

10 June 2019

Attn: Review of the National Disability Strategy National Disability Policy Reform Team Department of Social Services

By email: disabilityreform@dss.gov.au

Dear Colleague

Review of the National Disability Strategy: Submission from inner West Council

Please find enclosed a submission from Inner West Council on the Review of the national Disability Strategy.

Please do not hesitate to contact me should you require further information.

Yours sincerely

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Submission to the review of the National Disability Strategy 2010-2020

Introduction

Inner West Council has resolved to make a submission to the review of the National Disability Strategy 2010-2020. This submission reflects the themes of the Strategy. Advocacy is also included as a separate section, reflecting the importance Council attributes to the active participation of people with disability in shaping government service provision, and lives of dignity and respect. Included in each section are brief excerpts from Council engagement on this issue, which reflect how these issues relate to the lived experience of local people with disability in the Inner West. Finally, Attachment One provides data from Council's Access Advisory Committee discussion on this issue without filtering.

Council notes that a brief review of certain elements of the Strategy has been undertaken by the Social Policy Research Centre. The review does not adequately evaluate the complexity of service provision and social change inherent in a ten year strategy for up to 20% of the Australian population.

In particular, the review is notable for its absence of an outcomes or results framework that quantifies the real results achieved through a decade of investment across government programs in improving the lives of people with disability. Further, some of the review findings appear less than fully formed. For example, it is not clear how the need for centralised whole of government leadership in the next strategy could work when service provision to people with disability occurs in every government agency and in each jurisdiction.

1) Advocacy

The review of the NDS highlights a clear absence of real accountability to actual stakeholders including people with disability and their families and communities. And where the review argues for greater bureaucratic oversight in the next Strategy as the remedy for this problem, there are other alternatives. Key among these is greater advocacy and engagement from people with disability themselves.

Creating substantive change in attitudes and thinking about whole groups of people takes sustained work over time. This has been demonstrated through feminism and the women's movement, through creation of multicultural Australia, and most recently through the expansion of greater legal equality to homosexuals through marriage equality.

There is a notable failure to properly prepare younger people with disability for careers as public intellectuals and advocates who can help steer the public debate on equality, justice, safety and economic participation for the larger group of people with disability. Limited funding for systemic advocacy organisations will not address this need.

In fact in the Inner West the experience of younger people with disability is often one of alienation from the opportunities that other Australians take for granted and often includes homelessness, unemployment, physical violence and abuse, and extreme

difficulty in accessing the very services created to support them including for many the NDIS itself. Too many people are falling through the gaps between various government services, resulting in deep disadvantage and alienation form the opportunities most Australians take for granted.

Most of the young disabled people I know have been waiting more than six months to access the NDIS (myself 18 months now and still waiting) and have struggled with homelessness, basic needs not being met, deterioration of conditions and high rates of familial and carer abuse as a result; and also lack of other supports available to those not yet on the NDIS, severe lack of money to pay for appointments that will help us get on the NDIS in the first place (we live in poverty).

2) Inclusive and accessible communities

Council has made significant progress on improving inclusion and access for people with disability across its policy and service provision. Council commends the NSW Government for its mandatory Disability Inclusion Access Planning which has driven new responses in our planning and delivery.

This approach has seen people with disability engaged in new ways with Council policy and service planning and delivery, and in thinking about legal equality in access as a benchmark in new ways of solving access and inclusion challenges across Council businesses. As we approach the end of the second year of this plan, notable achievements include:

- Council in partnership with Ability Links NSW and Gig Buddies ran an *Including* You event tent during community events
- Council continued its involvement in events including Groovability, Blooming Arts, Mental Health Month, Access All Areas Short Film Festival; including a *Living Library* where people with disability participated in one on one conversations for 15 minutes
- Community Grants Program assessment considered alignment with Inclusion Action Plan directions and capacity to promote inclusion by proponents
- Council promoted disability inclusion in Youth Week including musical performances by people with disability
- Council supported and participated in DeafBlind Week in June and partnered to create interpreted theatre with DeafBlind participants telling their stories
- A book display promoting themes of inclusion and disability issues was also held over November-December for International Day of People with a Disability, along with six library Storytime sessions for children aged 2-5 years
- Council's Community Access Award was established as part of the Inner West Local Business Awards
- The Pedestrian Access and Mobility Plans were evaluated and outstanding actions consolidated to create a new plan of kerb, ramp and footpath works
- The Affordable Housing Policy endorsed in March 2017 identifies people with a disability as one of its key target groups

- The master planning for Dawn Fraser Baths and Leichhardt Park Aquatic Centre consider the needs of all the community
- Over 90% of bus stops in the Council area have been upgraded to accessible standards and a program for upgrading the balance is underway
- The new Council website, which is the primary interaction point for digital services, is compliant with web content accessibility standards
- Training was provided for all Customer Service staff on using the National Relay Service.

