



PLAN FIRST, DON'T 'RETROFIT'

Delivering on the promise of the National Disability Insurance Scheme (NDIS) for Aboriginal and CALD people in NSW.



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ABOUT NCOSS

The NSW Council of Social Service (NCOSS) works with and for people experiencing poverty and disadvantage to see positive change in our communities.

When rates of poverty and inequality are low, everyone in NSW benefits. With 80 years of knowledge and experience informing our vision, NCOSS is uniquely placed to bring together civil society to work with government and business to ensure communities in NSW are strong for everyone.

As the peak body for health and community services in NSW we support the sector to deliver innovative services that grow and evolve as needs and circumstances evolve.

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The information and views contained in this report and its recommendations are not intended as a statement of FACS policy, and do not necessarily reflect the views held by FACS or the NSW Government.

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MESSAGE FROM THE CEO

Delivering on the promise of the NDIS in NSW

The NDIS engenders the potential to transform the lives of people with a disability in Australia, through its focus on individualised funding and support. For Aboriginal and CALD people, ensuring that the NDIS lives up to its promise requires more than individual efforts on the part of the people who stand to benefit, but systemic change – in policies and practices – to address seemingly entrenched barriers to service access for these divergent and heterogeneous population groups.

Through a literature review and interviews with both CALD and Aboriginal providers working in the disability sector in both trial and roll-out sites, this report provides some practical guidance as to how these barriers might be effectively addressed prior to the scale-up of the NDIS across NSW. It opens with an overview of the barriers that persist for both population groups, charts innovative practice that already exists and provides recommendations on how to address these barriers at multiple levels.

Critically, this report argues that we need to change our way of working and respond to diversity at the design stage, through embracing system leadership. This involves a commitment to tackling silo-thinking and active efforts to connect services in a more systematic manner, to ensure that Aboriginal and CALD people with a disability can exercise greater choice and control over their own lives – in a way that works for them.



A handwritten signature in black ink that reads "Tracy Howe". The signature is written in a cursive, flowing style.

Tracy Howe

CEO

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EXECUTIVE SUMMARY

Get community together, have a conversation, form your networks and your stakeholder groups now....not just in the service provider space, not just in the community space, but integrate them both and have the conversation about here is the NDIS we need to roll out, here's what are the core pillar areas we need to take care of in the next six months.... how can we go about it? Commence that community consultation and the accountability at the start (Aboriginal provider, state-wide).

This report seeks to inform the development of policy and practices relating to the NDIS in NSW, through highlighting access barriers to the Scheme within the roll-out sites for Aboriginal and CALD people, as well as identifying opportunities for change. This is critical in light of the impending roll-out of the NDIS beyond the trial-site and the Nepean Blue Mountains area. To ensure adequate depth and rigour, and elicit rich information from a range of people, many of whom have worked with, and identify with, Aboriginal and CALD communities, we conducted in-depth interviews with a number of key informants (n=15). Participants worked in disability services as well as in policy and advocacy organisations within NSW, including the Hunter trial-site and the Nepean-Blue Mountains. These interviews were supplemented by a literature review which examined published reports, journal articles and publicly available information relevant to disability services and the NDIS in NSW.

It is important to note at the outset of this report that the terms 'Aboriginal' and 'CALD' (Culturally and Linguistically Diverse) have been utilised, in both instances, to group a range of peoples according to their sharing of a number of common elements relevant to their experience of the NDIS. This has been done for the purposes of addressing the potential for these very broad groupings to experience particular disadvantage in relation to their access to the NDIS. It is not intended for the use of these terms to suggest that either Aboriginal or CALD people with disability are homogenous communities that have a generalised experience, with universal requirements. Indeed, within both of these very broad groupings, there exist a diverse range of significant cultural, experiential and geographic variances that are relevant to their experience of disability and their interaction with disability and community services.

The report found that existing information concerning the NDIS, with the exception of the NSW Government's NDIS website, was too generic and not easily accessible to Aboriginal and CALD people. It also found that assumptions about planning, and the capacity to deliver on plan components, are sometimes at odds with the reality on the ground, particularly in regional and rural areas, where the full range of supports necessary to implement a plan may not exist. In general, we concluded that while there is evidence, to varying degrees, of institutional and organisational commitment to strengthening cultural competency, there is still significant work to do to improve culturally competent practice for Aboriginal and CALD people at an everyday level. Encouragingly, however, change is possible, provided that silo thinking is challenged, that partnerships materialise, particularly between Aboriginal and CALD-centred providers and larger organisations, and that the aspirations of a person with a disability drive service provision, which needs to be holistic, particularly during the planning stage.



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We also identified elements of best-practice, which we've termed enablers, to guide improved practice across the disability and other sectors:

Enablers: Working smarter with CALD people

- ***Build the cultural competence of organisations.*** This requires compliance guidelines, and resourcing, which ensures that organisations are committed to culturally appropriate practice at an everyday level and in all of their undertakings.
- ***Ensure good quality planning that is culturally appropriate and person-centred.*** As such, this should take into account aspects of a person's identity, including cultural and linguistic diversity, when designing supports to meet their aspirations.
- ***Information dissemination, assessment and referral processes that are easily understood and prioritise access,*** in spite of eligibility barriers under the NDIS Act, for example and that ensure people can gain access to at least some level of support.
- ***Work with communities to build a culture of human rights for people with a disability.*** Service-providers, policy-makers and other stakeholders should ensure that their engagement uses terms that engage families and individuals with a disability, but who may not, for a variety of reasons, identify as such. This could take the form of advertising information sessions or workshops as concerning 'health and wellbeing'. The imperative should be to 'de-medicalise' disability, to the furthest possible extent, whilst taking practical steps to engage other members of the community.



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Enablers: Working smarter with Aboriginal people:

- ***Develop and provide information that is relevant and culturally appropriate.*** Materials and resources developed for Aboriginal people should cater to the spectrum of communication needs, prioritising face-to-face interaction and existing community networks as means of information dissemination supported, and not led, by online platforms. Ensuring that Aboriginal staff lead engagement with communities, to build trust, is also vital to ensuring the culturally appropriate delivery of information and materials relating to the NDIS.
- ***Adequate resourcing of engagement plans and strategies.*** Engagement and information strategies must be resourced to respond to both place and culture so people are provided with information about what is possible and relevant; and who they can talk to locally to find out more. Engagement with the NDIS must be broadened beyond 'disability services' alone, to include others engaged in the health and wellbeing of communities, including Aboriginal Medical Services and trusted local general practitioners.
- ***Ensure quality planning.*** This should be holistic and, inclusive, taking into account a person's culture and addressing their needs and aspirations in the context of their wider family and kinship network. Planning processes should dedicate the time needed to deliver a quality plan that the person is satisfied with.
- ***Recognise that additional work is required to ensure that Aboriginal people and local communities can engage most effectively with the NDIS.*** Dedicate additional resources to addressing inequities in access and optimal support for Aboriginal people with a disability, recognising that there are unique historical factors and contemporary realities for Aboriginal people. This could include through additional face-to-face workshops and intensive community engagement once people develop a plan, to ensure they are deriving maximum benefit from that plan and related supports.
- ***Demonstrate leadership and inclusion by getting the timing right.*** Strategies for developing NDIS processes, implementation plans, procurement and roll out planning must, from the earliest stages, map how Aboriginal people and communities will be engaged and their needs responded to as a matter of priority. This will overcome any perception that these matters are dealt with retrospectively and will demonstrate a genuine commitment to inclusion and culturally responsive practice.
- ***Enable continual improvement of NDIS processes and service delivery.*** Make sure that resourcing is available to implement suggestions made through consultation(s) and continue to work closely with people in local communities.

On the basis of these findings, we recommend the following action(s) at multiple levels:

Macro level (Structural level factors)

Tendering

- Ensure that tendering processes, both within the NDIS and at state-level within the disability sector are informed by principles of local knowledge and connection and require lead agencies to apportion adequate funding to support listed partner agencies (co-applicants) where their tenders are successful, particularly those that purport to be working with Aboriginal communities and responding to local community diversity.
- Insert clauses in funding agreements that make it necessary to employ and train, where necessary, Aboriginal people to deliver services locally and ensure that similar clauses are included requiring improved data collection to measure the effectiveness of funding provided.

Engagement

- Ensure forward planning for rolling out the Scheme in each location includes the development of consumer engagement strategies for both Aboriginal and CALD communities.
- Develop consumer engagement strategies in consultation with Elders and members of Aboriginal and CALD communities, and resource them at levels that allow effective community engagement to occur.
- Ensure that Aboriginal community engagement with the NDIS occurs at least six months prior to the implementation of the Scheme in each site.

Workforce development

- Be aware that the workforce to deliver effective community engagement with Aboriginal and CALD communities may need time to scale up—so early engagement with Aboriginal and CALD community organisations and realistic processes of co-design will be key to delivering against the recommendations noted above.
- Employ Aboriginal and CALD staff at senior levels within organisations, including managers of Local Area Coordinators, and not just as frontline workers, to ensure accountability for both expenditure and outcomes at an organisational level.
- Ensure that organisations working in the sector can demonstrate high-level commitments to genuine inclusion for Aboriginal and Torres Strait Islander peoples, as well as CALD people.

Mid-level (Institutional systems and processes)

Recruitment and development

- Adequately remunerate staff members that undertake translation work, either through a payment-for-service approach, additional to base salaries, or through more attractive salary packages.
- Develop, and fund, project officer roles within existing organisations, whose function would be to work across agencies, individualise NDIS-related information for participants and their families and problem solve where current systems are not responsive to cultural needs. A cross-agency approach would broaden the reach of continuous improvement and assist Aboriginal and CALD people who are already engaged in the NDIS to get better outcomes from NDIS processes.

Outreach

- Develop scaffolding approaches to ensure that there is meaningful and ongoing engagement with peripheral service providers that interact with people with disability, such as Aboriginal Medical Services and trusted local general practitioners, to ensure that the NDIS is widely known and accessible to the people who need it most.
- Implement workshops that provide ongoing engagement with Aboriginal and CALD NDIS participants who already have a plan and experience in the system, to identify any systemic and ongoing barriers that may prevent them from accessing the full benefits of the scheme. These workshops should also focus on building people's capacity to access remedial systems, such as plan reviews and provide a forum for them to feedback to the NDIA as the Scheme evolves, enabling continuous improvement.

