Still outside the tent: cultural diversity and disability in a time of reform – a rapid review of evidence

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Contents

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Executive summary and key messages

Disability and reform

Australia is implementing a complex social and economic reform through the rights-based and inclusive vision articulated in the 10-year National Disability Strategy 2010–2020.

The most widely known aspect of this reform, the National Disability Insurance Scheme, commonly known as 'the NDIS', is designed to achieve this vision by transforming disability services and achieving better alignment with mainstream services.

This policy paper examines the goals and vision of the National Disability Strategy with a particular focus on people with disability from culturally and linguistically diverse (CALD) backgrounds.

In 2015, there were 4.3 million people or 18% of the Australian population with some level of disability. Of these, 715,000 people had a profound or severe disability.

The NDIS provides individual supports, to assist people with permanent and significant disability to participate in economic and social life, and give them more choice and control in the supports they receive.

The NDIS also includes the Information, Linkage and Capacity Building program, to assist all people with disability, including those who are ineligible for the NDIS, their families and carers with information and referrals to mainstream services, and to increase social and economic participation.

Disability and cultural diversity

An estimated 23% of the Australian population are from a CALD background by the NDIS definition of cultural and linguistic diversity.

The available evidence indicates that people from CALD backgrounds have rates of disability, and profound or severe disability, similar to the rest of the Australian population, which challenges notions of the so-called 'healthy migrant effect'.

ABS data has shown that the proportion of people born in a non-English speaking country who had any disability was the same as the rate of disability for all Australians.

Similarly, 6% of all Australians had a profound or severe core activity limitation, and the rate of profound or severe limitation was also 6% for people born in a non-English speaking country.

The available evidence also indicates that people with disability from CALD backgrounds have had much lower rates of utilisation of disability services – about a half to one-third of the rate of usage that people born in Australia have had (and there is no evidence to suggest that this is a reflection of their preferences or that they need less assistance).

The *Report on Government Services* drawing on a 2015 ABS survey shows that, of people with disability who received formal assistance for at least one activity, 10% were born in a non-English speaking country.

In 2016, 18% of the Australian population were people born in a non-English speaking country, and have similar rates of disability and needs for formal assistance as other Australians. This indicates that people with disability born in non-English speaking countries are about half as likely to receive formal assistance as people born in Australia.

In the transition of disability services to the NDIS, by the end of 2017 just 7% of NDIS participation plans across Australia were being delivered to people identified as being from a CALD background, approximately one-third of the 23% of NDIS potential participants who could be expected to be from a CALD background.

Indeed, the evaluation of the trial of the NDIS by the National Institute of Labour Studies (NILS) found that, while overall it has improved the lives of people with disability, it has to date left several minorities, including people from CALD backgrounds, no better off or even in a worse situation.

Barriers and challenges

The barriers for people with disability from CALD backgrounds accessing supports are reasonably well known; what is missing is the kind of enhanced response to enable people with disability from CALD backgrounds to achieve social and economic inclusion, as articulated by the National Disability Strategy.

We must not lose sight of the fact that it is the responsibility of the service system to be accessible to all people with disability and the underutilisation of services by CALD communities and other equity issues is not in any way inevitable.

As with all people with disability, there are barriers, but there are also enablers that can improve outcomes and deliver greater inclusion for people with disability from CALD backgrounds.

There is merit in adopting a comprehensive cultural competence framework to improve the responsiveness of the National Disability Insurance Agency (NDIA), disability providers in the NDIS market and mainstream services, and strengthen linkages and capacity building with communities to improve the participation of people with disability from CALD backgrounds.

The National Health and Medical Research Council has developed a comprehensive cultural competence framework which could be applied to the disability service system. The four dimensions of the framework – systemic, organisational, professional and individual – interrelate so that cultural competence at an individual and professional level is underpinned by systemic and organisational commitment and capacity.

Cultural competence is a developmental process that evolves over an extended period. Individuals, professionals, organisations and systems are at various levels of awareness, knowledge and skills along a cultural competence continuum.

The recently released NDIS Cultural and Linguistic Diversity Strategy 2018, which includes some elements of cultural competence, commits to give people with disability from CALD backgrounds the opportunity to benefit from NDIS on an equal basis.

However, the NDIS CALD Strategy would be enhanced by a more comprehensive framework, which could include the systemic, organisational, professional and individual dimensions of cultural competence.

In market terms, people with disability from CALD backgrounds represent a significant proportion of the potential participants in the NDIS and the customer base of NDIS providers.

Enablers and ways forward

There are programs that already fit well within a cultural competence framework and evidence that they can shift the needle towards stronger inclusion of people with disability from CALD backgrounds and improved capacity of services to be more responsive to cultural diversity.

The Ability Links NSW program uses intermediaries called Linkers, and has flexible and 'soft' entry points to the service system. SSI is one of the providers of Ability Links, and in the areas that SSI delivers the program, which are concentrated in outer Sydney, 64% of outcomes are with CALD participants.

Similarly, FutureAbility is a multiphase project delivering initiatives that are improving the capacity of CALD sector organisations to be 'NDIS-ready' and implementing strategies and campaigns targeting people with disability from CALD backgrounds.

Both of these initiatives are aligned with the Information, Linkage and Capacity Building program of the NDIS and we support the recent recommendation by the Productivity Commission that funding for this element of the NDIS should be increased to $131m per annum until 2023.

In SSI's experience there is great potential for Information, Linkages and Capacity Building initiatives to deliver stronger outcomes for nominated disadvantaged groups in the National Disability Strategy.

For example, these initiatives can help eligible people with disability to navigate pathways to the NDIS and strengthen mainstream supports and social and economic inclusion for people with disability who are ineligible for the NDIS.

Taken together, expanded Information, Linkages and Capacity Building funding and the adoption of a comprehensive cultural competence framework in the NDIA and the broader disability sector, can create lasting change for people with disability from CALD backgrounds.

This will help to achieve the vision of the National Disability Strategy, and help people with disability from culturally diverse backgrounds to live the lives they want to live and achieve greater social and economic inclusion.

A personal story:
Cecilia – How it would feel to spin

"Once when I was watching Korean TV I saw a group of people wheelchair dancing. The whole time this was on the screen, I couldn't look away; my heart was racing and I wanted desperately to dance like them. To spin my wheels and my body, forwards and backwards. I've thought about how this would feel almost every day since.