Attitudes to people with disabilities in the general public have drastically changes over the last 40 years and continue to improve. People are extremely helpful in general these days where we were often considered an inconvenience. Access is brilliant these days. When my son was young we were severely restricted in where we could go and activities we could pursue with two additional younger children.

More work should be done to acquaint the neighbours of people with disability living in the community so that emergencies may be catered before. I know a young women who uses a wheelchair who has created a "circle of care" with her neighbours with phone numbers being known and an alarm to next door. She recently fell out of bed and was able to call for help. Only one such call in 3 years but neighbours make sure they see her each day. With two or three people co-operating it would not be a chore.

Transport

Public transport is essential to people with disability achieving legal equality. Council appreciates that significant upgrades have occurred at key railway stations and that new bus routes, and new buses have increased the capacity for people with disability to actually board and utilise public transport. However, an absence of a public timetable for the next series of railway station upgrades means Council and private developers cannot plan for more accessible precincts with ease.

Transport is also essential for accessing employment and education. There is room for a national commitment to provision of more public transport to facilitate more people with disability into education and employment.

Public transport (my only transport option) is very inaccessible still, especially train stations, and I can't get into most shops in my area. There doesn't seem to be an effective method to effect change around inaccessible places.

While the importance of accessible transport is well acknowledged there is a vagary of purpose towards this goal evident in state and regional transport planning. The NSW Auditor General has reported NSW will not meet its targets and obligations under the DSAPT. As there has been 20 years to plan and resource these improvements (under the DSAPT) it is a disappointing outcome and while progress is apparent it is less than ideal or in alignment with the agreed outcomes reached with all levels of government.

The finding against the Queensland government on the procurement and introduction into service of a fleet of non-accessible trains further highlights a lack of accountability and intention to addressing this core need when planning and opportunities are present to advance the issue.

Housing

Housing affordability is acute for people with disability as their relative capacity to pay is lesser and proportionally more people live on government allowances, which are not increased with the cost of living as are wages. People with disability are over represented among the homeless and those living in insecure tenancies like boarding houses or short term rentals. Generally where there is availability of affordable housing, these are unlikely to be fully accessible which creates further disadvantage. 2019 research by the Summer Foundation has found an undersupply of almost 400 accessible residential properties for people with disability.

3) Rights protection, justice and legislation

Council notes incarceration rates of people with disability are among the highest for any group across our communities. Further, Council notes the establishment of a Royal Commission into: a) all forms of violence, abuse, neglect and exploitation of people with disability, in all settings where they occur and b) on the quality and safety of services for people with disability. Clearly there are very substantial problems in relation to violence, abuse and an absence of respect and fundamental rights for many people with disability. It would appear that this situation has worsened over the decade to 2020, and it is puzzling that more is not made of this failing in the review.

Council also notes specific failings in relation to freedom from personal and sexual violence for women and girls with disability. For example, 63,900 women with disability experienced sexual violence in 2016. The highest rates of violence are among those people with psychological and intellectual disability. There is need for specific strategies which offer purposeful solutions to this issue, and for urgent funding and action.

I generally find people are hugely patronising when I use my wheelchair. They invade my bodily autonomy by pushing me without asking, they speak to me like a child, they assume my dress sense is playing dress ups (as if I can't belong to an alternative subculture or have identities other than being disabled)

Legislative reform

The DDA predates the UN Convention and reform is needed to make the Act more effectively aligned with the CRPD including a mechanism to address issues of systemic discrimination. It remains of concern that it is incumbent on those under the protections of the Act to be the central advocate in the pursuit of rights and improvement. Much has been detailed about this approach, the inherent disadvantage and onus on people living with systemic discrimination to challenge and ultimately redress discriminatory systems who are often impoverished and by definition in the least resourced position to do so. The number of disability discrimination complaints to the Australian Human Rights Commission has steadily risen and is now the area where the Commission receives the

largest number of complaints. It surpasses complaints on race and gender combined. If the objective of the DDA was to remove or reduce discrimination then results to date highlight seem to confirm this relationship cannot work effectively as it is.

Exemptions to the DDA such as the provisions of the Immigration Act undermine Australia's attempts to reach its inclusion goals. Recent cases highlight this with people with a disability (including those born in Australia) and families at the mercy of ministerial intervention. The message this send to the Australian community reinforces the 'burden' narrative that the NDS aims to challenge.

Standards and research

Standards relating to access and mobility are not regularly updated and do not have a robust research or evidence background in their development. Often they are too prescriptive and lack the agility to respond to current and new/emerging technologies including changes in assistive technologies that would otherwise benefit people with disability. This can be most readily seen in transport, mobility equipment, lifts, communication technologies and wayfinding.