Information and resources

- Develop more flexible, including iconographic, approaches to ensure that those who are non-verbal have adequate opportunity to participate fully in disability support planning. Ensure that these resources are developed in consultation with, and allow for some evaluation by, CALD and Aboriginal people.
- Actively promote Aboriginal and CALD resources and informational materials to potential participants, and include easily-digestible information relating to the planning process in particular, as well as opportunities for plan review. This could take the form of a plain language charter of rights, for example, that lets people know what they can expect when they engage with the NDIS and related services.
- Use consumer engagement strategy development processes for Aboriginal and CALD people (as recommended above) to assess how people in each site access information and develop information resources that can be delivered through these channels (i.e. through community radio or local networks).

INTRODUCTION

It is important to reiterate that this report uses the terms 'Aboriginal' and 'CALD' (Culturally and Linguistically Diverse), in both instances, to group a range of peoples according to their sharing of a number of common elements relevant to their experience of the NDIS. This approach has been taken for the purposes of addressing the potential for these very broad groupings to experience particular disadvantage in relation to their access to the NDIS. It is not intended for the use of these terms to suggest that either Aboriginal or CALD people with disability are homogenous communities that have a generalised experience, with universal requirements. Indeed, within both of these very broad groupings, there exist a diverse range of significant cultural, experiential and geographic variances that are relevant to their experience of disability and their interaction with disability and community services.

The proportion of the population living with a disability in Australia is significant and growing. In 2009 alone, 18.5% (or 4.0 million persons) reported having a disability.¹ More recent data from the Australian Bureau of Statistics (ABS) indicates that approximately 1.3 million people in NSW currently have a disability.² Modeling conducted by the Australian Institute of Health and Welfare (AIHW) predicts that by 2030, the number of people living with a profound or severe core activity limitation is expected to reach 2.3 million, a number roughly equivalent to the size of the population of Western Australia.³ The National Disability Insurance Scheme (NDIS) actuary has estimated that of the Australians aged under 65 with a disability, approximately 410,000 people are likely to access the scheme as participants.⁴

This is unfolding against a nationwide demographic transition, characterised by an ageing and ethnically diverse population.⁵ Currently, one in four people were born overseas, a number pronounced in New South Wales (NSW), one of Australia's most diverse States in terms of country of birth and ethnicity. 31.3% of NSW residents were born overseas, with 'England (3.3% of all NSW residents), China (2.3%), New Zealand (1.7%), India (1.4%) and Vietnam (1%) accounting for the highest proportion of those born overseas.'⁶ Indigenous people comprised 2.88% of the NSW population (208,476), the second highest population of any Australian jurisdiction, based on 2011 data.⁷

Estimates of the number of CALD people with a disability vary considerably. It is critical to note that Australia's selective migration health criteria impacts on the number of overseas-born people with a disability (or more correctly, a profound core disability) resident in the country, although disability can be acquired across the life-course by people who are born-overseas, through occupational injuries or other means.⁸ The number of disability service users who are Aboriginal has increased in NSW. A report by Family and Community Services (FaCS) in NSW, noted that "[b]y 2011/12, 7.3% (3,855) of the disability service users were identified as Aboriginal, compared to 6.3% in 2009/10."⁹ Additionally, the number of Aboriginal people receiving specialist disability services has increased over time, bolstered by organisations providing Aboriginal specific services, including those who are Aboriginal-controlled.¹⁰



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The NDIS, established under the *National Disability Insurance Scheme Act 2013 (Cth)*, seeks to address the burgeoning needs arising from this demographic transition. Three-year trials of the NDIS commenced on 1 July 2013 in specific trial sites within NSW, Victoria, South Australia and Tasmania. In NSW, the trial is centred in the Hunter region, a partial roll-out is occurring in Penrith and the Blue Mountains and the recently signed Bilateral Agreement between the NSW and Commonwealth Governments charts the full roll of the Scheme due for completion by 2018. As a system, the NDIS engenders the potential to enable people with disabilities to live in their community, providing a greater degree of autonomy for people, improving their mobility and quality of life more broadly, as envisaged by article 19(b) of the *Convention on the Rights of Persons with a Disability (CRPD)*—namely the right of people to live in the community.¹¹

While attention has increasingly been afforded to examining barriers to, and enablers, of access to disability services, and to a lesser extent the relatively new NDIS, comparatively little attention has been paid to the issues faced by Aboriginal and Culturally and Linguistically Diverse (CALD) communities in accessing such services in Australia.¹² These are critical gaps. Although universal interventions, such as the NDIS, engender the potential to promote choice, some aspects may exacerbate existing inequities in access to services¹³, unless focused approaches to bridge these gaps are integrated.

A snapshot of uptake rates at different time-points provides some indication of improved Scheme access for Aboriginal people, although not to the same extent for CALD people. For instance, the June 2015 report of the NDIA to the COAG Disability Reform Council provided base-line data across trial-sites, and partial roll-out sites, in all relevant states and territories. It showed that of the 4,605 people with a plan in NSW, 5% of participants were Aboriginal and/or Torres Strait Islander, whilst 2% were CALD.¹⁴ The more recent November 2015 quarterly report prepared by the NDIA, showed that in the Hunter trial site, 6% of participants were Aboriginal or Torres Strait Islander, whilst 2% were CALD and in the Nepean Blue Mountains roll-out site, 2% were Aboriginal or Torres Strait Islander and 4% were CALD (although, admittedly, with a very small number of people registered with a plan).¹⁵

Previous reports have also highlighted the lack of systematic data collection and disaggregation by ethnicity or Aboriginality,¹⁶ which may be attributable to data collection processes themselves. This presents issues in terms of equity, insofar as it can render levels of access, and unmet need invisible.

This report provides an overview of barriers to access to the NDIS for CALD and Aboriginal people in NSW. It also seeks to identify factors that facilitate access to available services and explore whether there is a gap between stated policy goals and practice(s). It opens with an analysis of broader barriers to access to services for people with a disability, drawing on the international and local literature. Owing to the commonalities in some of the issues encountered, the findings are presented thematically, but reflecting an acknowledgement of different lived experiences for specific population groups. The findings of in-depth interviews conducted with key informants from both Aboriginal and CALD backgrounds are then presented thematically, prior to a critical discussion.

THE NEED

I am confident that the community disability sector is committed to addressing the issues of access to services for all. However, the practical reality is that putting resources (that cannot meet present needs) into areas such as ethnic access are not likely to be seen as high priorities without additional funding.¹⁷

Intergenerational disadvantage

The presence of intergenerational disadvantage is an ongoing issue for many Aboriginal people accessing the NDIS. Gilroy, drawing on the work of Eckerman, describes this as part of the spiral of colonisation and alienation in Aboriginal Australia.¹⁸ Intergenerational disadvantage shapes people's expectations and exposes them to particular challenges in everyday life, including the inability to secure adequate housing, healthcare, employment in some instances, as well as sustainable and accessible transport options.¹⁹ Aboriginal people across Australia, as well as within NSW, experience persistent disparities across specific health and social wellbeing indicators, including:

- Poor living conditions, leading to greater exposure to infectious disease and placing people at risk of subsequent impairment.²⁰ For example, 94% of vision loss amongst Indigenous peoples nationally is preventable. The leading eye conditions are cataract, refractive error, optic atrophy, diabetic retinopathy, and trachoma.²¹
- Poorer socio-economic outcomes generally, which can intersect with factors such as living in rural or remote areas.²²
- Higher levels of incarceration and specifically pronounced levels of incarceration of Aboriginal people with mental disabilities in NSW.²³

The burden of intergenerational disadvantage is reflected in disparities in rates of disability between Indigenous and non-Indigenous Australians.²⁴ The age-standardised rate for Indigenous Australians who have a profound or severe core activity limitation, for example, is approximately 2.2 times the rate for non-Indigenous Australians.²⁵ Additionally, the risk of developing a mental illness is higher when a person has a physical or intellectual disability and/or experiences poverty or neglect.²⁶ Intergenerational disadvantage therefore not only drives existing disparities, but also exacerbates the burden, particularly when measured in terms of mental ill-health, for people already living with a disability.²⁷ Recognising the magnitude of this problem, a recent Productivity Commission report cautiously identified some levers for reform, noting:

There is some scope for the National Disability Insurance Agency, in cooperation with government agencies and local communities, to attempt to address the high rate of disability among Indigenous Australians through prevention measures and early intervention. However, addressing the socio-economic disadvantage that underlies the higher rate of disability among Indigenous Australians is an issue for all of Australian society and requires a long term whole-of-government approach.²⁸

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Whilst this represents welcome recognition of the nature of the issues, it does not articulate what form responses could take, and where responsibility for more seemingly intractable issues lies. A survey of 'multicultural' service providers, conducted by the Federation of Ethnic Community Councils (FECCA) found that, for CALD communities, these issues were also relevant. One respondent to the survey noted, for example:

Transport is constantly being identified by the government agencies as an enabler yet both Federal and State governments continue to defer the discussion on how people with disability can access affordable, accessible transport, such as trains, buses, taxis or community transport.²⁹

Eligibility

The challenges posed by restrictive eligibility criteria, governing access to both the NDIS and existing disability services, have been noted in the extant literature.³⁰ This affects migrants in specific visa sub-classes as well as service providers. It can also affect Aboriginal people, where adverse determinations are made around eligibility, impacting on a person's ability to develop a plan and gain access to the services and equipment they need. The latest NDIS report to the COAG Disability Council noted the following in relation to eligibility determinations:

26,142 access requests to the Scheme have been made by individuals, with 22,595 people currently eligible for the Scheme (85% of access requests), and 1,795 people (7%) found ineligible (this falls to 6% when ineligibility due to age and residency requirements are excluded). Only 355 (1.4%) of these access request decisions have been requested to be internally reviewed.³¹

In relation to the issue of eligibility and visa status, the report on disability in the Barwon area noted that "[v]isa status causes confusion in regard to NDIS eligibility and entitlements that DSPs [disability service providers] can support."³²

People holding temporary visas, including international students who have children while living in Australia, can be affected by these eligibility criteria. Another group affected by eligibility criteria based on visa status are New Zealand migrants to Australia who migrated following the 2001 changes to the *Migration Act 1958* and *Migration Regulations 1994*, which severely curtailed eligibility for a range of social services for this particular group. The majority of these people resident in Australia are Special Category Visa (sub-class 444) holders, meaning they are legally designated as *residents*, but not *permanent residents* and, as such, are not eligible to access the NDIS and many existing disability services in areas where they live. As at 31st of December 2014, the number of New Zealand citizens resident in Australia, and holding a sub-class 444 visa, totaled approximately 623,440 people.³³

Ability to navigate services

It is an irony that the people who have the resources [disability workers] aren't seeing the clients, but the people who don't have the resources [ethnic workers] are! This is why you need a lot more liaison going on.³⁴

The ability to navigate available pathways of service provision functions as a critical enabler of timely access to the NDIS, including for Aboriginal and CALD people. The notion of service navigation is analogous to the concept of health literacy, which has been defined as:

The degree to which people are able to access, understand, appraise and communicate information to engage with the demands of different health contexts in order to promote and maintain good health across the life-course.³⁵

This concept incorporates three levels, including *functional*, which pertains to basic skills in reading and writing, *interactive*, which involves the ability to probe more complex ideas and concepts and *complex*, which refers to the ability to critically analyse available information in a manner that enables one to overcome embedded barriers in the provision of services.³⁶

High levels of service navigation, characterised by *complex* skills, often lead to improved social wellbeing outcomes, through enabling people to make informed decisions in the context of their own lives (albeit in the absence of widespread or systematic discrimination, which has a confounding effect). Conversely, low levels of service navigation tend to lead to poorer outcomes. This can occur specifically through stifling a person's ability to exercise choice in real-world settings. A person who has a low level of literacy generally, and who is experiencing living with the sudden onset of disability as a result of a motor vehicle accident, for instance, may have their ability to exercise *informed choice* considerably impeded.

