectives under 'choice and control' are apparent, but less apparent are the barriers that take away the rights and recognition of carers and caring families to achieve their own objectives under a 'choice and control' model. Further consideration and action are required to truly provide rights and recognition for carers and caring families in our communities.

Just as we have required care to survive and thrive, so we need to provide conditions that allow others – including those who do the [unpaid] work of caring – to receive the care they need to survive and thrive. (Eva Feder Kittay, Love's Labor, 1997, p.107. Extracted from Does your carer take sugar? See reference below.)

Further reading:

Commonwealth Government (2010) Carer Recognition Act 2010 (Clth). Accessible: *https://tinyurl.com/ms4a6vq*

Carers NSW (2013) Does your carer take sugar? Carers and human rights: the parallel struggles of disabled people and carers for equal treatment. Author Professor Luke Clement, first published in the Washington and Lee Journal of Civil Rights and Social Justice (JCRSJ) [2013] Volume 19.2 and reproduced with permission. Accessible: *https://tinyurl.com/knb9fpo*

Colleen Sheen, Senior Policy Advisor Carers ACT

Vox Populi

(n) "the voice of the people." (L)

CHOICE AND EMPOWERMENT

Laura: "Yes to more choice once I have understood that I am not stuck with ringing organisations and at the mercy of their scheduling and staff changes, especially when you really connect with a staff member. Being able to choose my own support workers through HireUp has been amazing. Do I feel empowered? A little yes, mostly no. At the moment my plan is in limbo land and has been for a long time waiting for an internal decision and plan review decision. I don't feel empowered when I (and supporting health professionals) KNOW what is reasonable, necessary and will be most supportive and beneficial – and I have to fight to the point of being unwell to be heard and have these needs considered. Being at the mercy of what the NDIS decide they feel is reasonable and necessary is not empowering. My plan is quite small compared to many I know, and I don't need to to be a whole lot bigger – but just to cover the supports I actually need, instead of just giving me support worker hours."

Cath: "The support I'm getting from committed workers is coming along great, there is still issues but I feel I am getting more support in this area now and that i have the right to ask for it and be able to receive it.

I don't particularly feel empowered although the fighting I'm having to do for myself to get the supports I need (although exhausting and stressful) must be helping me empower myself a bit but I'd prefer not to have to fight and go through hell to feel empowered. I've been through enough already.

Especially when a whole heap of my funding was cut for no reason and further supports requested were rejected I felt far from empowered. I felt hopeless.

It's working well for some people. I wish I was one of them

Choice: there are more services being created due to ndis but they all seem pretty much the same. I sometimes feel like I have to choose between quality and affordability and that doesn't feel right. We should be able to receive both together."

Ian: "I feel that it will empower participants however being the biggest policy implementation since Medicare it will have many problems and will need to be monitired closely to ensure it is meeting the needs of those it needs too. It is apparent that more training needs to be undertaken by those building packages for participants and lines of communication need to be improved. Participants need to continue to voice problems and concerns and the NDIA needs to be open, fluid and accepting of changes that will need to be made now and into the future. Giving our community empowerment over their future is a great achievement but to do this they need the right mechinisms, support and communication platforms to achieve success and all stakeholders need to play their part."

Victoria: "I'm seeing this in the ACT trial site. People for whom English is not their first language and others who have difficulty dealing with bureaucratic red tape (and that includes a lot of us) are having trouble with planners not listening to the clients' priorities and ending up with plans that include services that don't correspond with their needs. A lot of people are having to wait up to six months to find a service provider who can deliver a service approved under the plan. I am also hearing about service providers who are charging for more hours than they actually provide and charging way above market rates for a standard service such as domestic help. I'm not sure what measures are in place to keep the service providers honest and prevent them taking advantage of people who might find it hard to have their adverse observations taken seriously."

On 25 March 2017 People with Disability Australia held a social media forum on the NDIS and asked people whether the scheme had bought them the choice, power and control promised. We present some representative comments here.

ON SUPPLY IN THE MARKET

Barbara: "...I think it also depends on us as consumers – we need to get used to the fact that we can DEMAND services and better services... how do we do that I don't actually know I think it will just take us some time.