When I lived in Korea I was unable to work because the country has no jobs for people with disabilities. Then, when I came to Australia, I had to look after my children, and language barriers made it hard to find work. As my children grew up, I found time to go to TAFE to improve my English, but because I didn't really leave my home it was not easy for me to improve my speaking or social skills. We did not speak English in my home.

I first called Ability Links after reading about the organisation in a Korean magazine, and the first person I spoke to during that phone call became my Linker. It was amazing. I met her for the first time after that in a local café, and over time she helped me improve my social skills and gave me a lot of information which has improved my quality of life.

When I look back on life, I know having a disability has given me extra challenges to overcome. It has made it difficult for me to face what I have needed to do in order to succeed at my goals. But now I feel I can face challenges, because Ability Links has made me feel supported. Not just supported, but inspired. I've learned I need to take initiative and I've started writing essays for the Korean community. I know my quality of life depends upon me and my motivation.

Which brings me back to the wheelchair dancing. Because I am always thinking about it. I told my Linker this, that I am always thinking about it. She nodded and said she would see what she could do, but I told her I had done research: there were no wheelchair dancing groups in Australia. So together we made plans. We agreed we would form our own wheelchair dancing group, and my husband said he would help us do it.

A few weeks ago, I was told Ability Links has found an instructor and a function room — all we need now is a starting date. I've given up on dreams before, in the past. But if I do this, I will call it my triumph. I will say that I have won." [2]

Introduction

Australia is in the midst of implementing one of the most significant social and economic policy reforms ever undertaken. A key milestone in this reform was when the Council of Australian Governments (COAG) committed to a 10-year agenda articulated in the National Disability Strategy 2010–2020.

At its heart, the Strategy is guided by a vision to help people with disability to live the lives they want to live and achieve greater social and economic inclusion. The most widely known aspect of this reform agenda, the National Disability Insurance Scheme (NDIS), is one of the major components designed to work towards achieving this vision.

This paper examines this vision with a particular focus on people with disability from culturally and linguistically diverse (CALD) backgrounds. Arguably, these people, their families and carers have not fared well under the 'old' disability system, so it is timely to examine how they are faring at a time of significant social policy reform.

Settlement Services International (SSI) has a long-standing track record in delivering services and providing leadership and advocacy for newly arrived migrants and refugees. More recently, SSI has leveraged this expertise and developed a stronger capacity in the disability area, most notably through being the largest provider of the Ability Links program in NSW and also implementing a range of targeted initiatives through the FutureAbility project across NSW. SSI is well placed to reflect on this social policy reform by bringing a settlement and disability lens to this paper.

Disability and reform

Medical and social models of disability

Historically, Australia, like many other countries, had a largely institutional response to meeting the needs of people with disability – that is, they were placed in purpose-built asylums, hospitals and other institutions, often against their will. These establishments were renowned for overcrowding, harsh treatment and neglect of the people detained there, until their closure from the mid-1970s onwards. [3, p.4]

This type of institutional response was, in part, a product of the medical model of disability, which is historically how disability has been framed. Essentially, in the medical model, disability is a condition that needs to be dealt with by professionals, usually medical professionals. [4] People with disability are thought to be different to 'what is normal', and 'disability' is largely seen as a problem that needs to be fixed or cured, with the emphasis usually on what a person cannot do and cannot be. [4]

In contrast, in the social model, disability is seen as primarily being the result of the interaction between people living with impairments and the physical, attitudinal, communication and social barriers in their environment. [4] A social model perspective does not deny the reality of impairment nor its impact on the individual. However, it does challenge us to accommodate impairments that are part and parcel of human diversity.

The social model works to change society in order to accommodate people living with impairment; it does not seek to change persons with impairment to accommodate society. It supports the view that people with disability have a right to participate as citizens on an equal basis with others.

The wider adoption of the social model of disability has helped to shift institutional responses to disability, which were gradually replaced after 1986 with the advent of the National Disability Program – later the National Disability Agreement (NDA) – which provides a framework of government block funding for disability services. [3] There is broad recognition that, under the NDA, the services and supports provided to people with disability as a whole were inadequate, to meet either their direct needs for care and assistance, or their aspirations to participate fully in society.

In 2009, a Commonwealth report *Shut Out: The Experience of People with Disabilities and their Families in Australia*, drew on public submissions and consultations and noted:

'More than half of the submissions received … said that services and programs act as a barrier to, rather than a facilitator of, their [social and economic] participation.'[1]

A rights-based and inclusive approach to disability

Australia ratified the United Nations Convention on the Rights of Persons with Disabilities, a human rights instrument, in 2008. [5] The purpose of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. [6]

Arising from this commitment, the National Disability Strategy 2010–2020 was developed to underpin the implementation of the UN convention, to improve the lives of people with disability in Australia and help address the historical disadvantage that they face. It was signed by the COAG in 2011, committing all governments to:

'a national approach to supporting people with disability to maximise their potential and participate as equal citizens in Australian society.' [5, p.3]

In signing the National Disability Strategy, Australian governments recognised that:

'people with disability are more likely to experience: relatively poor health; lower levels of participation in education, training and employment; social exclusion; lack of access to goods, services and facilities; ongoing discrimination.' [5, p.12]

The Strategy aligns with a rights-based and inclusive approach and outlines a strategic intent across six policy areas for people with disability:

- Inclusive and accessible communities (including transport, buildings, housing, communications technology, and social and cultural life)

- Rights protection, justice and legislation (including anti-discrimination, advocacy and justice system)

- Economic security (including employment and income support)

- Personal and community support (specialist disability support and mainstream services, participation in the community)

- Learning and skills (education and training)

- Health and wellbeing (health services)[5, p.10]

The Strategy also emphasises the importance of individual and systemic advocacy to support people with disability to safeguard their rights and participate in the community. [5]

National Disability Insurance Scheme

During the development of the National Disability Strategy, the Commonwealth Government asked the Productivity Commission to inquire into a national long-term care and support scheme, primarily focussing on the Strategy policy area of personal and community support.

At that time, specialist disability services were delivered by the Commonwealth and states through block funding of services under the NDA.

The subsequent landmark 2011 Productivity Commission inquiry report *Disability Care and Support* reached conclusions consistent with the 2008 *Shut Out* report, finding that:

'People with disabilities and their carers are among the most disadvantaged in Australian society … This disadvantage is linked to a lack of sufficient supports.