People living with a disability and who also identify as Aboriginal or CALD can experience low levels of effective service navigation, although a gradient exists depending on levels of education, particularly literacy, proficiency in English and, in some instances, duration of residence in the country.³⁷ The Australian Institute of Health and Welfare has also identified that only 16% of Indigenous Australians with a severe or profound disability completed high school, compared to 28% in the same age range (18-64 years) for non-Indigenous Australians.³⁸ CALD people also report language barriers, although admittedly this is more of an issue for people from non-English speaking backgrounds, including older migrants in particular.³⁹ In practical terms, the existing Australian literature on access to disability services has identified that low levels of literacy can lead to challenges in completing forms and difficulty in understanding eligibility criteria, which can compromise the ability of a person to secure an optimal outcome.⁴⁰ For example, a manual prepared for use in Western Australia notes that:

[T]he unfamiliarity of processes is very common amongst CaLD people as with anyone who has arrived in Australia or has encountered a new situation. Often this is not recognised by service providers who operate with a level of expectation that the client is familiar with services and how they work.⁴¹



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A recent report by Diversitat, focusing on the NDIS Barwon trial site in Victoria, also noted the challenges that exist in ensuring people can navigate the system and access services they may be eligible for, commenting “[m]any new arrivals with disability have not been linked with a disability service provider in the past so they will not automatically move to the NDIS, and in some cases may not be aware of the NDIS.”⁴²

Significantly, these issues can also be affected by shame, or a reticence to engage with services and openly share personal information as well. A report by the Victorian Government’s Department of Human Services, for example, identified issues in adequately accessing the level of need for Aboriginal people presenting to disability services:

*Access to services requires filling out forms and talking your issues up – community members are not comfortable talking about what is really going on because of the shame. They will tell you what they think you want to hear ...mainstream workers assume people understand, but they don’t... it is all jargon.*⁴³

In a Western Australian report by Stopher and D’Antoine, Aboriginal participants similarly reported the difficulties that arise when highly complex language is used to communicate the existence of available services, outline eligibility criteria, and assist people to navigate the process of gaining access to equipment and services.⁴⁴ A participant in the Lower Great Southern region (Western Australia) commented pointedly, for example: “Wadjellas have got ways of talking that Noongars don’t understand.” Another participant from the metropolitan region (Western Australia) also commented: “My daughter’s Aboriginality comes before her disability. It is very important to me that service providers understand that she is Aboriginal first and then has a disability.”

This has been termed a ‘hidden script’, reflecting what members of minority communities feel they can share with members of dominant, or majority, communities in public and interpersonal interactions.⁴⁵ Whilst this has often been considered to extend to public discourse, it operates within community and service-provider settings too and presumably not only impacts on interactions between providers and consumers, but planners too, in the context of the NDIS. This is particularly the case, as some Aboriginal or CALD people may be more reticent about specifying their needs and less aware of the available resources under the NDIS. This may hamper the development of effective plans and, later, access to equipment and services.

Nonetheless, findings from within the literature provide some instructive guidance on how to address these issues for both Aboriginal and CALD people. A report from the Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women’s Council⁴⁶, near Alice Springs in South Australia, for example, highlights the importance of messaging tailored to local communities. The report, which provides a place-specific perspective, notes:

*Community messaging relating to the NDIS needs to be two-pronged. While service providers need a clear statement of the role of the NDIS and its operations in the Lands, possibly in poster and brochure form, Anangu base their knowledge in word of mouth rather than going to written sources for information.*⁴⁷



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Moreover, a funded state-based program, Ability Links NSW, has reported some successful cases of effective support to ensure access to services for people with multiple needs. A 2015 evaluation report by Urbis provided one such case study:

Mark is an Aboriginal man in his 30's with a chronic health condition and severe mental health problems. His uncle stated that he really struggles to catch public transport due to his literacy skills. The Linker worked with the participant to identify linkages within the community that could assist him to overcome the barriers he faced. He has been linked in to a specialist mental health support program to assist him with his activities of daily living and linked to community transport services to assist him in attending his various medical appointments.⁴⁸

In certain CALD communities, specific funded programs that promote access to information about the NDIS provide instructive guidance as to how to empower people and address issues concerning service navigation. The CALD Consumer Capacity Building Project (CALD CCBP), administered by the Ethnic Community Services Co-operative and funded by the Department of Family and Community Services (FACS) in NSW, is one such example. Targeting new and emerging communities, it will involve researching and consulting with these communities on their needs, raising awareness of the NDIS and networking with local organisations to ensure access to information and support, in particular. Specific regions, and ethnic communities, of interest are:

- Sydney Metro (Fairfield and Blacktown): Assyrian and Bhutanese;
- Newcastle: Ethiopian and Sudanese;
- Coffs Harbour: Afghani and Congolese; and
- Wagga Wagga: Afghani and Burmese.⁴⁹

An earlier study conducted in Queensland, by Carlson and van Kooten Prasad, also identified the following broad strategies as central to facilitating access to disability services for CALD people:

- disseminate local examples of effective practice throughout disability services;
- provide family brokerage options and some services for people from particular cultural or linguistic groups;
- improve data collection about service users' cultural or linguistic background;
- foster feedback and consultation processes within ethnic communities;
- identify needs of family carers;
- plan ahead with families to facilitate their acceptance of gradual transitions to support options beyond the immediate family;
- use ethnic community venues and involve ethnic community leaders when providing services.⁵⁰

This highlights the importance of place-based engagement, in addition to forms of engagement centred on ethnicity, which involves tailoring services to specific needs.



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The NDIS released a *Framework for Information, Linkages and Capacity Building*⁵¹ in early 2015 to 'provide guidance to the NDIA in developing a transition and implementation strategy'. There is only one specific mention of Aboriginal or CALD under 'Stream one: Information Linkages and referrals' and again it is about access to information for people with disability, their families and carers:

- information that addresses the needs of culturally and linguistically diverse communities through the context of location and background
- information that addresses the needs of Indigenous Australians and their respective language, social or nation groups.⁵²

The NDIS has one primary fact sheet about the NDIS, *What is the National Disability Insurance Scheme?* It provides basic information about the NDIS, and sections titled 'For people who access the NDIS (participants)', 'For people who need assistance', 'For families and Carers', 'Can I access the NDIS?' and 'Next Steps'. It is offered online⁵³ in 7 languages including two versions of Chinese: Arabic, Chinese simplified; Chinese traditional; Greek; Italian; Spanish, and Vietnamese, plus a version clearly promoted for Indigenous people. In English it is available in pdf and in word (word versions often being needed for speech translators for people with vision impairment). There is also an audio link to the similar information on the webpage from which downloads can be accessed.

Moreover, in December 2014 the NDIA initiated the Disability Support Organisation Capacity Building Project.⁵⁴ The NDIA has funded 'grassroots community organisations' called DSOs to 'facilitate and support up to 20 local peer support or mutual support groups'. The Aboriginal Disability Network NSW and First Peoples Disability Network (Australia) are two of the 20 organisations selected for the first stage of the project and the only recognisable Aboriginal specialists. There is no obvious specialist DSO for CALD people so specialist capacity building for those communities may have to rely on alternative funding from State government initiatives such as those mentioned above for which the funding period ends shortly.⁵⁵ With the DSOs planning their own strategies, in consultation with the NDIA, the goals of the local support groups are to 'build the capacity' of people with disability and their families to:

- exercise choice and control;
- effectively engage with the NDIS;
- effectively engage with mainstream programs, services and activities; and
- increase opportunities for independence, self-management and community inclusion.

This literature cumulatively highlights the importance of addressing barriers to effective service navigation by taking into account the needs of local communities, and particularly forms of communication that extend beyond written forms, as well as engaging directly in referral and networking activities for members of these communities. Unfortunately, early reports on the implementation on the NDIS, including the *Interim report: Review of the optimal approach to transition to the full NDIS*, do not make reference to this specific issue for CALD or Aboriginal people.⁵⁶ Whilst the *Framework for Information, Linkages and Capacity Building* articulates the importance of the provision of information, activities that support this goal do appear to be disparate and not unfolding as part of a broader, cohesive strategy to ensure access to the NDIS for Aboriginal and CALD people.

Social and family support

Current literature notes that social and family support, or rather lack thereof, is a major barrier to access for CALD people in particular. Lack of social support can refer, for example, to stigma and negative dispositions towards people living with a disability within a community, whilst family support refers to the support a person receives from those closest to them, levels of which can vary depending on a person's situation.⁵⁷ As a result of family dispersion due to migration, many people may not have extended family support networks, as many Australian-born people would. This poses challenges for systems that rely heavily on notions of empowerment and which situate the locus of decision-making at the level of individuals and their families.