I also think there is a hangover effect from disability services always being provided by charities – people think that just because they are charities and not for profits that they are nice and are out to help people. The reality is that charities still need to make a profit – they just can't keep it the way companies can.

Home mods are a real issue I have waited a year – it has been approved but there is only one provider."

Cath: "I have moved from support agency to support agency trying to find one that works I haven't been able to use my funding as intended. A lot of time has been spent trying to find supports and lock them in. 3 years of being in the scheme and I'm now only just finding I am using my budget as nearly intended. This is because getting the right supports on board have been difficult."

Laura: "I have NEVER been offered the option on how to manage. I only found out about "plan managed" from a new coordinator of supports I engaged a couple of months ago – and I have been in the NDIS over 3 years. I wasn't given a choice or information around this. Last review I was given some self managed funds in one category but not explained what this meant. Currently asking to be plan or self managed for the whole plan now I have learned more about it from social media, and options to use Hireup, etc and not just orgs. My new COS is extremely knowledgeable and has helped me understand a LOT, more than the past 3 years worth – even orgs admit they don't really understand the NDIS. I think having an advocate or COS who can really help you understand everything, one-to-one, explaining things to you in the best way you understand and communicate really helps."

**Names have been de-identified*

Choice amidst discrimination?

Being able to cope with the costs of living where you live is fundamental to a decent life in which you can meet your needs, participate and contribute. In Canberra many people don't cope with the costs of living. People living with disabilities face a double whammy regarding costs of living. People living with disabilities who face social and economic exclusion for other reasons (such as being exposed to racism, not having English as a first language, having a history of trauma, being exposed to domestic and/or family and/or sexual violence, facing gender discrimination, low education attainment or no formal post-school qualifications) face a triple whammy. This means the choices people can make and the control people have over their circumstances are deeply compromised.

Housing, especially rental housing, is expensive. For people living with disabilities finding accessible housing is extremely difficult, especially if you are in the private rental market. Aboriginal and/or Torres Strait Islander peoples are discriminated against in the rental market.

Transport spending is second highest of all the capital cities, low income households spend relatively more on transport than higher income households, and the transport costs that are increasing (eg fuel, repair costs) are more relevant to people on low incomes. Public transport is not available to people who need to get to shift work jobs or out/home later than 7pm on a Sunday. For people living with disabilities, public transport is not accessible and the routes too far from bus stops are poorly lit and too often do not have safe, or sometimes any, foot path. Women often feel unsafe in public places after dark.

The main pathway out of financial insecurity and to coping well with the costs of living is access to adequate income. The fastest growing industry in the ACT is community and health services, which is a relatively low paid sector. The other industries that are slated for investment and growth are education, retail, hospitality and information technology. All of these industries have growing numbers of underemployed workers and insecure jobs. People living with disabilities have marginal access to work and are more likely to be in insecure work, or work with not enough hours to earn an income that enables them to cover the costs of meeting their needs, engaging with family and friends, participating in and contributing to their communities. The ACT labour market does not offer much hope to people with disabilities who want to get and keep a job with a living wage. It offers even less hope for people with disabilities who have no post school qualifications.

Improved choice and control for people living with disabilities was the rallying cry for people who led and contributed to the Everybody Counts campaign to establish the National Disability Insurance Scheme. The need for more choice and control, and for the specialised service system, the broader market for goods and services, our social and political institutions and public infrastructure to adapt to provide more choice and control for people living with disabilities was promoted by the Productivity Commission, accepted by all major political parties, and agreed by all levels of government in Australia. The National Disability Strategy enshrined choice and control as a central tenet.

So why are we still complaining about lack of choice and control? Because we have been distracted from this objective by the marketization agenda. Bringing market forces and market discipline to the provision of services, the development of better and new goods and services and investment in infrastructure is one limited mechanism for achieving choice and control. A severely limited mechanism if you consider the existing inadequacies, gaps and discrimination experienced by people with disability, and people with disability who experience inter-sectional disadvantage, in the market.