Stages in public auditoriums vary in height but usually within a predictable range and yet affordable lift options are only permitted within a much smaller range regardless of the reality in public venues across Australia. Compliant solutions as a result are more intrusive to the structures and operations, often less convenient for those that need to use them and costs are beyond the resources to address at each and every location.

Often technology is available, designed and built in countries with similar safety and economic profile as Australia. New technologies are being developed to assist people and the NDIS is predicated on a market forming to address issues yet this is hampered by static regulatory mechanisms which are no longer effective to demand. Evidence based on research led by the priorities of people with disabilities and who are integral to its administration should be in the gamut of the next NDS. Support to develop and operate a new model of standards development should also be available to assist a vibrant diverse market to develop that will have flow on benefits to the economy.

A review of the mechanisms that delivery credible and current standards and their relationship with regulations is important and overdue

4) Economic security

People aged between 15 and 64 years with disability have both lower participation (53%) and higher unemployment rates (9.4%) than people without disability (83% and 4.9% respectively). Almost three-quarters (71%) of National Disability Insurance Scheme service users aged 15 years and over who were in the labour force are unemployed compared to 4.9% for Australians without disability. Further, people with disability aged 15-24 years are 10 times more likely to experience discrimination than those aged 65 years and over. The source of discrimination is an employer in almost half of those instances.

Council notes that a fundamental premise of the National Disability Insurance System is that through providing new supports, many more people with disability will secure and maintain employment. There is no evidence in the review that this is occurring. No evidence for any increase in employment is offered and no evidence on increased investment in supports that would support employment from the NDIA are offered.

5) Personal and community support

The opportunities for community and cultural enlivenment that all citizens enjoy should be more readily available for people with disability. While additional resources for personal supports are useful, it is the infrastructure of cities and communities that is a major structural barrier. For example, there are only two lift and change facilities in Sydney CBD. One at the International Convention Centre at Darling Harbour, and one at Westfield shopping centre in Pitt Street. There are no such facilities at Circular Quay, at Central Station or at Barangaroo.

Clearly the NDIS has been a game changer for people with disability and their families. It has gained a high public profile in the media and a focus of political attention. As a result it has increased the profile of disability issues nationally.

Much has also been written on the scheme's progress and the implementation challenges. However there is significant support for the scheme and the original values underpinning it. It is also clear that its success or rather the capacity for people to truly participate is intrinsically linked not just to support arrangements but the other policy areas of the NDS that haven't received the same attention or progress to date as illustrated in the examples above.

Young people with disability living in nursing homes need advocates to help them investigate alternative accommodation and relocate if a place becomes available. There should be funding to facilitate this and if volunteer advocates cannot be found, paid workers should be sourced. (In my experience, a young man who was able to move had very few clothes, sheets, towels, basic toiletries and comforts. It was only the families of others in the group home who provided this out of caring for him).

For people eligible for NDIS, funding often needed for advocates and case managers to help them with this. Family members and friends often do not have the skills to do this and need help too. What has been happening in my experience is that traditional providers of care are doing the planning and in some cases are maximising the return to them from NDIA while not providing a range of choices to the client. e.g. people from houses managed by the service are transported to a centre daily where it is basically "babysitting" and then they are taken back. The services charges NDIA for transport each way but also says there is expert care on the bus, which is just the driver, and for education and activities at the centre. There is no individual choice at the centre but it is charged for. Because the plan has been left up to the service, clients and families are unaware of this. Therapy services are often accessed when it is questionable that they are needed and clients are often subject to their decisions, their own choices being over ruled.

6) Learning and skills

People with disability continue to have lower levels of educational attainment than those without disability. People with disability are underrepresented in higher education and in the trades. Access to education, as well as the level of education attained, can affect participation in other key life areas, including employment and the ability to achieve financial independence. In 2015, around 1 in 3 people with disability aged 20 and over (32%), and 1 in 4 with severe or profound limitation (25%), had completed Year 12 or equivalent. This was much lower than the 2 in 3 people without disability completing Year 12 (62%). This issue needs urgent national action.

7) Health and wellbeing

People with disability access health services at lower levels than Australians without disability. Among those with disability, people with severe or profound activity limitation accessed services at lower rates than those with milder impairments. People with disability generally have lesser longevity than Australians without disability.

I have concerns too that medical staff in public hospitals are undertrained in treating acute emergencies related to chronic illnesses and disabilities, and many disabled and chronically ill people are receiving substandard and sometimes traumatising treatment. I would note that access to professional medical training is poor for disabled people, despite it being a field that many of us would excel in, and that making that education more readily available would over time ensure more compassionate care.