Additionally, there are other considerations, concerning gendered power relations. In relation to management of plans, for example, and deciding whether there is an unreasonable risk for the participant in self-managed funding, the National Ethnic Disability Alliance (NEDA) suggests that risk monitoring of how funds are spent should be in place because 'participants may or may not be manipulated by their carers or family members'. For instance, it was recommended that the Agency needed to address the risks that women may face due to gender roles masquerading as cultural considerations. It was suggested that 'it is important for the Agency to assess participants' relationship with significant others as in some NESB/CALD groups, a woman may not be given appropriate support to self-manage funds'.⁵⁸

In order to address this issue, and to ensure that interventions are responsive to people's needs, a number of recommendations have been made, including:

...culturally appropriate services, designed and implemented in consultation with people with disabilities from non-English speaking backgrounds, are essential to accessible service delivery and basic human rights.⁵⁹

Family and kinship networks have been identified as critical supports in the extant literature on Aboriginal people's access to disability services. Gilroy, in a study on access to disability services for Aboriginal people in NSW, highlights how even people who did not receive disability services, in a formal sense, can be recipients of family support, through kinship bonds and a notion of shared responsibility. This can rest on notions of 'owning' disability, but similarly it can rest upon historical lack of access to services. As Gilroy notes:

Some of the participants stated that there was a relationship between the 'awareness' and 'conceptualisation' of disability services and the expectation that family and kinship networks would fulfil the caring role of people with a disability in Aboriginal communities.⁶⁰

Summary

Given its recent introduction, there is not a great deal of literature specifically examining persistent barriers to CALD and Aboriginal people's access to supports under the NDIS. In light of the intersection of disability with other attributes, such as ethnicity, the extant literature does nonetheless outline three key issues that shape access; issues that exist for both CALD and Aboriginal people in NSW.

The first is the persistence of *intergenerational disadvantage*, characterised by poverty and material barriers to access existing services. The burden of intergenerational disadvantage, borne largely by Aboriginal people, although it can affect other population groups, drives not only disparities in rates of disability between Indigenous and non-Indigenous Australians, but exacerbates the burden on members of Aboriginal communities and can work synergistically to produce poor health outcomes, particularly in terms of mental health. This is an issue that, as the Productivity Commission has noted, requires action from all spheres of government, and across portfolios. Whilst this is outside the scope of the current project, it nonetheless highlights the importance of factors operating outside of the 'disability sector', but impacting on access. There is no expectation that the NDIS can or should work to overcome intergenerational disadvantage as a broad-scale concept. Rather, acknowledgement and understanding of its existence provides an instructive context that can guide decisions and priorities about resource targeting and the need to develop systems that work to ensure the NDIS works to bring advantages that are within its scope to the lives of Aboriginal and CALD people.

The second barrier is varying levels of *service navigation skills*, which impede an individual's ability to access timely and appropriate disability supports in some instances, and are equally heavily influenced by system design. Within the extant body of literature, including publicly available information, there is still relatively little published concerning specific NDIS processes that facilitate access to reasonable and necessary supports for Aboriginal people and people from CALD communities and there is limited, but growing, work on translating information about the NDIS, aside from stated goals to improve information dissemination and disparate activities. The existing literature highlights particular strategies that may remedy this situation, including tailoring messages to local communities and funding strategies and interventions that enable 'word of mouth' to promote access, particularly in rural and remote Aboriginal communities.

The third is *inadequate social or family support*. This denotes the inability of people, including those from CALD backgrounds to draw on extensive social support networks, owing to patterns of migration and settlement, which may render them as relatively isolated or unable to draw on support when they need it most. For some people, this is exacerbated by acculturative stress, arising as a result of migration. Here, tailored support, including additional resources and referral networks could play a constructive role in enabling timely access to optimal services, as outlined in the review. This report seeks to address the extent to which these issues persist for Aboriginal and CALD people with a disability in NSW.



PLAN FIRST, DON'T 'RETROFIT'

Good practice: A summary from the literature

- Place-based strategies (such as those that address the needs of rural communities), and not just generic approaches, should be adopted to ensure the participation of Aboriginal and CALD people;
- Outreach and information initiatives that involve face-to-face engagement should be employed in engaging with Aboriginal and CALD people.
- Services can ensure that they are accessible and easy to navigate by removing requirements to complete excessive paperwork (or providing support to complete it) and integrating referral processes. This can reduce the burden on a person to tell their story repeatedly to different agencies and providers each time they attempt to access specific supports.
- Where there is ineligibility for services, additional resourcing and planning is required to ensure that people can access at least some level of service provision.

OUR APPROACH

Research questions

This research project sought to address the following key questions:

1. What barriers exist to both Aboriginal and CALD people's access to the NDIS, as well as disability services more broadly, in NSW?
2. How might current best-practice, and innovative models of outreach, planning or service provision inform the scale-up and full roll-out of the NDIS in NSW, to effectively address these barriers?

Methodology

This project was guided by a qualitative approach, encompassing three step-wise phases of data collection and analysis (see figure one, below). A qualitative approach enables researchers to elicit detailed data reflecting peoples lived experiences, at a particular point in time, in their "natural settings, attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them."⁶¹

Utilising methodological insights drawn from a broad qualitative paradigm, we adopted a range of specific methods suited for detailed analysis, including semi-structured interviews⁶² (see Appendix One for interview schedules), case-studies⁶³ and visual mapping of access pathways.

Figure one: Data collection and analysis process



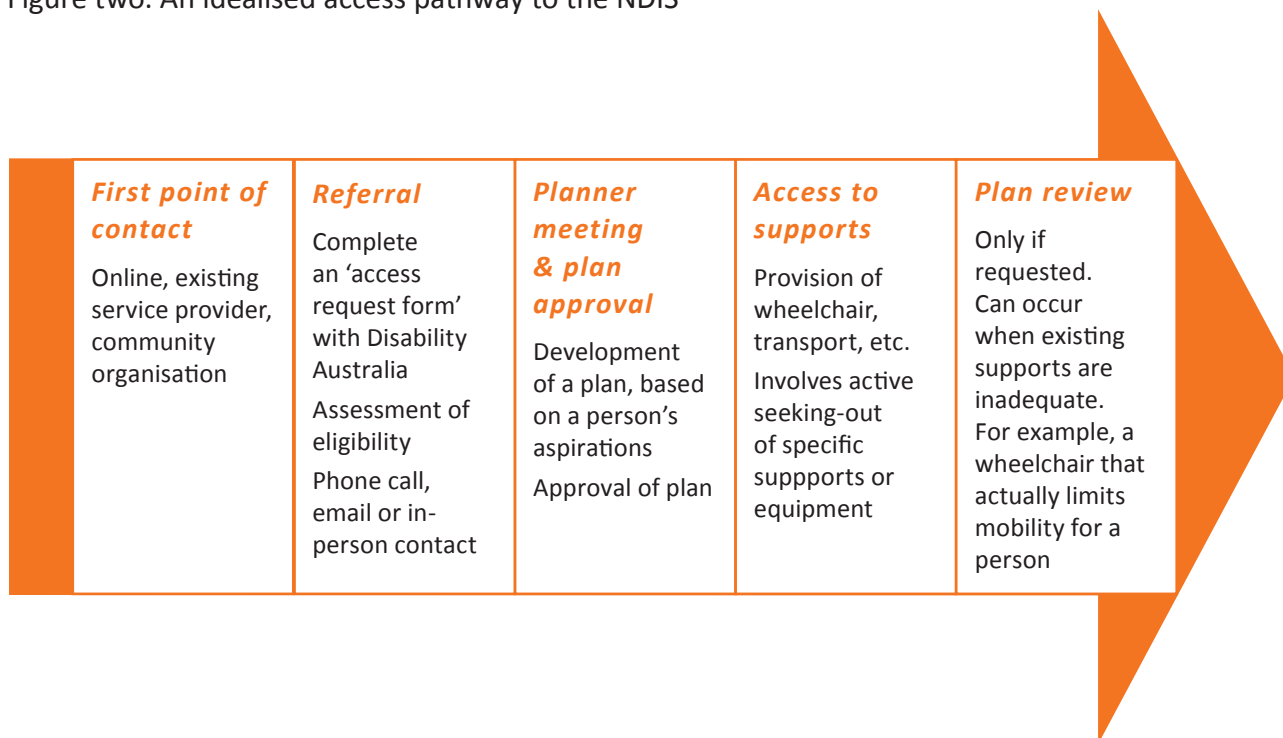
Methods and data collection

As the first stage of data collection and analysis, relevant literature (both published and 'grey') was identified using a snow-ball sampling technique. We accessed the websites of Aboriginal and CALD disability providers, as well as University research repositories (UNSW and the University of Sydney) and identified and reviewed publications, and further references that related to disability services in NSW. Inclusion criteria, for the purposes of this report centred on the relevance of publications to Aboriginal and CALD access to disability services, as well as the NDIS, in NSW specifically, and Australia more broadly. This enabled prominent publications in the field to be identified and references contained therein to be consulted further and included, where necessary.

PLAN FIRST, DON'T 'RETROFIT'

Secondly, we undertook a visual mapping of the idealised access pathway for the NDIS, drawing on publicly available information, including information detailed on the NDIS website. This was subsequently examined in light of participants' responses concerning real-life scenarios involving access to the scheme. This included how people became aware of the scheme, and disability services more broadly, as well as how they negotiated access to the planning process. A conceptual diagram depicting this access pathway is provided below.

Figure two: An idealised access pathway to the NDIS



Thirdly, we conducted a scoping audit of available resources relating to both CALD and Aboriginal people with a disability in NSW, and indeed nationally. We initially began general internet searches using keywords such as 'NDIS', 'Aboriginal communities', 'CALD communities', 'factsheets', 'workshops. We also accessed the national NDIS website and the NSW NDIS website when it was launched in October 2015. We then consulted the websites of peak bodies that represent the interests of the project target groups. Some of these websites provide fact-sheets, provide links to relevant workshops and other relevant websites and resources. Visiting these sites also allowed us to make direct enquiries, as the organisation's website usually provided a contact email address. Of the organisations we approached, respondents were either (a) quite prompt and forthcoming with their responses and direction to resources, or (b) responded that they did not have specific, targeted resources for CALD or Aboriginal people, or were working on producing them - as funding was slowing coming in, or (C) declined to reply. This enabled us to gauge the extent of information currently available, and identify new resources becoming available as the NDIS becomes a reality for more people in NSW.