We need to get back on task with the human rights based choice and control agenda. Investment is urgently needed to enable the full expression of choice and control by people living with disabilities. This would include properly funding disability people's organisations, systemic advocacy (especially planning of infrastructure renewal) with disability access as a top priority. It would also include formal, funded mechanisms for people living with disabilities, their families and carers to advice decision makers in the public, private and community sectors to inform their decisions about priorities, investments and diversification of goods, services and infrastructure. And we need to formally monitor our progress against all components of the National Disability Strategy, including but also beyond the NDIS.

Susan Helyar
Director, ACT Council of Social Service Inc. (ACTCOSS)

Seven years later...

"Where are we now? Where are we now?
The moment you know
You know, you know ...
Fingers are crossed, Just in case"
– From a track by David Bowie, 2013

Cast your mind back to 2010.

Kevin Rudd was still Prime Minister and hadn't gone, come back again and then marched to defeat in a general election; Twitter was brand new bringing together trolls and media people before they eventually combined into one; and, speaking of twitter, Donald Trump was best known as the host of Celebrity Apprentice. Seven years ago the National Disability and Carers Council was also releasing a paper entitled *SHUT OUT: The Experience of People with Disabilities and their Families in Australia.*

The landmark report had its origins over two years. In late 2008, the Australian Government released a discussion paper asking the community to respond to a series of questions about their experience of disability. The consultations were intended to inform the development of a National Disability Strategy. More than 750 submissions were received in response to the discussion paper and more than 2,500 people also attended consultations in capital cities in every state and territory of Australia, as well as in regional and remote areas.

People with disabilities believed little progress had been made in challenging prevailing attitudes towards disability. Submissions suggested that there was still widespread misconceptions and stereotypes informing the attitudes and behaviour of service providers, businesses, community groups, governments and individuals.

Submissions argued that discrimination is both systemic and systematic, entrenched in the everyday practices of government, businesses, community groups and individuals.

SHUT OUT identified a lack of services and support; workforce issues, a lack of aids, equipment and assistive technologies; a lack of housing options; health and wellbeing; poverty and the cost of living with disability; the need for a lifetime care and support scheme; the lack of jobs; the lack of access to the built environment; the lack of access to information; wasted years in education; and the social experience of disability.

Seven years, two NDS implementation reports and one National Disability Insurance Scheme launch later some things have changed and other haven't. We wanted to ask how far we've come in Canberra towards improving choice and control for people with disability in key areas identified by SHUT OUT:

EMPLOYMENT

SHUT OUT: What we said needed to change in 2010...

Lack of employment has resulted in high levels of unemployment and underemployment among people with disabilities compared to the rest of the Australian population—Australian Bureau of

Statistics data demonstrate that labour force participation for people with disabilities is 53 per cent, compared to 81 per cent for people without disabilities

Negative attitudes and misconceptions about disability means few employers—whether government, non-government or corporate—appear willing to employ anyone with a disability. In some cases there was clear discrimination, with qualified candidates reportedly sidelined solely because of their disability. People with a history of mental illness or an intellectual disability appeared to be particularly stigmatised.

Many people with disabilities and their families are therefore forced to rely on government assistance and find themselves trapped in a poverty cycle of low income and high costs. A number of submissions said that the inflexibility of the Disability Support Pension acts as a disincentive to employment and recommended a review.

Where are we now? The view from Canberra in 2017...

- Human Rights Commission data shows the ACT public service disability employment rate of 2.2 per cent (458 people) is lower than all other jurisdictions except South Australia at 1.3 per cent.
- The federal public sector had 3.3 per cent of its workforce identified as disabled in 2015 and the ACT government's own target was 3.4 per cent (655 employees).
- An ABS survey in 2015 recorded that 15.8 per cent of people in the ACT had a disability.
- Across Australia, only 53.4 per cent of working-age people with disability were in the labour force compared with 83.2 per cent of people with no disability.
- A report by Patrick McClure recommends making the transition between work and income support less complex but an automated debt recovery program linking Centrelink data and ATO data reportedly causes thousands of Centrelink customers to feel less confident about work.
- Major newspapers call disabled people rorters and bludgers after Federal Government media drops and Federal Minister Kevin Andrews focusses on people with mental illness in media commentary.
- The Australian Government commences a compensation scheme for workers in low paid Australian Disability Enterprises.