'There is significant unmet need for disability services in Australia, and this has been the case for decades …' [7, p.111]

'The current disability support system is underfunded, unfair, fragmented and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports.' [7, p.2]

The report recommended a new national scheme, and in 2012 COAG agreed to launch the NDIS, which is expected to be fully implemented in all states and territories by mid-2019. Administered by the National Disability Insurance Agency (NDIA), the NDIS replaces block funding of specialist disability support services. [8]

The NDIS provides 'reasonable and necessary' individual supports to assist people with permanent and significant disability to participate in economic and social life. Individuals are assessed and individual support packages are developed and funded to those who are eligible. The development of supports is market-based with individuals choosing the supports they need. The scheme has an insurance-based approach and provides early intervention where this is cost effective. [8]

A key feature of the NDIS is that it is designed to give people much more choice, being able to choose their own provider and have support packages tailored to their individual needs. [7] The development and marketing of these tailored supports is the responsibility of providers in the NDIS market. The Productivity Commission projected that the NDIS will generate significant economic benefits, including through increased employment of people with mild to profound difficulties. [7]

When fully implemented in 2019, the NDIS will provide individual packages to about 475,000 people aged 0–65 with a permanent and significant disability. [8]

In 2015, there were 4.3 million people with disability in Australia [9], many more than the number who will require or be eligible for an individual support package under the NDIS. Consequently, the NDIS also includes the Information, Linkages and Capacity Building (ILC) program to assist all people with disability, their families and carers, with information and referrals to mainstream

services including health, education, employment, justice, transport and housing. The ILC is also designed to increase social and economic participation by promoting social inclusion. [8] The NDIS is a 'world-first' model [10] and there has been some uncertainty around what works best in terms of promoting social inclusion and therefore how best to configure the ILC program. [8]

A 2017 Productivity Commission study report on NDIS costs, drawing on an analysis of the NDIS Outcomes Framework and a National Institute of Labour Studies independent evaluation, found that the NDIS has increased supports, improved the wellbeing of NDIS participants and given people more choice over their supports. However, the report also cautioned that:

'not all are reporting improved outcomes under the NDIS. The groups at risk of having a less positive experience include those with psychosocial disability, complex and multiple disabilities, and language and cultural barriers …' [8, p.20]

Levelling the playing field: equity policies for CALD people with disability

The UN Convention on the Rights of Persons with Disability recognises 'the diversity of persons with disabilities'. [6, p.2]

In turn, the National Disability Strategy 2010–2020 recognises that in Australia 'people from culturally and linguistically diverse backgrounds … can be particularly vulnerable' and that 'the diversity of experiences of people with disability underpins the six outcome areas of the Strategy'. [5, p.14]

Regarding cultural diversity and equity more broadly, the Australian Government has a multicultural equity policy which applies to all of its agencies, which requires:

'Australian government programs and services [to] meet the needs of all Australians, regardless of their cultural and linguistic backgrounds.' [11]

Similarly, a central aim of the NDIS is to provide equity of access to disability supports and equity of outcomes under the scheme [12]. The National Disability Insurance Agency released its Cultural and Linguistic Diversity Strategy 2018, which makes a commitment to give people with disability from CALD backgrounds 'the opportunity to benefit from the NDIS on an equal basis'. [13]

At state level, NSW has legislated Multicultural Principles, which require equity in access to and the use of government programs. [14, 15]

Equity policies have often faced a valid criticism that they are frequently not implemented in practice, with evidence of continued unequal access to services and programs. Indeed, the evaluation of the trial of the NDIS found that, while overall it has improved the lives of many people with disability, it has to date 'left several minorities either in their pre-NDIS situation, or even in a worse situation', including people from CALD backgrounds.[12, p.xix]

The current evidence base

Despite long-standing commitments to equity by governments across Australia, the evidence base on people with disability from CALD backgrounds and other disadvantaged groups is sparse. A major national audit of disability research in Australia concluded that people from CALD backgrounds were significantly under-represented in the existing evidence base.

Part of the audit examined disability research that addressed diverse or disadvantaged groups and found that, of almost 1,700 documents retrieved, only 137 or 8% were concerned with one of these groups.

'By far the greatest proportion of research does not address … nominated diverse and/or disadvantaged groups.' [16]

Of these, only 24 or 1.5% of the research documents retrieved addressed people from CALD backgrounds, which the audit noted was a significant under-representation in the research base and the priorities identified by the National Disability Research and Development Agenda.

The audit also found that choice, empowerment and person-centred support were notably absent from disability research, and therefore it was not well aligned with the current policy impetus around choice and control. In particular, it found that much of the existing research focused on 'problems' and that evidence on how to improve access to services and achieve social and economic inclusion for people with disability, and at sufficient scale, is currently missing from the research base in Australia.

A personal story:
Jubran – taking the pain away

"When the car accident in Iraq happened, I didn't feel any pain. It's funny, everyone else in the accident, my brothers and cousins, they were all in so much pain, but I felt none. We were in hospital together, and while we were there I prayed to take the pain away and to help my family. And then something must have happened, because now I am the one with a disability, and everyone else is healthy and happy. Again, it's funny, but it's not so funny. I was 21.

I didn't let the accident stop me. Even after the back injury became a part of my life, I had a business and I was independent. In my house I had a coffee lounge, a Billiards table, a table tennis table, and a PlayStation. But Iraq was unsafe. I didn't want to have a family there. And so we came to Australia in 2015 – my wife has a citizenship here, and I was able to travel over with my brother after a brief couple of years living in Turkey.

From the moment I arrived in Australia, I knew I loved this country. The weather, the people, even the government! I've felt very supported as an immigrant and life is much easier when you know you are safe in your own home and community.

My case worker connected me with Ability Links pretty quickly. My Linker helped me apply for the NDIS, for transport assistance, and for the companion card. Not every application worked out, but that was okay. We did as good as we could, and I know my Linker is around to help me if I need anything, anytime. Like I said, this life is good. I enjoy this country.

I enjoy this country so much, in fact, that I'm going to TAFE to learn English. That's my first priority right now, and my Linker has been very supportive of this as I look forward in time. I like planning, I like thinking of the future. Like I said, I used to own a business in Iraq, and so I know how to do good things in a community. I know I cannot stop. I cannot stop working and learning so I'll be able to support my wife and twins.