PLAN FIRST, DON'T 'RETROFIT'

The Project team attended events relating to the NDIS throughout the term of the project to ensure that contemporary knowledge of the Scheme, as it was evolving, informed every stage of work. These events included workshops, Advisory Group meetings and a conference — enabling the team to engage with a range of stakeholders from the NDIA, NSW Government, academia, service providers and consumers.⁶⁴

Finally, employing a purposive approach, we conducted semi-structured interviews with people engaged in service provision (n=15) in the disability sector, and who engage with CALD and Aboriginal people, to identify barriers to accessing disability services for Aboriginal or Torres Strait Islander and CALD people, as well as factors that promote timely access to supports. Participants were people with extensive experience in the disability sector, but did not necessarily identify as living with a disability. Interviews were conducted in English, either on-site or via telephone, and lasted for a minimum of twenty minutes and a maximum of forty-five minutes. Select verbatim notes were made from audio-files, to avoid the need for full transcription, as were more detailed notes when areas of conversation were deemed relevant to analysis. According to Halcomb and Davidson, selective transcription, following reflective journalising of key issues that arose during an interview, aides the ability of researchers to engage with what participants recounted.⁶⁵ Written consent was sought, and provided, by all participants, prior to interviews taking place. Figure three, below, provides an overview of participant characteristics.

Figure three: Participant demographics - An overview

<i>Participant group</i>	<i>Participants</i>
<i>CALD</i>	<i>6</i>
<i>Aboriginal</i>	<i>5</i>
<i>Service providers/ key agencies</i>	<i>4</i>

These forms of data analysis were complemented by direct engagement by NCOSS project team members in community forums during the life of the project, including an interagency meeting, FaCS Expert Advisory Group (EAG) meetings, where NDIA and FaCS staff were present, and individual face-to-face consultations in Sydney and Newcastle, with members of communities and people working in the disability area.

Analysis

Data analysis was an iterative process. Data source triangulation was utilised, to enable the findings of the interviews to be analysed in light of the earlier findings of the literature review.⁶⁶ Data source triangulation involves the comparison of different data sources, with the aim of ensuring that findings are robust and the analysis is sound. It provides a means to guard against the tendency to merely accept one form of data in a study, with Mills observing that “researchers should not rely on any single source of data, interview, observation, or instrument.”⁶⁷

To supplement this process of data-source analysis, we undertook a process of investigator triangulation, where initial findings were presented to Advisory Group members for critical review, with a view, again, to strengthening the validity of research findings. Recognising the manner in which a researcher, or funders, views impact on the questions posed, and the findings and recommendations of a study, we exhibited critical awareness, or reflexivity, through the process of analysis.

PLAN FIRST, DON'T 'RETROFIT'

Advisory Group

To inform the project design, conduct and provide oversight concerning the written work, we formed a project Advisory Group, comprising of representatives from the following organisations, who met three times during the course of the project, and were consulted once out-of-session in relation to the initial literature review:

<i>Organisation</i>	<i>Representative</i>
<i>UNSW Law/ Social Policy Research Centre</i>	<i>Dr Rosemary Kayess</i>
<i>First Peoples Disability Network/ Aboriginal Disability Network</i>	<i>Andrew Fernando</i>
<i>PWD Australia</i>	<i>Kate Finch and Ngila Bevan</i>
<i>MDAA</i>	<i>Maria Katrivesis</i>
<i>FACS</i>	<i>Colin Jensen</i>
<i>FACS</i>	<i>Nattlie Smith</i>
<i>FACS</i>	<i>Maxine Mackay</i>
<i>FACS</i>	<i>Gosia Dybcka</i>

THE CHALLENGES

CALD PEOPLE

A culture of not accessing services

Many participants noted the historic lack of access to services by CALD people from the outset. This included instances of people not receiving any services, receiving very limited services for co-morbidities, and other cases of receipt of services for a disability that were not optimal. One provider noted:

People from a culturally diverse background end up getting the services that nobody else wants (CALD provider, state-wide).

A lot of people we work with aren't already connected with services. So there might be cases of families starting school and it's that school that picks up on an issue with a child...so they've missed out on years of earlier intervention (CALD provider, state-wide).

However, participants provided different explanations as to why this is the case. Some articulated systemic barriers, including those experienced by migrants in the country of their birth, as key determinants of this historic lack of access. One CALD worker remarked, for example:

A lot of people don't have the experience of using the services similar to here. For example...in South Asian countries, the disability services are not developed at the [same] level [they are] in Australia. So their lack of experience will be a challenge for them to engage with the service providers. Also, some of them might have bad experiences of accessing some government [services]... might have experienced some abuses. So these experiences can prevent them from articulating their goals (CALD provider, trial site).

Another reflected on the fact that new arrivals face specific issues relating to settlement:

For new arrivals...a lot of them are living in crisis mode, so we find it really difficult for them to engage in the content. They might still be worried about finding a job, their kid going to school. They're just kind of living day to day. Certainly, learning about disability might not be a big priority for them, especially if they don't know when the NDIS is coming to their area (CALD provider, state-wide).

This can result in a situation where, as another participant pointedly observed, "[s]ome groups just aren't aware that they're entitled to this [disability services]," reflecting different notions of entitlement. Whilst the NDIS is intended to address some of these entrenched issues, there is no guarantee that it will remedy inequities without sustained engagement with CALD communities.



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Other participants rationalised the barriers to access that exist as not only systemic, but as arising from attitudes towards disability within communities, whether due to stigmatised notions of a disability as a “sickness” or attributable to “superstitious beliefs”, as two participants framed it, or notions of self-sufficiency, which can arise from a distrust of bureaucracy. One participant working in an NDIS roll-out site, observed, for example:

A lot of cultures don't access services. They feel they're going to face some sort of abuse in their community for asking for services and accessing outside help (CALD worker, NDIS roll-out site).

A lot of people think it's something they should deal with in their families (CALD worker, state-wide).

These notions about what constitutes adequate care and support for the aspirations of a person with a disability can have profound implications for how workers engage with CALD people with a disability, as well as their families. Intergenerational issues, marked by a young person with a disability and a parent without the ability to converse fluently in English, can compound the challenges people with a disability face in these communities. As one CALD worker recounted:

Quite often...I've had conversations...where they've said 'I've spoke[n] to my dad and he said no'. The fact of the matter is that in most cases, the parent's capabilities in English are worse off than the person I'm dealing with. So you know that by letting them go they can't [get] the help they need and their parents aren't gonna be able to direct them to where they need to go, and there's only so far you can push that (CALD worker, NDIS roll-out site).

With more established CALD groups, where you might have the adult child with a disability who might have been born in Australia, but the carer/parent might have very different literacy levels in their mother tongue or English (CALD worker, NDIS roll-out site).

However, many participants cautioned against generalising these issues across diverse CALD population groups, or attributing lack of access to people's ethnic or national backgrounds alone. One participant mentioned that such explanations are a ‘cop-out from the mainstream’, and provide an excuse for a lack of concerted attention being afforded to access issues for CALD people with a disability, whilst another referred to the tendency to identify families as a ‘problem or barrier’, rather than as potential allies, as a serious issue in terms of engagement. As one participant neatly summarised, though, poor levels of access to services for CALD people are not “because they don't need them, it's because they don't know they exist or how to get them.”

Translating language, not concepts

The ability to effectively translate primary materials (including pamphlets, booklets and other resources) in a way that renders them comprehensible for CALD people, as well as people with low levels of literacy, was consistently highlighted as an issue by CALD participants. Many participants noted the poor quality and quantity of available resources in the disability sector, much of which was being replicated, even if inadvertently, with the arrival of the NDIS:

Enough information is not available in other languages. Even if it is available, they just use the technical jargon that doesn't make sense to CALD people (CALD worker, state-wide).

It's patchy. You've got some positive initiatives. There's some examples of good practice....but overall there's very little knowledge of what's available in the disability sector.... some communities are so far behind (CALD worker, non-NDIS).

We've failed to communicate a whole lot of stuff to ethnic communities, and so they're stuck in whatever they're stuck in around disabilities (CALD worker, state-wide).

Even where good quality resources existed, some participants reported challenges in making this information readily available to CALD people who are seeking access to the NDIS or disability services more generally. Reflecting on this, one participant, who works across NSW, pointedly remarked:

A lot of the government stuff is very general, if you can find it. The government may have a great resource that's in twenty languages, but to get there you have to click through eight pages of English.

For example, during our review of available information and resources, the national NDIS website itself was identified as relatively inaccessible and not user-friendly, particularly for CALD people. Once people are engaged in the system itself, including through trying to assess what they may be able to receive, there can be challenges in retaining them and ensuring they gain access to these reasonable and necessary supports for daily life. For instance, a participant who works within a current site in Western Sydney noted that identifying relevant staff for specific client needs was a key issue:

One of the most difficult things is trying to access staff. I find interpreters to be a quite a difficult process for people because you've got a third party...If the interpreters are a third-party they don't understand the concept of what we do. It's becoming quite difficult for people to access services if we don't have the staff to do it.



PLAN FIRST, DON'T 'RETROFIT'

These findings are consistent with those of earlier research reports in the disability sector. A report prepared by National Disability Services (NDS), which examined translation services in the disability sector, found that translators were often poorly remunerated and that existing staff who undertook translation services often did so on an un-paid basis. The report noted that this practice can have a serious impact on the ability to foster, and sustain, a workforce fit-for-purpose in this area, observing that:

[L]ow remuneration has a significant impact on the ability for interpreters to invest their time and money into additional courses and other professional development opportunities. For most interpreters, the cost of training courses and workshops is largely (if not entirely) self-funded, and as a result, this issue has been raised as one of the prime disincentives for interpreters to invest in their own development.⁶⁸

Of particular note, as many participants remarked, is the inability to directly translate concepts in the disability sector into relevant community languages. One participant observed, for example, that the term 'respite' care has no direct correlate in many community languages, commenting further: "the carer is often from their own family, so it doesn't make sense to them." Further still, some CALD people are "illiterate in their own language," as one participant observed, meaning that information needs to be more effectively explained to them. In these situations, translation of resources into community languages alone will not suffice, and more active engagement, through workshops, community outreach and community language mediums, such as radio, needs to take place. One participant remarked that this situation is the result of a tendency to view service provision to CALD people as an exercise in placation, where organisations "translate a couple of pamphlets and that's it."

Another participant remarked that the use of complex concepts and the subtle assumptions that are made around system-awareness, for all Australians, are often based on a lack of understanding:

You can't have that [opportunity] if families don't understand things like funding your son and daughter's strengths. The opportunities of inclusion, of having a job, of having a life, of following a dream and vision. If you haven't even got that, how can you talk about the NDIS as a system? Because the families are not going to have the basis on which to get the most out of the NDIS (CALD worker, state-wide).

Another participant noted, in this regard, that having bilingual staff can play an important role in overcoming some of these barriers, at least at an organisational level, because "you don't have to talk through a third person, you can talk directly to the organisation...in the words that you're using."