VERDICT:

Neither the Federal or ACT Government, business or community sector has made significant progress in the employment of people with disability since 2010. The Federal Government has made attitudes worse with ill timed media drops labelling people as rorters and bludges while many income support customers with disabilities trying to manage part time work have been caught in its disastrous robodebt debacle. Public service employment continues to slide and people with disabilities have been axed from key positions in the media, community organisations and – for a time – even in the Federal Governments own disability commissioner position!

SERVICES AND SUPPORT

SHUT OUT: What we said needed to change in 2010...

The disability service system was characterised as irretrievably broken and broke, chronically underfunded and under-resourced, crisis driven, struggling against a vast tide of unmet need. As a result many felt more time was spent rationing services than delivering them.

Services were characterised as unavailable or unaffordable or of such poor quality as to be of little benefit. Many submissions said that there is little or no choice in services provided, particularly in regional or remote areas. Submissions and participants at community consultations said that the system is characterised by a 'one-size-fits-all' approach in which there is very little

choice or flexibility. Programs and services are built around organisational and system needs rather than the needs of clients.

It is not unusual for people to be left to sleep in their wheelchairs through lack of care hours to get them to bed, or for them to be left without a meal as there is no-one who can prepare it for them.

Many submissions expressed frustration with the bureaucratic nature of service provision. They describe the system as difficult to navigate, excruciatingly slow and unresponsive. Endless assessments and endless forms seem to lead only to a frustratingly inadequate service. The layers of bureaucracy and red tape not only make locating and accessing support difficult, but appear to bleed the system of much-needed resources.

Where are we now? The view from Canberra in 2017...

- The National Disability Insurance Scheme is introduced in stages in ACT with a series of grants through the enhanced service offer followed by full roll out of the scheme to different groups from 2014.
- There are 60,000 people in the scheme nationally and in the next three years there are going to be 400,000 people in the scheme
- There are 5541 people with eligible plans approved in the ACT
- There are 535 registered providers in the ACT[1]
- 85 per cent of surveyed participants rated their experience either good or very good
- Participants on the ground report good outcomes once they have plans but delays in getting plans, variations based on planners, issues locating plan managers, OT's and providers and challenges with the online payments system. Pricing schedules in some areas leave providers floundering
- Supports from the ACT and Australian Government focus on service provider readiness but there is limited support for consumer readiness and local disability consumer organisations are left out of the loop with no grassroots consumer advisory body
- ILC funding round appears to misunderstand the extent of ILC support needed in the ACT and the need to build information and capacity building services with the capacity for ongoing growth.

VERDICT:

~~EXCELLENT~~ GOOD, NEEDS IMPROVEMENT

Disability supports have been transformed since 2010 with 5541 people moved onto plans including people who have never had supports before. Many people reporting improved levels of wellbeing according to the NDIS dashboard. Chance of a mark of excellent dashed by fumbles in the implementation and the lack of investment in consumer readiness and consultation. Some disability services are slow to get to get the message about transformation or to change their service models. Some of the old red tape has been replaced by new red tape.

ACCESS TO PLACES AND SPACES

SHUT OUT: What we said needed to change in 2010...

For many people with disabilities the built environment acts as a powerful barrier to their full inclusion in the community. It affects their day-to-day functioning in ways few others can appreciate. The inability of people with disabilities to access the facilities that everyone else in the community takes for granted—cafes, public buildings, swimming pools, libraries, sporting facilities and movie theatres—limits their independence and compromises their quality of life. More than 27 per cent of respondents said that lack of access to the environment acts as a barrier to their full participation in the life of the community.

Where are we now? The view from Canberra in 2017...