That's been the best part about living here instead of Iraq: feeling safe to raise my children. They are good and they will grow up strong here. I will teach them to be strong, even though I am disabled. Back injury or not, I will fight to support my family and to live all together the best life we can in this country." [2]

Disability and cultural diversity

Data on disability and cultural diversity in Australia and NSW

The two primary sources of data on people with disability in Australia are:

- the Australian Census, conducted every five years, most recently in 2016 [17]

- the Survey of Disability, Ageing and Carers (SDAC), conducted every three years, and most recently in 2015 by the ABS, through a survey of around 75,000 people. [9]

These two sources of population data measure disability in slightly different ways which, when combined, give us a picture of the extent of disability in the Australian population.

In 2015, there were an estimated 4.3 million people with disability in Australia, or just over 18% of the population, and approximately 715,000 people aged 0–65 with a profound or severe disability. (Table 1) [9]

Table 1: People with disability in Australia, 2015

In 2015 in Australia all people with disability totalled 4.3 million people, or 18.3% of the Australian population. People with profound or severe disability of all ages were 1.37 million or 5.8% of the population. There were 655,000 people with profound or severe disability aged over 65, 2.8% of the population, and 715,000 people with profound or severe disability aged 0 to 64, which was 3% of the population. Source: ABS [9]

When we look at Australia's cultural and linguistic diversity (CALD), there is variation in how this diversity is defined and measured. The NDIS identifies a participant as being from a CALD background if their country of birth is not English speaking, or their primary language spoken at home is not English [8]. (English speaking countries are identified as Australia, New Zealand, the United Kingdom, the United States of America, Canada or South Africa.) This is consistent with the ABS SDAC data for cultural and linguistic diversity. [9]

For the purposes of this paper, the SDAC and NDIS definition of CALD will be used throughout, even though other definitions of the CALD population are arguably broader.

The National Centre for Classification in Health (NCCH), in an analysis of 2011 Census data, found that almost 4.5 million people or 21% of the Australian population in 2011 were from a CALD background. [18, p.848] By 2016 an estimated 23% of the Australian population were from a CALD background (Table 2).

Table 2: Culturally and Linguistically Diverse (CALD) population Australia and NSW, 2011 and 2016

People born in a non-English speaking country were 16% of the population of Australia in 2011, 18% in 2016, and 21% of the NSW population in 2016.

People whose main language spoken at home is other than English were 17% of the population of Australia in 2011, 19% in 2016, and 23% of the NSW population in 2016.

People who speak a language other than English were 18% of the population of Australia in 2011, 21% in 2016, and 25% of the NSW population in 2016.

People who are CALD (ie born in a non-English speaking country or main language spoken at home is other than English) were 21% of the population of Australia in 2011, 23% in 2016, and 27% of the NSW population in 2016.

NSW has higher percentages than the Australian average of people born in a non-English speaking country and of people who mainly speak a language other than English at home. At the 2016 Census, an estimated 27% of the NSW population was from a CALD background (Table 2).

[end of table]

When we consider people with disability and country of birth (Table 3), the 2012 SDAC shows that 19.1% of all Australians (excluding recently arrived migrants) have a disability, and that 19.4% of those born in a non-English speaking country are people with disability. [19] Similarly, 5.8% of Australians had a profound or severe core activity limitation, while that figure was 6.1% for people born in a non-English speaking country. [19] In market terms, people with disability from CALD backgrounds represent a significant proportion of the potential participants in the NDIS and the customer base of NDIS providers.

In summary, reliable population data indicate that people born in non-English speaking countries have rates of disability, and rates of profound or severe disability, similar to the general Australian population.

This runs counter to debates around the so-called 'healthy migrant effect' on the extent of disability among people from CALD backgrounds. Essentially these debates centre on the fact that Australia's migration program, and in particular the health requirement, excludes people with disability (and people with a range of health conditions).

For example, the Australian Institute of Health and Welfare (AIHW), in a broad analysis of the health of Australians, proposed that migrants have lower rates of ill health and disability because of the selective nature of health screening in the migration program, and used this to explain their lower usage of specialist disability services. [20]

However, a detailed analysis of 2011 Census data by Qingsheng Zhou specifically tested the theory of the healthy migrant effect. His analysis found that the age-standardised rate of people needing assistance for core activities was nearly the same for people born in Australia and people born in non-English speaking countries, and slightly higher for people who mainly speak a language other than English at home. [18, p.850] He therefore concluded that there is no evidence of a healthy migrant effect in disability.

Zhou also referenced ABS and AIHW data which showed a 'service access gap', with much lower levels of use of specialist disability services by people born in a non-English speaking country compared to the broader community, [18] and concluded that:

'This cannot be explained by the difference in the level of need for assistance between Australian-born and migrant populations.' [18, p.844]

Utilisation of disability services by CALD communities

When we examine the uptake of disability services by people from CALD backgrounds, this service access gap is consistently found across several data sources. Each year, data on the utilisation of disability services in Australia is collated in the Report on Government Services, produced by the Productivity Commission. The report is predominantly data on the use of the 'old' disability services under the NDA, which is being replaced by the NDIS, alongside data from the SDAC and the Census, as well as data on users of disability services by country of birth.

The 2015 SDAC shows that 355,000 people with disability aged 15–64 received formal assistance for at least one activity, and 37,000 or 10% of these people were born in a non-English speaking country. [21, Table 15A.60] In 2016, 18% of the Australian population were born in a non-English speaking country. [22] As outlined previously, people born in non-English speaking countries have similar rates of disability and needs for formal assistance as the general population. Therefore, the *Report on Government Services* [21] indicates that people with disability born in non-English speaking countries are about half as likely to receive formal assistance as people born in Australia.

The Report also presents more refined data on users of specialist disability services, compared to the potential population. 'Potential population' means people who potentially have a need for each category of specialist disability service, based on ABS Census data, so this data identifies the rate of service use by such people. There are striking differences in rates of specialist disability service use between people born in English speaking countries (including Australia) and non-English speaking countries at a national level and at State/Territory level.