Further work is warranted to promote the social model of disability within the health sector. Much confusion and misunderstanding results from the inconsistent use of language regarding disability and impairment and the intersection of health issues with disability. This obstructs genuine progress, participation and wellbeing for people with disability.

Attachment One

Notes from Inner West Council, Access Advisory Committee discussion on the future NDS, 2 May 2019

- 1. What is important to people with a disability, their families and carers now and for the next ten years?
 - Accessible and affordable housing
 - Continuing to be part of community
 - A successful royal commission
 - Legislation with penalties for not adhering to legislation
 - Being included
 - Health and happiness (income)
 - Jobs/employment
 - Targeted employment opportunities
 - Inquiry into if people with disabilities lose jobs quicker
 - Research into barriers to employment (recruitment) as well as once within employment
 - Inclusive workplaces
 - Recognising access requirements
 - Evaluating where modifications are required
 - Given a (reasonable) chance to succeed
 - Advocacy
 - NDIS means disability advocacy services are losing funding
 - Adequate funding for planners and advocates
 - Properly funding plans (NDIS) and being consistent.
- 2. What issues are people with disability still facing?
 - Human rights still not being respected
 - Discrimination rampant
 - Woefully inadequate funding, particularly health
 - Not inclusive society, goals of inclusion are not being met
 - Basic levels of understanding of what disability is (UN convention) not being met
 - Equitable economic participation
 - Equitable access to accommodation/housing
 - People's awareness of different disabilities especially hidden/invisible disabilities
 - Public transport and getting around, general accessibility
 - Mental health being under resourced/addressed
 - · Mental health plus disability- intersectionality and problems are compounding
 - People still being left behind
 - Barriers in community
 - Barriers to inclusive education.
- 3. Have there have been changes in community attitude towards people with a disability?
 - Yes, over the ten years
 - Yes a change but very slow
 - Like to be positive but there is a long way to go yet (if you blink you miss it)
 - Positive about the future
 - Disability has become more visible

- Politicians with disability have improved profile of issues, has dragged disability into people's view
- Social media commodification of disability- focus on individual still rather than a social collective response needed.
- Give people money (still a cause) image and as a response to tragedy
- Inaccessible social media inaccessible social justice
- Barriers disguised in different ways
- Technological barriers persist
- Access for people with disabilities has limitation
- Intellectual disability access requirements (transport, venues etc.)
- Community awareness needs to be raised of invisible disabilities
- Transport barriers. Changes have occurred but limited, no priority on maintenance of assets i.e. lifts so often out of service
- Awareness of the spectrum on which impairment and disability present
- Acknowledgement of all disabilities limitation on what disability is.
- 4. How can we make sure the next strategy leads action and improves outcomes for people with a disability?
 - Write a new strategy
 - Learn from mistakes
 - Become a ground rock for advocacy
 - Start to increase consultation/community in every state and region
 - ICAC for disability- ombudsman
 - Upskilling to enact strategy
 - Gap for delivering or evaluation of strategy
 - No penalties for not using or not enacting strategies
 - Banking royal commission showed enforces of rules not working/serving the community or functioning. Same can be said of disability rights enforcement
 - Have ombudsman provide a report to state government and the state government be responsible for enacting the report but advocacy groups are the ones that enforce and they are largely being defunded.
- 5. How implementation can be improved such as through stronger measurements and more effective reporting?
 - Independent third party reporting available to the public
 - Problems of NDIS (employment system)
 - Professional public servants needed
 - Privatisation issues will be hidden
 - Delivery of NDIS fairer and tracked- equal access to good advocates and planners with understating of disability
 - Consultation is sometimes tokenistic
 - Reporting also tokenistic when real issues are confronting, they need to be addressed
 - Concept of choice is not available in regional/rural areas. Not all service providers are good, and people have no other options
 - Less choice of providers in regional and rural areas can cause significant hardship
 - Not limited to rural though as there is also market failure in city as well
 - Service providers can be dictatorial
 - A free market is not quality controlled
 - Privatization not working in all contexts
 - Less care-full funding for complex needs

- Intellectual disability/ mental health/ behavioural issues- prior to NDIS ADHAC was a last resort for complex needs- group homes have been known to drop people off at the hospital
- Safety net provided by ADHC no longer there in NSW
- NDIS and health gap- e.g. oxygen bottles or none to do diabetes injection
- Parents of young people with disabilities and have been relinquishing care
- Also young people with disabilities becoming locked into aged care facilities and conflict arising from understanding difference of aged care model vs disability service model
- Exorbitant costs for the same programs like respite
- · Government paying money for non-service
- NDIS royal commission
- Legislation (bedding down policies so they are clear)
- Overall responsibility is not clear especially between state and federal jurisdictions. COAG funding agreements – misunderstanding of what disability is and with health related issues
- Set up a series of star chambers (public committees) as a watch dog.