- In July 2015 PWD ACT commenced a consultation process around disability access issues in Canberra including a social media forum; an online 'survey monkey' survey; and access phone out to all our 30 organisational members as well as other key stakeholders during September/October; and a forum at the ACT Legislative Assembly.
- Key findings focussed on the lack of access in the "court areas" around Phillip and Belconnen as well as in older parts of the city like Fyshwick and Manuka; the lack of access to ATM's due to height and design issues; poor street lighting in some suburbs causing trip hazards and people feeling unsafe; poor access in iconic buildings like Parliament House including heavy doors and heavy carpet; ACT residents not being subsidised for the costs of visual smoke detectors; Narrow doorways and a lack of access into nightclubs and venues; hotels in Canberra advertising access and then failing to deliver; Trees, bushes, long grass and shrubs cover foot paths making it near impossible to use the foot paths with a mobility aid; problems with sensory processing for people with a hearing disability due to flooring, noisy devices like driers; issues at National Convention Centre; disability toilets used for storage; footpaths being cracked, steep, uneven and having poor camber (sloping into the road); people illegally parking in disability spaces throughout Canberra
- Canberra residents and visitors alike offered positive feedback to Canberra events such as Floriade. Access to the National Capital Precinct and newer buildings was also praised. But there were some exceptions like at Parliament House.
- The consultation identified a number of coordination issues. A range of people are undertaking work to plan, educate, promote, broker and regulate solutions for access and this work may be high quality but it is not always coordi-

1 https://tinyurl.com/l8z4dm9

nated for maximum effect. Many people with disability are also unclear about who is responsible for access issues within the ACT Government and how to raise them. The lines of responsibility within Government are also unclear.

- The Parliamentary Agreement included a commitment to a resourced Disability Reference Group to include people with disabilities and to address access issues for transport and new developments.

VERDICT:

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The Commonwealth has finally included Disability Standards within the Building Code of Australia and access issues were highlighted within the recent election campaign. There is a commitment to a resourced Disability Reference Group within the Parliamentary Agreement but that's likely to face an uphill battle without a discrete access taskforce as recommended in PWD ACT's comprehensive 2016 Budget submission.

TRANSPORT

SHUT OUT: What we said needed to change in 2010...

The cost of transport or the lack of availability of transport often means that people with disability cannot access education, employment, services or the community. It is a pivotal support service which is often not available which then excludes the person from many or all aspects of their community.

For most, the inaccessibility of public transport leaves them reliant on family or friends or on the taxi system. Both compromise their ability to live independently. And while most states operate a taxi voucher scheme, few provide enough assistance to meet day-to-day needs. This leaves people with disabilities and their families with no other option but to meet all additional costs.

Many respondents noted that poorly trained staff are also an issue on public transport. Staff refusing to provide access or assistance despite being required to do so is a particular problem. People with disabilities are clearly still at significant risk of discrimination at the hands of individual operators. Participants at consultations also expressed concern over safety issues when using public transport.

A small number of submissions detailed continuing concerns about travel by air. Despite considerable attention to the issue, people with disabilities are still unable to access air travel in the same way as other members of the community. The inability or unwillingness of staff to assist travellers and the requirement to purchase additional tickets for carers are two issues that remain unresolved.

Where are we now? The view from Canberra in 2017...

- In July 2015 PWD ACT commenced a consultation process around disability access issues in Canberra. The consultation found widespread concerns about transport – wheelchair taxis; action buses taking off before passengers are seated subjecting people to injury and falls; a lack of any hire cars with hand-controls for visitors; and people illegally parking in disability spaces throughout Canberra. There were also concerns about pedestrian thoroughfares including people needing to travel along overgrown verges and rough ground to get to curb cuts.
- Under two thirds of buses are accessible in Canberra and full accessibility across the whole fleet isn't slated until nearly a quarter of the way into the 21st Century by 2022.
- An article in the Canberra Times points out smaller planes on many domestic routes mean thousands of passengers at Canberra Airport board and disembark on the tarmac via stairs in all weather and wheelchair users are "lowered to the ground in a narrow temporary wheelchair on an open-air, scissor-lift style device" (CT 26/12/14). In 2017 a cut in the number of jets flying out of Canberra means that even more travellers must experience difficult transfers onto smaller planes.