National data (Table 4) and NSW data (Table 5) show that for most NDA service categories, in 2015–2016, people born in a non-English speaking country were a third or half as likely to use these specialist services when needed, compared to people born in Australia or another English speaking country. For example, data on accommodation support services in NSW shows that for every 1,000 people aged under 65 with a potential need for this service and born in a non-English speaking country, 21.3 people used accommodation support. By comparison, in the same year, for people born in an English speaking country (mostly born in Australia), 60.7 people used this service per 1,000 with a potential need. These patterns of low uptake are more or less consistent in national and NSW data across all disability services categories. The sole exception is NDA employment services, with similar rates of utilisation independent of country of birth in recent years. [21, Table 15A.36]

Table 4: Users of NDA specialist disability services, country of birth, 2015–16, Australia

Table 4 shows users of National Disability Agreement (NDA) services per 1,000 potential population under 65, by country of birth, for Australia 2015-2016.

For accommodation support services, people born in a non-English speaking country have 24.8 users per 1,000 potential users, compared to 64.9 per thousand potential users for people born in an English speaking country. Therefore potential users born in a non-English speaking country are only 36% as likely to use these services as those born in an English speaking country.

Similarly for Community support services the comparative figures for Non-English speaking country and English-speaking birthplace are 112.5 and 239.7 per 1,000 potential users, so people born in a non-English speaking country are only 47% as likely to use the services.

Figures for other NDA services also show less use by those born in a non-English speaking country, with the figures for Community access services being 59.2 compared to 82.2 which is 72%. For respite services the figures are 67.9 and 143.5, or 47%, and for NDA employment services they are 453.1 and 484.9, which is 93%.

Table 5: Users of NDA specialist disability services, country of birth, 2015–16, NSW

Table 5 shows the same data as for Table 4, but for NSW instead of Australia. The NSW 2015 – 2016 figures on NDA service usage per 1,000 potential population, for Accommodation support services are 21.3 per 1,000 potential population for people born in a non-English speaking country, and 60.7 for people born in an English speaking country, so those born in a non-English speaking country are only 35% as likely to use these services. For Community support services in NSW the figures are 74.5 and 212.4 for 35%, for Community access services its 44.5 and 96.9 for 46%,

Respite Services are 65.7 and 154.1 for 43%, and NDA employment services are 469.8 and 514.1 for 91%.

[end of table]

Therefore, despite people from CALD backgrounds having similar rates of disability and need for assistance as the general Australian community, in 2015–16 they had significantly lower use of most specialist disability services, a pattern that has persisted for decades. The NSW Department of Family and Community Services (FACS), which has portfolio responsibility for delivering disability services, reached a similar conclusion:

'At present, people born in main non-English speaking countries are three times less likely to use a government funded disability service than a person born in an English speaking country.' [23, p.9]

NDIS program data (Table 6) indicates that, despite the scheme being a radically different approach to the delivery of human services, it appears to be underperforming when it comes to people from CALD backgrounds.

With 23% of the Australian population from a CALD background, according to the NDIA definition in 2016 (see Table 2), and people born in non-English speaking countries having similar rates of disability as other Australians (see Table 3), we would expect approximately 23% of NDIS participants should be from a CALD background.

However, at 31 December 2017 just 7.2% of NDIS participation plans in Australia, and 8.5% of plans in NSW, were being delivered to people from a CALD background. [24, p.26] This is approximately one third of the proportion of people from CALD backgrounds we would expect to be accessing the NDIS – arguably no better than under the 'old' disability service system.

Table 6: NDIS participants and CALD participation at 31 December 2017, Australia and NSW

Table 6 shows that for Australia there were 130,455 NDIS participant plans at 31 December 2017, and of these 92% were non-CALD, and 7.2% were CALD participants, while 23% of Australian population was CALD by the NDIA definition. Similarly, NSW had 72,513 NDIS participant plans, with 8.5% of these CALD participants, while 27% of the NSW population was CALD. Source: NDIA [24]

[end of table]

At the end of 2017, the NDIS had in place 130,455 active participants out of the 475,000 it anticipates at full rollout in 2019. [8, 24] This represents 27% of the final projected total. Therefore the significant under-representation of people from CALD backgrounds cannot simply be attributed to a small sample size or to the demography of NDIS trial site locations.

In the area of disability, it is generally accepted that there are barriers to CALD people accessing services, but it has also been suggested that some migrants may choose not to access disability services.

The 2018 *Report on Government Services* suggests that lower rates of utilisation for disability services by 'special needs groups' can indicate reduced motivation to access services, while also acknowledging that the available data does not provide information on whether the services were appropriate or correctly targeted to meet the needs of the people receiving them. [21] The Productivity Commission points out that lower use of disability services by people born in a non-English speaking country and other special needs groups:

'…can also represent strong alternative informal support networks (and a consequent lower level of unmet need), or a lower tendency of people in a special need group to choose to access NDA specialist disability services.' [21, pp.15.9-15.10]

This suggests that low service use could be caused by migrants choosing not to use services, rather than barriers to service use, which could be the result of migrant families and communities having greater capacity to provide support, and being reluctant to use disability services for cultural or other reasons.

However, there is no evidence that migrant families have a greater capacity to provide informal care. In fact, many migrants and refugees have few resources or connections in Australia, and experience social isolation. [25]

There may indeed be cultural stigma around disability and some distrust of government agencies, which can present barriers to using services. Some CALD families may not wish to identify their family member as having a disability due to stigma, and they can be concerned at being isolated from their community, which may be an important form of support. In such cases, a person with disability may not receive an appropriate diagnosis or services, and only receive informal care in the family. [26]

However, migrants who do access disability services appear to value them at similar levels as the general population. The SDAC 2012 shows that 74% of people born in a non-English speaking country were satisfied with the quality of assistance received from formal disability services, compared to 80% of people born in Australia. [27, Table 3.8] We need to be cautious about this measure as people from CALD backgrounds are an underserved population in terms of access to disability services, and there may be response bias in terms of them being 'grateful' recipients of services that they are entitled to receive.

A personal story:
Shobna – the boss of the house

"To me, the most important part of being a mum is that a mum knows what is wrong and what is right. I've been unemployed for a long time, and I worry that I'm not able to teach my kids properly, because I don't feel very connected to the real world. Sure, I've done a lot of volunteer work, like at playgroup when my kids were younger, or at the canteen of the school where my kids go now, but it's not a career. I don't make any money volunteering, so I can't feel like the boss of the house. But I still like to do it, and funnily enough it's actually while volunteering at the canteen that I met my Linker.