Nonetheless, through interviews with participants and the scoping review of resources we conducted, we identified a range of resources currently in use in NSW, or being developed by organisations, that engender the potential to improve access to information for CALD people, as profiled in case studies one and two, below. Additionally, the NSW NDIS website, launched in mid-2015, contains user-friendly plain-language content, with community language represented as well, although these resources were the last to go live.



PLAN FIRST, DON'T 'RETROFIT'

Additionally, many participants provided insights into their own models of practice that aim to improve engagement with CALD communities, concerning either the NDIS specifically, or disability services more broadly. The ethos of their service model was centred on making things meaningful and tangible to CALD people with a disability, principally through interpreting complex eligibility criteria and identifying other available supports, to optimise people's access to services. This involves the use of cultivated skills of listening and judgement. As one provider who works in a trial site asserted, "[w]e pride ourselves on being able to talk to people and speak to them at their level", further commenting, in relation to language barriers, "[i]n the past, I've used picture cards, and if that's the solution, then so be it."

Another participant remarked that they undertake active outreach to ensure that they reach CALD people with a disability, their families and carers:

Often we go to them. We've started by contacting settlement services...they already had those relationships with families; they knew which ones would need the information.

Many of these approaches at engagement exhibit characteristics of what de Certeau terms 'tactics'. Tactics are "isolated actions" taking place in the "the space of the other...a terrain imposed on it and organised by the law of a foreign power."⁶⁹ They are creative approaches that individuals, including people with a disability themselves, but more often their families and key workers, adopt to erode barriers to access and receipt of services and supports. Such tactics provide a critical counterpoint to 'strategies', which belong to the powerful, including institutions such as the NDIA, through the scheme rules, in favour of efforts that seek to erode exclusion, to assert a notion of agency.

To support these efforts on the part of people with a disability, their families, and carers, there is significant scope for agencies to develop more flexible, including iconographic, resources. This would ensure that those who are non-verbal have a full awareness of the breadth of available supports and adequate opportunity to participate fully in disability support planning.

PLAN FIRST, DON'T 'RETROFIT'

Case study 1: My Choice Matters (NSW Consumer Development Fund)

The organisation: My Choice Matters is an initiative of the NSW government, and is governed in partnership between the NSW Council for Intellectual Disability (NSW CID) and the Ageing, Disability and Home Care, NSW Department of Families and Community Services (ADHC). Its aim is to work with people living with disability and their families, listening to their needs and wants in order to successfully navigate the changing disability system.

The work: My Choice Matters provides online factsheets regarding the NDIS, and other publications in the following languages: Arabic, Chinese, Greek, Hindi, Korean, Russian, Spanish, Tamil, and Vietnamese.

My Choice Matters is also one of the few organisations who have run, and continue to run, workshops in community languages. Although some organisations in the CALD sphere have run workshops, they tend to focus on capacity building within the CALD space, rather than directly engaging with CALD people with a disability and accessing the NDIS.

Examples of past events:

'Get More Skills' for the Turkish Community: Auburn (21st October, 28th October, 4th November)

'Get More Skills' for the Vietnamese Community: Canleyvale (22nd October).

'Get More Skills' for the Arabic speaking Community: Auburn (18th November)

Source: MyChoiceMatters 2015

Case study 2: Plumtree

The organisation: Plumtree is a not-for-profit registered charity in NSW. It currently serves over 270 children with a developmental delay or disability, and their families, on an annual basis.

The work: Plumtree has developed a series of resources, some of which are web-based, and others that are in hard-copy format, to assist families and young people with a disability to navigate access to NDIS and non-NDIS services and, particularly, the planning process. These include step-wise audio-visual testimonies from parents who have walked through the service with their children, to assist other families to understand the process, as well as a Velcro planning template, developed in collaboration with an international expert, that uses iconography to articulate goals and aspirations, rather than traditional approaches that rely on expression and transcription. This enables people who routinely converse in a language other than English, or those who are non-verbal, to engage more fully with the planning process.

Intended outcomes: To make the process of developing a plan for children more comprehensible and easy to navigate as a result, and to reduce the barriers to receipt of a comprehensive and timely plan for CALD, and non-verbal children in NSW.

Source: Plumtree Strategic Plan 2015-2017.⁷⁰

Enablers: Guidance for active involvement

There are many factors that hold promise in addressing the barriers described in this section. These include:

- **Embrace family support.** Both Aboriginal and CALD families should be seen as allies and sources of information in the initial phase of increasing awareness of the NDIS and during the planning process. They can, and should be enlisted, and worked alongside, to ensure that NDIS participants can derive maximum benefit from the scheme.
- **Disseminate information in a timely manner, rather than sequentially.** To avoid the perception that either Aboriginal or CALD people are minorities who wait until the 'mainstream' have received service(s), ensure that information and resources are translated and tailored prior to launch, so that each and every Australian can access information in a timely manner and feel invested in critical reforms. Plan Aboriginal engagement 6 months prior to the launch, recognising historical inequities in access to many critical supports and services.
- **Utilise bilingual staff appropriately.** Many organisations already have bilingual staff working with, and for, them. Ensuring that these staff can use their skills, particularly in initial awareness-raising and subsequent planning, is critical, as is creating an environment where they are adequately remunerated for their critical skills, through salary-loading, for example.

One-size fits all? The planning process

The aspiration of the NDIS and person-centred approaches more broadly is for more individual control, choice and empowerment when it comes to accessing supports. However, many CALD participants noted that whilst the provision of resources and supports under the NDIS may greatly improve, poor quality planning processes may undermine this aspiration. To illuminate the potential danger of these challenges, one CALD participant recounted her experience engaging a planner for her son, who has a disability, commenting:

I thought it might be a good to get an external planner, got a consultant in and that consultant, within two minutes of walking in, asked [my son] "so, do you want to move out of home?" And it was really an uncomfortable situation....in my view that was a really inappropriate way....she did not know anything about [him], did not have an opportunity to establish rapport with him, she just went straight in.

Another participant in a trial site remarked that for some humanitarian entrants, including people who have lived in refugee camps, their conception of what is possible, and what constitutes an aspiration can be quite circumscribed:

Some people haven't had a diagnosis, they arrive in Australia with no understanding of what disability means (CALD participant, roll-out site).

People themselves don't know what they're entitled to. Don't know if they have any rights. Don't know what is possible (CALD participant, statewide).



PLAN FIRST, DON'T 'RETROFIT'

Yet another participant pointed out the geographical variation in terms of readiness for planning, with levels of awareness and preparedness within CALD communities, as well as between the CALD community and the general population, particularly striking:

You go to the North Shore and they all have their plan ready. They know how much money they want to get...they've got really high expectations. You go to Bonnyrigg.... with a whole bunch of Vietnamese families and they look at you and go 'what's this NDIS?' (CALD participant, roll-out site).

Another CALD participant noted that in the Newcastle area, part of a NSW NDIS trial site, issues in terms of geographic fragmentation and isolation were pronounced:

CALD communities here are pretty spread...they're all over the place and there is no one single...stream-lined communication process.

These reported variations in understandings of what a plan is, and how to participate actively in the planning process, suggest that place-based, as well as culturally-appropriate, planning needs to be prioritised in efforts to ensure access to the NDIS for CALD people. Additionally, factors such as the inability to conceive of what an aspiration is, and poor, and culturally inappropriate planning, can have profound impacts on notions of entitlement for CALD people.

Cumulatively, these examples highlight the potential for what is meant to be individualised planning to devolve into a 'one-size-fits-all' approach, where the potential for specific forms of disability to be assessed in similar ways, social circumstances being taken into account, may result in blanket, pro-forma plans being developed. A report prepared for Disability Care Australia by Richmond RPA noted, in a similar vein, how "person-centred planning' appears simple but is actually complex. Its success depends primarily on the characteristics of its facilitator/planner."⁷¹

In the case of *Robinson v Minister for Immigration and Multicultural and Indigenous Affairs*, the Federal Court held that immigration assessment, as per the *Migration Act 1958 (Cth)* and *Migration Regulations 1994 (Cth)* could not rest on generalised 'cost' assessment centred on a hypothetical person alone, without having regard to the specificities of a person's disability and how that disability manifests on an *individual* basis.⁷² Whilst this case, perhaps ironically, centred on immigration law, the lessons arising from it can be generalized to highlight the importance of paying attention to individual needs in context— including during the planning process. In this respect, a survey conducted by the Federation of Ethnic Community Councils Australia (FECCA), found that 41% of respondents felt that self-assessment on engagement with people with a disability and their carers 'needs improvement.'⁷³

Because the promise of the NDIS for CALD people is contingent on improving the level of support people receive, all of which is mediated through the planning process, culturally appropriate planning is imperative. This imperative has been noted internationally, with a United Kingdom report, developed on the basis of local consultation, similarly concluding that there was a need to be aware of the advantages and disadvantages of 'personalised' approaches, and the centrality of tailored planning. The report's authors conclude:

PLAN FIRST, DON'T 'RETROFIT'

A properly personalised approach to individuals' needs should, in theory, be good news for people from different BME [black and minority ethnic] communities for whom the standard 'off the shelf' package is especially inadequate. However, people in the sites warned against an overoptimistic view: for personalisation to succeed across different individual and cultural experiences and expectations requires significant local effort and commissioners, providers and families working together.⁷⁴

For this reason, the quality of planning for CALD people should be a key focus in professional development activities and through quality assurance initiatives. Moreover, plan review mechanisms should provide assurance to members of CALD communities that, in the event of poor planning for a family, or community member, plans can be adequately revised and the decision-making process followed during this revision is robust.

Eligibility

Another issue that featured in interviews with some CALD participants was the eligibility criteria for determining access to the NDIS, particularly on the basis of residency status. The residency requirements, as prescribed in s.23(1) of the *National Disability Insurance Scheme Act 2013 (Cth)* and supplemented by the Agency's rules, specify the following eligibility criteria:

1. A person meets the residence requirements if the person:
 - a. resides in Australia; and
 - b. is one of the following:
 - i. an Australian citizen;
 - ii. the holder of a permanent visa;
 - iii. a special category visa holder who is a protected SCV holder; and
 - c. satisfies the other requirements in relation to residence that are prescribed by the National Disability Insurance Scheme rules.

In practice, the use of these residency criteria exclude people in a wide range of visa sub-classes and who are, in many cases, members of the Australian community, even if not defined as such by statute.