VERDICT:

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There is some progress but far too slow and some areas, like air travel, seem to be actually getting worse.

Compiled by Craig Wallace

The limits of money and markets

For this edition of *The Canberra Disability Review* we've cast a critical gaze across the idea of money and markets and asked about their potential and limits.

Money and control is fixing much for people with a disability. People are getting therapy and equipment they have waited decades for. They are getting modifications to help them stay in work or their homes. They are getting transport assistance and the ability to set aside services who acted as if we existed to fit into their rules and schedules rather than sitting at the centre of their world.

And while money makes a difference its clear that there are limits to its reach.

If people with disability are 1 in 5 Australians and older people are the fastest growing group in the population then why isn't the community knocking down our doors to provide accessible tourism, transport, infrastructure, housing, allied health services and education?

Why can we still wheel down the streets in Weston, Dickson and the courts in Phillip and Belconnen and see entire streets where every shop has a step? Why are there still steps at dentists, doctors and even aged care accommodation places? Why are there significant access issues in our hospitals including the parking around the National Capital Private Hospital? Why are we waiting to 2020 to make all the buses accessible in our city when tourism is the biggest growing area of our economy and the grey nomads are the biggest growing group if tourists? If markets responded rationally, reasonably and automatically to demand then the invisible hand would have fixed them decades ago.

Maybe then, choice and control needs to be seen in a human rights framework as well as about having people who care enough to solve your problem. There is need but problems don't always respond to money. They respond to other levers – shame, the law, or even just "people power", time and expertise being available.

A broken piece of equipment isn't just fixed by money. You could be a millionaire and it still comes down to someone who is clever enough to do it and has the time, the expertise, the tools and the skills to solve the problem and above all, cares enough about you, to bother to solve it with you.

People with disability won't just buy inclusion. We will have to win it – by fighting for rights, access to justice, quality social infrastructure, housing that's affordable and universally designed, an education system that treats us as equals and an employment and income support system that don't work against us.

It is because money and markets have limits that we need to retain quality consumer services to complete the choice and control jigsaw and to ensure that we step up and address key areas of market failure for people with disability that sadly are not going away any time soon.

That is why the Canberra Disability Review shares concerns outlined in a recent Canberra Times editorial about the slow motion train wreck that has been facing a number of advocacy, health, peer support, bespoke and citizen voice services and programs that fill gaps in the (very welcome) street paving of the NDIS.

When the NDIS was first proposed by the Productivity Commission it was clear that there would need to be a large ongoing investment in some services that could not be purchased as part of packages due to the way they were formed or used. These supports were later described as information linkages and capacity building services. Yet the ILC funding when it eventually arrived – too late to save some services – was framed as project funding and with total grants of $1.5 million can never hope to cover the range of services which are outside the NDIS.

We did not fight for the NDIS to see all of the services we own be replaced by distant corporates.

To see every information service, equipment provider, community housing provider or advocacy service that was created by consumers go to the wall.

It is ironic that the disability services that have closed or face the greatest peril are the ones that have been created, lead and staffed by Canberra people with disability throughout their service histories.

These include Nican, SHOUT, TAD ACT, 1 RPH, Canberra Community Housing and even our own organisation here at PWD ACT.

And yet the NDIA has engaged Local Area Coordination from Feros Care – a Coolangatta based aged care provider that hasn't had a significant footprint on the ground here until very recently.

The Canberra Disability Review does not question the capabilities of this firm but we do think that it's valid to contrast this appointment with the lack of nurture being shown to home grown consumer organisations by various levels of Government and the NDIA itself in the NDIS transition.

It's time for the Federal and ACT Governments to guarantee funding for services lost in the cracks of transition that we need to maintain our human rights and manage broken markets and we call on the Barr and Turnbull governments to help us secure them.

These include: mentoring for people with psychosocial disability; genuine inclusive community housing for people with disability; systemic advocacy; support to self help groups; radio for the print handicapped and technical aids for equipment servicing and repair which cannot be done by commercial providers.

YOU CAN
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THE CANBERRA DISABILITY REVIEW

Contact the office on **6286 4223**
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