I asked my Linker to help me find part-time work. My kids are 14 and 16, so I'm looking to get a job I can do during school hours. The first thing my Linker did was work with me to update my resume to the right format so I could start applying. Then we planned for courses of interest that would be important for particular jobs. My Linker was then able to connect me with First Aid and Mental Health First Aid courses which I completed. I believe these courses will hopefully make it easier for me to get a job in the future. Most importantly though, finishing the courses has given me the confidence to learn new skills again. I used to work at McDonalds before my kids became my priority, so I do have employable skills, but my Linker has been very helpful in helping me plan and work with me to bring back my confidence so I can get ready to start working again.

I am still working towards getting a job, and I'm applying a lot. My Linker has been great; supporting me in different ways so that I can make myself more employable, or do better in interviews – but the truth is I know I have a lot of those skills on my own. I know how to dress well, how to get myself out there. What Ability Links is doing is helping me prove that again. My Linker

was able to introduce me to a Job Readiness Program, and I undertook all four sessions. With the support of my Linker, I am doing everything I can to get employed again.

I hope to be independent very soon, I hope I will be able to support my kids, and to prove myself to the world again. Once I prove myself to the world then I can teach my kids about it. That's a mother's role – the role I want to fulfil." [2]

Barriers and challenges for CALD communities

One of the dominant themes in the evidence base for people with disability from CALD backgrounds is the intersectionality of multiple issues that heighten vulnerabilities and compound the barriers and challenges they face.

This is exemplified by the lived experience of one migrant family:

'I care for a mother with a psychiatric disability. My mother is from Greek background. I remember my mother … in social events with her extended family [and] the medication she was taking making her drowsy … she was excluded from the main table of events and left sitting alone for long periods. As I got older I was able to speak up and change doctors to put her on a newer type medication. My father was unable to do this due to language barriers – at the time he knew nothing of community mental health centres. He did not have any information in his own language about where to go for help.' [1, p.57]

This theme of multiple barriers is also highlighted in the National Disability Strategy 2010–2020 which recognises that:

'People from culturally and linguistically diverse backgrounds … can be particularly vulnerable. Those with disability are likely to experience multiple disadvantages. Lack of accessible information, communication difficulties or cultural sensitivities and differences can create barriers to services and support.' [5, p.14]

Likewise, NSW Family and Community Services has pointed out:

'The available literature indicates a broad range of issues and barriers experienced by people from CALD backgrounds that impact on service delivery in general. These can be divided into cultural, structural and service-related barriers.' [23, p.9]

The 'old' system of disability services was often characterised as being complex and difficult to access, even for people born in Australia who are reasonably familiar with a 'Western' system of government services and entitlements.

Soldatic and her colleagues examined the intersectionality of disability, cultural difference and low English proficiency, and noted that each of these factors can compound social and economic exclusion. [26] Advocates in multicultural communities have also drawn attention to these compounding barriers including: disability services not being appropriate for the needs of CALD communities; poor understanding of disability by some families; and distrust of government agencies due to negative experiences in other countries.

The Federation of Ethnic Communities' Councils of Australia (FECCA) has pointed to a lack of community awareness about disability support services and a lack of information in community languages. [28] Others, such as the National Ethnic Disability Alliance (NEDA), have highlighted a gap in understanding of the disability service system in situations where migrants' countries of origin do not have disability services, or where those services and supports that exist are radically different to those in Australia. [29]

However, we must not lose sight of the fact that it is the responsibility of the service system to be accessible to all people with disability. Regarding the capacity of disability services to be culturally responsive, the 2009 *Shut Out* report – based on consultations and submissions from stakeholders, including people with disability, their families and carers – reported the following in terms of people from CALD backgrounds:

'Most noted that few disability services possess the skills or resources to meet the specific needs of people with disabilities from differing backgrounds, and their relative inexperience with different cultural groups can make them insensitive to the issues involved.' [1, p.58]

Emerging challenges under the NDIS

The NDIS is the most widely known aspect of the current disability reform agenda and one of the major components designed to work towards achieving the vision of the National Disability Strategy. Worryingly, the early evidence is that the low rates of access for migrant communities, seen under the 'old' disability system, are being replicated in the market-based approach of the NDIS. [8, 12]

The Evaluation of the NDIS by the National Institute of Labour Studies (NILS 2018) notes that 'the need for equity and fairness is a fundamental ethical underpinning of the NDIS'. However, it found that participants from CALD backgrounds, and other disadvantaged groups such as people with intellectual disability, were 'at risk of being allocated lower levels of funded supports'. [12, p.185]

We know that market conditions by themselves do not necessarily create options and choices for people. [30] The NDIS requires participants or their families to self-advocate to have their needs met, and disadvantaged groups are less able to do this for themselves, compared to individuals and families who understand the NDIS system and are better able to articulate their needs. The NILS evaluation noted that 'the NDIS was considered by providers … to be working particularly well for articulate, English speaking participants.' [12] As one provider said:

'If you're an educated, middle-class, white person, it's fine, it works well.' [12, p.198]

Furthermore, the Productivity Commission has highlighted that under the NDIS, where the number of participants or providers of supports are too small, this can create shortages of services for CALD people and other groups [8] and refers to this phenomenon as 'thin markets'. In addition, NDIA staff have identified a range of hurdles to meeting the needs of CALD participants, including a lack of direction by NDIA in working in culturally responsive ways, lack of translated and culturally appropriate resources, and limited staff awareness of different cultural understandings of disability. [12]

These early indications from the NDIS are a signpost that a more comprehensive and targeted response is required in the NDIS by the NDIA and other service providers to enable greater access and inclusion by people with disability from CALD backgrounds. People from CALD backgrounds have often been framed historically through a deficit lens, highlighting their poor English language skills or traditional cultural beliefs as the 'cause' of their low usage of services or limited participation in society. The persistent patterns of underutilisation of services for decades by people from CALD backgrounds raises a question: what efforts were made to achieve equity for

people from CALD backgrounds from block-funded services? In the market-based NDIS, it raises a different question: what is the rationale for providers of services to underserve a significant proportion of their potential customer base?