One participant from a service that provides support for families expressed concern that residency requirements in particular may result in barriers to access for specific groups of migrants who hold temporary visas, citing the case of international students who live and work in Australia and who may have a child born with a disability while they are resident in the country. The participant sought information from case-workers within the agency and estimated that, with the removal of what is currently state-based bulk-funding for disability services in NSW, this group would likely lose the ability to access key supports as the NDIS is rolled-out, unless agencies shouldered the costs themselves which, cumulatively at least, can be quite significant. The participant commented:

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I felt very concerned around the residency guidelines.... I just did a quick email out to my staff to see how many families we're working with at the moment who are not residents. And as I've said to you, it was 10-12 families out of 200.... If each of those families are not funded under the NDIS, it was \$8,000 each.... that is for us the equivalent of 1 FTE [full time equivalent] staff professional. That's being funded by the grace of block funding and other kind of funding mechanisms that not-for-profits can harness. How are we going to be able to do that in the future? They're at a significant disadvantage because of their visa circumstances....These are families that are really on the margins and struggling.

Another participant, working across the state with CALD communities, noted that concern for other groups potentially affected by the specific residency criterion had been expressed within the CALD community, stating:

There's some concern in relation to the humanitarian entrants. In the NDIS, there's specified eligibility criteria for who has the residence visa or citizenship (CALD participant, trial and non-trial site).

In the course of our research, we identified the following visa categories as being primarily affected by the prevailing eligibility criteria for the NDIS (without listing the hundreds of specific sub-classes):

- Student visas;
- Working visas (including 457 visa holders); and
- People in the non-protected sub-class 444 visa category (New Zealand citizen's resident in Australia who arrived after 26th February 2001).

Additionally, issues with eligibility criteria, primarily relating to co-morbidities, featured in interviews with participants. Eligibility criteria affected people who may require access to other services, for related co-morbidities, such as mental illness, for example. The Mental Health Co-ordinating Council (MHCC) has noted that Tier 3 (specialised supports) eligibility is an ongoing issue, commenting that "people who are occasionally or frequently acutely mentally unwell but have no or little residual disability when well are typically not going to be eligible for NDIS Tier 3."⁷⁵ One participant, who works for a CALD organisation, commented that this had not been communicated to potential NDIS users:

Individual packages will only be for people with permanent, significant disability and I don't think that message has gotten across. My worry is that there's a lot of expectation out there that people are going to get money...there's heaps of confusion...but the more mild to moderate [disabilities] won't even qualify for a package.



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Another participant recounted one such case, but where the agency had capacity, through the existing services they provide, to facilitate contact with broader social support systems. This alleviated the potential for ineligibility to lead to no access to services at all: “We’re able to link them into a few activities. For instance, a young woman with a few mental health issues and epilepsy.”

Cumulatively, these findings suggest that there are multiple, intersecting and compounding factors, including historical access to services, quality and availability of information, and eligibility criteria that function as barriers to timely access to disability services for CALD people, which are not yet being adequately addressed within the context of the NDIS sites, or the broader state-wide readiness initiatives.

Enablers: Working smarter with CALD people

- ***Build the cultural competence of organisations.*** This requires compliance guidelines, and resourcing, which ensures that organisations are committed to culturally appropriate practice at an everyday level and in all of their undertakings.
- ***Ensure good quality planning that is culturally appropriate and person-centred.*** As such, this should take into account aspects of a person’s identity, including cultural and linguistic diversity, when designing supports to meet their aspirations.
- ***Information dissemination, assessment and referral processes that are easily understood and prioritise access,*** in spite of eligibility barriers under the NDIS Act, for example and that ensure people can gain access to at least some level of support.
- ***Work with communities to build a culture of human rights for people with a disability.*** Service-providers, policy-makers and other stakeholders should ensure that their engagement uses terms that engage families and individuals with a disability, but who may not, for a variety of reasons, identify as such. This could take the form of advertising information sessions or workshops as concerning ‘health and wellbeing’. The imperative should be to ‘de-medicalise’ disability, to the furthest possible extent, whilst taking practical steps to engage other members of the community.

ABORIGINAL PEOPLE

Information and engagement

Aboriginal participants spoke about the variability in available information resources concerning the NDIS in particular, and disability services more broadly, in terms of *quality*, as well as the lack of *targeted* and *effective* engagement strategies. Whilst many participants noted the increasing use of internet-based resources, some of which are not adequately targeted to Aboriginal people, they questioned the reliance on these resources as the primary means of increasing awareness about the NDIS, or engagement in the planning process. A number of participants commented that the choice of such a medium of communication was a key determinant of both the existing quality and reach of information resources. Some participants remarked, for instance, that the style of communication used by some Aboriginal people differed:

Aboriginal people are really visual and also oral people so you wouldn't want to put them on or send them to an internet address because they wouldn't be able to engage with that. ...they want people speaking to them... (Aboriginal provider, roll-out site)

Our clients don't go online. I can probably tell you I'd be lucky if three of our clients used online (Aboriginal provider, roll-out site).

Instead, participants stressed the importance of information that is accessible and available in formats that communities, and particularly those that are rural, can relate to. This, participants noted, included oral, namely face-to-face, and visual formats:

In order to bring them in visually we make the presentations very visual, very hands on, so that we're looking at that kinesthetic style of learning ... minimum of two hours ...prefers four hour workshop... many questions.... I can't imagine Aboriginal people engaging with any other model (Aboriginal service provider, roll-out site).

For some participants, the poor choice of communication medium for some Aboriginal people was intricately connected to how information dissemination was occurring at a national level. One participant commented, quite pointedly, that the systemic infrastructure was lacking to support effective engagement with Aboriginal people and communities at this level, with particular implications for Aboriginal communities, in terms of their ability to engage with the NDIS:

They're [the NDIS] falling down a big way in the coms department, if I can put it that way. It's not hitting the mark, they're not promoting specifically to Aboriginal communities very well. It's not in a form that Aboriginal communities are digesting very well (Aboriginal provider, statewide).

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I don't think the current methods are working. The information's not getting to the clients...the format of the information sessions and the content of the information sessions, it isn't easy to understand.(Aboriginal provider, statewide).

Other participants expressed a view that information is not communicated adequately to ensure that families are able to maximise their access to services or utilise existing resources, even under current disability services. One general service provider who works closely with Aboriginal children and young people testified to this, observing that:

Many of the Aboriginal families we know, they've got FAHCSIA funding for their child who's got autism. They haven't touched it, they haven't spent it...because they see that with some kind of suspicion.(General provider, statewide).

Another Aboriginal provider, primarily working in a non-trial site, similarly noted that a “distrust of government” existed, which impacted on how communities interpret official information and resources and was exacerbated when poor decisions were made concerning communication(s). Aboriginal providers spoke about the related challenges that often arise once general information that is not particularly clear and targeted, but already in the public domain, is interpreted in light of this particular history. This can have implications for attempts to meaningfully connect with communities, as one provider recounted:

We are trying to address an environment of rumour innuendo and speculation...some of the things if you go out into regional areas...are alarming stories. We had one lady who told me that her understanding of the NDIS is that they were going to build institutions - they were going to build large institutions to take away Aboriginal children again.

The same participant went on to observe that the ability to make sense of the how the NDIS is intended to function is not limited to prospective participants in the scheme, but extended to agencies and services themselves:

Communities...and service providers...are still trying to get their heads around how it all fits together. Aboriginal people are saying the processes need to be different for Aboriginal people.

The lack of clear communication about how the NDIS is intended to function is compounded by a failure to fully engage Aboriginal communities at everyday levels. In many instances, a clear contributing factor is the lack of dedicated and Aboriginal-identified staff to conduct the required face-to-face engagement:

They [the NDIS] lack Aboriginal engagement staff. So, if you want to get someone from the NDIS to come and talk – what it is and how it works, you don't get an Aboriginal person. Which automatically makes them in a very difficult position to effectively communicate with the community....

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Many rationalised these issues, in terms of information and engagement, as arising primarily from two factors: (1) the failure, whether intentional or not, to adequately consider Aboriginal needs; and (2) the pace of the roll-out itself, which necessitated rapid preparation of resources, dissemination of information and the establishment of physical infrastructure. As one participant presciently remarked:

Because of the speed in which this is all being rolled-out, Aboriginal capacity is a priority that fits well down the list for organisations. So, in terms of who is undertaking readiness activities for cultural service delivery, they're very few at the moment, because everyone is realigning their business....The cultural capacity building side isn't yet being adequately addressed at any end.

Accordingly, as the NDIS roll-out takes place, targeted initiatives that build on existing community knowledge, practices and networks to improve access to meaningful and timely information for Aboriginal people, should be prioritised, rather than generic approaches.

Case Study 3: Aboriginal Disability Network NSW (ADNNSW)

The organisation: The ADNNSW is an incorporated association, and registered charity for Aboriginal people with a disability, their carers and families residing in NSW.

The work: The Living My Way Project currently consists of three resources that are available online and in hard-copy format directly sourced from the ADNNSW office.

Living My Way video: the video resource was developed by the organisation to enhance understanding of disability within the Aboriginal community. The video depicts Aboriginal people and their families discussing their experience with disability, and telling their stories. The video is designed to be viewed and shared by other Aboriginal people with a disability in order to raise awareness. The video is available for viewing on the ADNNSW website and YouTube.

Living My Way 'Getting Prepared': online resource that provides information in the following areas: What is 'disability'?, Planning, Your goals and aspirations, How to develop your individual plan, types of support, and Phone numbers.

Living My Way Planning Booklet: the book is designed to aid Aboriginal people in designing their individual plans under the NDIS. ADNNSW has also incorporated illustrations from Bundjalung artist Bronwyn Bancroft. The booklet, and the introduction of how to use it, is available via direct contact with the ADNNSW (telephone, email, or the office in Redfern).

Additionally, a number of workshops are being held across NSW, aimed at discussing the goals and vision of people seeking access to the NDIS with members of Aboriginal communities. These emphasise face-to-face engagement.

Source: Aboriginal Disability Network NSW (ADNNSW) 2015

Unfinished Business: Stories from Aboriginal Australian and Torres Strait Islander People with Disabilities (Art Exhibition)

The exhibition is comprised of a series of photographs and videos documenting the stories of 30 Aboriginal and Torres Strait Islander people with disabilities.

The purpose of the exhibition is to draw attention to the ways in which disability impact their lives, but also gives members of this community the opportunity to express their experiences in their own voice. As it is an artistic work, it implements techniques that are intended to draw the audience in and consider disability in a manner that is more personal, and seeks to elicit empathy and compassion from the viewer.