The underutilisation of services by CALD communities and other equity issues is not in any way inevitable. As with all people with disability, there are barriers, but there are also enablers that can improve outcomes and deliver greater inclusion for people with disability from CALD backgrounds.

A personal story:
Kyung – twenty-one years

"For 21 years, I did not get any help with Justin. I thought: 'I can help my son, I can support my son, I can look after my son alone until I die.' But I did not know what would happen to Justin after I died, and I thought about that a lot.

Justin often struggles with talking, and so last year I took him to his GP to get some help finding a speech therapist. I hoped for Justin to be able to communicate better with me and his peers at the special school he attends. During our appointment, the GP recommended Ability Links, and shortly after that we met our Linker.

It didn't take long after that for us to be connected to services and communities we had never accessed before, and that we did not even know existed. As well as the many services that support Justin, I have also been connected to a carers' group, and am now part of a community of people in similar situations to me. I have friends now who I can open up to and share my experiences with, and they understand me, and this has taken a lot of the weight off my shoulders.

My son loves the new Community Support Centre. Before we were introduced to Ability Links, I took Justin with me everywhere, even when he wasn't interested, because there was no one else to look after him. Thanks to our Linker, Justin is now connected to a place where he can participate in activities and be made to feel happy. And so I feel happy too.

What Ability Links has done is made me feel more confident in my son's future. I love Justin and I always will, and with the support and connections that Ability Links and our Linker have provided, I can now see a future where my son will one day be independent in the community." [2]

Enablers and ways forward for CALD people with disability

The National Disability Strategy provides a strong intergovernmental framework for a rights-based and inclusive approach across a range of policy areas for people with disability. However, an enhanced response is required to enable people with disability from CALD backgrounds to live the lives they want to live and achieve greater social and economic inclusion. A starting point for scoping this is to use a cultural competence framework to help improve the responsiveness of disability and mainstream service systems.

Cultural competence has been defined as:

'a set of congruent behaviours, attitudes, policies and practices that come together in a system, agency or among professionals which enables them … to work effectively in cross-cultural situations.' [31]

In 2006, the National Health and Medical Research Council released a framework to help the overall health system and services to be more responsive to CALD communities. [32] The complexity and breadth of the health system is comparable to that of the disability service system. The four dimensions of the framework – systemic, organisational, professional and individual – interrelate 'so that cultural competence at an individual and professional level is underpinned by systemic and organisational commitment and capacity'. [33]

Cultural competence is also a developmental process that evolves over an extended period. Individuals, professionals, organisations and systems are at various levels of awareness, knowledge and skills along a cultural competence continuum.

The NDIA's recently released Cultural and Linguistic Diversity Strategy 2018 [13] provides a welcome starting point for developing cultural competence within the NDIS. Here we argue that the implementation of the Cultural and Linguistic Diversity Strategy could be enhanced through actions across the four dimensions of cultural competence.

In the past year, the Productivity Commission and the NILS Evaluation Report have pointed to systemic barriers to CALD participants in the NDIS. Both identified the importance of funded formal intermediaries, to assist CALD and other disadvantaged participants to navigate the NDIS planning process and achieve the NDIS supports that they require. [12, p.202] People with disability from CALD backgrounds may not have the sociocultural literacy of the service system that is needed to get the support they need [26], and the Productivity Commission has concluded that many people eligible for the NDIS will need additional support to get what they need and want from the scheme. [8]

A 2018 Parliamentary Committee report reached a similar conclusion, recommending 'tailored pathways' designed to support participants from CALD and other disadvantaged groups. [34]

Another effective solution to systemic access issues for CALD communities (and other disadvantaged groups) is to design flexible and 'soft' entry points in community-based settings, flexible eligibility criteria with no unnecessary barriers or upfront costs, and a 'soft' touch approach to support that maximises the opportunity for establishing rapport and trust.

Formal intermediaries and flexible approaches could be built into the ILC initiatives of the NDIS, which aim to build the capacity of people with disability and their families to access mainstream services and participate in the community. [35] We support the recent recommendation by the Productivity Commission that funding for this element of the NDIS should be substantially increased to $131m per annum for the remainder of the NDIS transition period to 2023. [8]

Organisational-level responses are also needed, especially for NDIS service providers which do not yet have experience or competence to engage and work with CALD participants. All providers should be encouraged by the NDIA to develop a suite of services that match the aspirations of participants, including CALD participants. NDIS providers should analyse the demographics, in terms of cultural diversity, of their service catchment areas and compare this to the demographic indicators of people choosing their services. This would highlight gaps and identify new potential customer bases for their services.

Another effective approach is to develop the 'NDIS readiness' of providers that are strongly grounded in CALD communities, are already strongly attuned to communities' aspirations and have competence in providing culturally appropriate services. These organisations can develop, incubate and deliver culturally responsive services in the NDIS environment. Where disability providers are not strongly connected to CALD communities, partnerships with ethnospecific or multicultural organisations offer a way to engage more strongly with CALD participants. The

FutureAbility program in NSW is an effective model for building the capacity of existing culturally competent organisations to deliver services under the NDIS.

Other organisational or sector-wide strategies that are effective in building capacity to work better with CALD participants in human services include:

- recruiting culturally diverse staff who are competent to work across cultures

- recruiting staff with targeted language skills and cultural knowledge

- providing training for staff in culturally responsive practice

- developing standards and resources to include culturally responsive practices

- providing interpreter services and training staff on the use of interpreters

- providing translated information and resources and using multicultural marketing strategies to reach CALD participants

- creating a business unit that is responsible for coordinating multicultural strategies.

The Productivity Commission has recommended that, in some contexts, where there is not a large enough market to provide a service to CALD participants and other groups in an area (called 'thin markets'), then the NDIA should intervene by establishing a provider of last resort, or provide block funding for these services. [8]

At the professional level (e.g. case workers, social workers, personal care assistants, intermediaries, etc.), cultural competence implies that practices are modified and responsive to participant preferences. In health-care settings, family-centred practice has been proposed as a way to better meet these preferences in communities where collectivist notions of identity are often more prevalent and valued. [36] The use of intermediaries is also important, to assist CALD participants to navigate service systems.

Cultural competence at the individual level focuses on self-reflection, and disability service practitioners and staff being aware of their own personal culture, assumptions and mindsets. Staff can develop a deeper understanding of cultural differences to inform how they respond and provide a person-centred approach to service delivery. The participant is an expert on their own culture, needs and preferences. Asking participants about their cultural understanding of disability, and tailoring services to these individual aspirations and culture is a hallmark of person-centred care. Individual competence can also involve strengthening communication skills, including through the use of interpreters.

There are already examples of disability programs and initiatives that fit well within a cultural competence frame, and evidence that they can shift the needle towards stronger inclusion for people with disability from CALD backgrounds and improve the capacity of services to be more responsive to cultural diversity. Two examples, FutureAbility and Ability Links NSW, both delivered by SSI, illustrate cultural competence in action.

Cultural competence in action – FutureAbility

FutureAbility is a multiphase project, funded by the NSW Government, which is primarily working to improve the capacity of the CALD sector and CALD communities in NSW to be 'NDIS-ready'. FutureAbility has implemented a range of initiatives over the past four years to achieve this goal. [37] A scoping study to assess the readiness of the CALD sector to provide supports in the NDIS environment, and the development of a data cube to allow easier access by service providers to

CALD disability data both illustrate the systemic dimensions of cultural competence. At an organisational level, FutureAbility is working to develop the NDIS readiness of CALD sector agencies which are strongly embedded in CALD communities and have expertise in how to provide culturally appropriate services.

The organisational and professional dimensions of cultural competence are exemplified through FutureAbility's work in developing and disseminating disability policies and procedures to facilitate CALD sector organisations to become 'NDIS-ready', distributing business development grants to 16 CALD organisations and delivering more than 20 culturally responsive practice workshops to NDIA, Local Area Coordination and disability providers. Multicultural marketing strategies designed to reach CALD audiences, promote awareness and increase demand for NDIS services included in-language theatre plays and a comprehensive SBS radio campaign in 13 languages from late 2017 to mid-2018. FutureAbility has also implemented strategies which illustrate cultural competence in action at an individual level, targeting people with disability from CALD backgrounds, their families, carers and communities. These included in-language NDIS information sessions in more than 20 languages.

Cultural competence in action – Ability Links NSW

Ability Links NSW (ALNSW) was established by the NSW Government, which funds a range of non-government organisations to deliver the program through staff called Linkers. ALNSW aligns with the early intervention and ILC aspects of the NDIS and the National Disability Strategy. Linkers support people with disability aged 0–64 (with or without a diagnosis), and their families or carers to identify their goals and connect with their community and mainstream services. Linkers also support community organisations, mainstream services and businesses (referred to as linked organisations) to become more inclusive of people with disability.

'After finding Ability Links I've met more people and that's been magic like a great colour, because my Linker's done exactly what her name says she should do; she linked me to the community.' [38, p.1]

An independent evaluation of the statewide ALNSW found that it was generating positive individual and community outcomes for participants and reported a 3 to 1 ratio of benefits to costs, not including community and intangible social benefits. [39]

SSI commissioned an independent evaluation of its own delivery of Ability Links in 2017. Using similar methods to the statewide evaluation, it found that 64% of SSI's Ability Links individual outcomes were with CALD people, which represented 75% of the statewide program outcomes for CALD participants in NSW. [38]

The evaluation found that the strong performance of SSI's Ability Links with CALD participants was supported by the design of the Ability Links program, which is flexible, holistic, and free of cost with no upfront barriers in terms of diagnosis – all of which arguably demonstrates a systemic level of cultural competence. [38] Importantly, the evaluation found that all participants benefited from these elements of the program design with SSI also delivering strong outcomes for non-CALD participants. In addition, Linkers are able to act as intermediaries to help CALD participants to navigate and access the services they need, which offers a potential solution to a persistent weakness identified in the current delivery of services in the NDIS.

'Ability Links helped me to understand and access the NDIS and get it approved which made a huge difference. Nothing would have happened without them because of the language barrier.' [38, p.8]

Stakeholders attributed the culturally competent elements of the program including SSI Linkers being bilingual, from diverse backgrounds and connected to their communities as key to supporting outcomes, with program participants and Linkers having a shared understanding which facilitates developing rapport and building trusting relationships that help to minimise cultural and linguistic barriers.

Collectively the design elements of ALNSW and the suite of strategies implemented by SSI fit within the organisational and professional dimensions of a cultural competence framework. The evaluation found that ALNSW would have ongoing value in the NDIS environment because it supports participants, including people from CALD backgrounds who are eligible for the NDIS, and those not eligible, and effectively engages them at the local community level. [38]

Conclusion

Australia is in the midst of implementing a complex social and economic reform with the NDIS, the most visible component of the National Disability Strategy 2010–2020. An estimated 23% of the Australian population are from a CALD background, and the available evidence indicates that people from CALD backgrounds have similar rates of disability as the general population. Historically, CALD people with disability have had much lower utilisation rates of disability services than the Australian-born and migrants from English speaking countries.

The National Disability Strategy, and specifically the NDIS, does not appear to have been able to shift the needle in terms of improving access to disability services for people from CALD backgrounds. In fact the evaluation of the trial of the NDIS notes that to date it has left several minorities, including people from CALD backgrounds, no better off or even in a worse situation.

The barriers for people with disability from CALD backgrounds accessing supports are reasonably well known, what is missing is the kind of enhanced response to enable people with disability from CALD backgrounds to achieve social and economic inclusion as articulated by the National Disability Strategy.

There is merit in adopting a cultural competence framework to improve the responsiveness of the NDIA and disability providers in the NDIS market and mainstream services, services that have traditionally underserved people from CALD backgrounds. Cultural competence can also guide work to strengthen linkages and capacity building with communities to improve the social and economic participation of people with disability from CALD backgrounds. There are programs that already fit well within a cultural competence framework and evidence that they can achieve stronger inclusion of people with disability from CALD backgrounds and improve the capacity of services to be more responsive to cultural diversity.

The Ability Links NSW program and the multiphase strategies of FutureAbility are examples of these kinds of initiatives. Both of these initiatives are aligned with the ILC program of the NDIS and we support the recent recommendation by the Productivity Commission that funding for this element of the NDIS should be increased to $131m per annum until 2023.

This expanded funding and the adoption of a comprehensive cultural competence framework in the NDIA and the broader disability sector can create lasting change for people with disability from CALD backgrounds, and achieve the vision of the National Disability Strategy to help people with disability to live the lives they want to live and achieve greater social and economic inclusion.

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