The exhibition was launched in September 2013 at the Palais des Nations in Geneva. The project was supported by the First People's Disability Network and the Department of Foreign Affairs and Trade. The works represented the Australian contribution to the United Nation's 2014 World Conference on Indigenous Persons.

There are three copies of the work available for Asia, Europe, and the Americas. The exhibition is currently touring Australia, following the launch in June 2015. Many of the photographs and videos are also available for viewing online via the Unfinished Business website.

Planning – necessary support(s)

The quality of planning, and access to culturally appropriate planners that are responsive to families and communities, was a significant issue for Aboriginal participants. Some referred to specific factors, such as trust, often associated with familiarity, as being critical, whilst others referred to specific ways of working, including taking time and listening attentively, as pivotal to effective planning with Aboriginal people, particularly in developing an initial plan. A number of participants commented, for example:

With assessment centres and services and that sort of thing, there's no option for Aboriginal services or Aboriginal people to go out and give that information and they're not comfortable with an outsider coming into their home or sharing personal information with an outsider...there's that issues of shame...there's that issue of mistrust (Aboriginal provider, statewide)

Assessments...[are] limited to one hour. We do our assessments, generally, in up to four hours. I just can't see an Aboriginal person opening up and telling someone all the issues and then we're gonna have to go and re-asses them because they didn't tell anyone the truth at the start (Aboriginal provider, roll-out site).

Some participants were critical of the online assessment process, and specifically the checklist favoured by the NDIA, claiming it was not appropriate for the circumstances they work in, on a daily basis: "[i]f we went out to our clients with a form and sat down with them, they'd run a mile."

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These comments illustrate the importance of inclusive approaches to planning, and specifically, the articulation by people of their aspirations, which may be inhibited by complex assessment forms that resemble other bureaucratic requirements.

Another issue complicating access to timely and culturally appropriate planning for Aboriginal people was the environment created by tender processes themselves, and the tendency to exclude Aboriginal-controlled organisations once a tender is awarded and funding commences. One Aboriginal provider, commented, for example: “[t]he tender structure works so that we weren’t viable.” This situation arose, as one participant asserted, where a large organisation with an economy of scale started work in planning, only to realise that engagement with Aboriginal people required dedicated support staff. Instead of building this capacity, the large agency requested the assistance of the smaller Aboriginal-controlled organisation, without offering any form of monetary compensation for their services. As the participant further commented:

They’re sending out mainstream assessors to their home. And then these mainstream assessors are calling us and saying ‘can you go along with the client and help them with the assessment? And we’re saying...you’re gonna be paid to go out and assess these clients... we’re not being paid (Aboriginal provider, roll-out site).

They won’t go to mainstream providers, they won’t go to the government directly...they just won’t (Aboriginal provider, roll-out site).

Case study 4: Stacey’s planning story

Stacey (not her real name) is a young Aboriginal woman who has cerebral palsy. She lives with her father in one of the areas that was a trial site under the NDIS and sought assistance under the Scheme so that she could plan her own life. Stacey was deemed eligible under the scheme and gained access to a planner, who developed a plan for her shortly thereafter. However, the approach the planner took was very much ‘one-size-fits-all’, based on the notion that all young people with cerebral palsy have similar needs. The plan, as a result, does not meet Stacey’s needs and fails to take into account that some of the supports listed in the plan do not align with her aspirations, or take into consideration the fact that her father’s capacity to support her is somewhat limited. As a result, Stacey is seeking a plan review, but only after she discussed the inadequacies of her plan with an Aboriginal-controlled organisation working within the disability sector.

Stacey’s experience, where a plan was developed and some supports provided, but not all of which met her aspirations and expectations, is consistent with the existing literature on access to appropriate supports for Aboriginal people. The evaluation of *Our Way* in Nowra, an ADHC-funded program that focused on wrap-around and person-centred support for Aboriginal people and their families, recounted the experience of a family who, prior to the arrival of the *Our Way* model were provided with an electric, rather than manual, wheelchair.⁷⁶ This made accessibility an issue when visiting family members. The participant recounted:



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So I said you have to take it back. I want a manual base. So that's more wasted money. They just don't listen to what we find will be easier. Electric wheelchair, we can't visit family because if there's a step we can't get into the house. Where a manual one we can tip it up to get in.

Unlike the issues outlined in Stacey's story, and in the above excerpt, Aboriginal specific providers often adopted clear approaches to enable planning that was more responsive to individual needs, and these prioritised *listening* to people's aspirations. One provider recounted the approach they take to planning, which involves connecting people with practical *local* services and supports once they have gauged what is available:

We always take the local community's lead- what's in your community, tell us what's available ... what if we connect you with these people? Similar to what the Ability Links role is ... I always like Ability Linkers to come with me. ... There's no point us saying we'll put you in contact with this organization in Sydney because that's not relevant. We need to give them information that's nearby, locally relevant so that when we walk away we make a community...richer (Aboriginal provider, roll-out site).

The importance of paying attention to local needs and local context(s) was highlighted by the lack of choice available to some people where there was a rush to draft a plan, in the absence of resources or a suite of available services:

Definitely in the last part of our planning mechanisms, before we start writing a pre-plan, before the process, we look at the sustainability and in some towns, in some communities, there's going to be no services ... People are walking out with \$50,000 plans and no services to buy. How do we fix that? (Aboriginal provider, roll-out site).

The same participant commented on the need for deep local relationships, based on trust, for the purposes of planning, to be able to meet the aspirations of people:

To address the isolation nothing's going to happen online. Because when you go to communities like Wilcannia, Broken Hill, Bourke - they don't have the same luxury to go online and find what they need. What can we do? Definitely it has to be face-to-face....An assessor and a planner has to have that relationship because if they don't have that relationship no-one's plan is ever going to meet their expectations. You have to have a relationship and in order to have a relationship you have to have a rapport and you can only do that face-to-face.



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These comments highlight the importance of not merely appropriate planning support in identifying aspirations, including through active listening, but also ensuring that the necessary infrastructure exists after the development of a plan to ensure that participants receive the resources they need, and in a timely manner. Critically, whilst participants recounted stories of difficulties in securing a plan and resourcing it to an adequate level, the fact that only in some cases action was taken to rectify this immediately highlights uncertainty over the review process for plans developed under the NDIS. Plan review is envisaged as a step available to plan participants in the access pathway outlined on page 13 of this report. It is a way for people, who are unsatisfied with their plan, or who have had a change of circumstances to have their plan revisited and adjusted. It is also a component of the NDIS program logic, insofar as each participant can request a review, so this lack of awareness and/or engagement remains a concern. Key questions that arise in this respect include: (1) are people aware of the possibilities provided by a plan review? (2) do they know where to go to receive assistance in having a plan reviewed and (3) what outcomes can participants expect following a review? This report suggests that, on the basis of respondent feedback, there was relatively little awareness of the potential of planning review in ensuring people receive necessary supports in a timely manner.

Keeping an eye on disadvantage

The unmet need is already fairly underrepresented and underestimated in a lot of areas...it is really just the tip of the iceberg (Aboriginal provider, State-wide).

Many participants noted the manner in which disparities in access to disability services were connected to other experiences of marginalisation for Aboriginal people, and that the levels of disability-related unmet need were sometimes obscured due to broader social issues prevalent in communities. This is consistent with the existing literature in NSW that speaks to intergenerational trauma as a determinant of health for Aboriginal people, including in the disability arena, operating through pathways such as poverty and substance abuse. In a study by Gilroy, concerning Aboriginal people's engagement with disability services, one Aboriginal NGO manager is cited as saying:

... [disability] goes back to the beginning of colonisation ... from the cycle of poverty, then you've got bad housing, lack of education, lack of nourishment ... people living in poverty suffer ill health probably more so than other people. So you've also got the disabilities ... Also with the alcoholic syndrome, babies are born with problems. Heroin intake – babies are born addicted. So the cycle of poverty sets up a lot of substance abuse.⁷⁷

These historical issues also have contemporary manifestations. For instance, some participants expressed the view that limited proactive efforts were made to ensure that Aboriginal people gained access to the full suite of services they required in different areas of their lives (for instance, education, disability, health and so forth). In some rural communities, for example, where there is compounding disadvantage, this poses particular challenges:



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I went to a community earlier this year and they didn't even know who ADHC was. And when they started telling me about their child who was 16 and his complex needs... that really alarmed me. Any front line counter person, even at the hospital, should have said you need to be in touch with ADHC (Aboriginal provider, roll-out site).

Whilst the engagement of other service providers and agencies in the health and social services arena (for instance, Aboriginal Medical Services and trusted local GPs) presents opportunities for engagement with local Aboriginal people, another participant remarked that, to date, agencies outside of the disability sector were poorly engaged in the NDIS:

The conversation about the NDIS is only occurring in the disability space effectively. So it's not an agenda that's really being pushed and a conversation that's really being had...they're not integrating and building partnerships across those areas very well (Aboriginal provider, statewide).

Given that, in these instances, such approaches to 'scaffolding', where agencies build off existing resources and networks, provide the opportunity to achieve greater efficiencies, and improve awareness of the NDIS in people's everyday lives, there is a real opportunity to improve engagement in this regard.

However, integrated service delivery, or wrap-around approaches, need to be carefully tailored to the needs of specific communities, including their histories which, for Aboriginal people include dispossession and the use of state agencies to marginalise and oppress. For this reason, agencies working in the disability area, including the NDIA need to be cognisant of some of the dangers of co-location which, despite good intentions, may exacerbate existing tensions within, and between communities. One participant remarked, for instance:

You have to understand the history of that community. If you co-locate with someone who's got a long history with that community...antagonism or issues, you're not going necessarily repair that organisation's image in the community; you're going to bring your own down to where that is. Things like...Centrelink offices...they're contentious in communities (Aboriginal provider, statewide).

Accordingly, planning to ensure timely and seamless access to services for Aboriginal people with a disability entails being mindful of histories of disadvantage and inequity; and tailoring solutions to address these seemingly entrenched issues. Here, co-design strategies can play a strong role, where communities are consulted, listened to, and positioned as active players in managing their own business, or everyday lives.



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Enablers: Working smarter with Aboriginal people:

- **Develop and provide information that is relevant and culturally appropriate.** Materials and resources developed for Aboriginal people should cater to the spectrum of communication needs, prioritising face-to-face interaction and existing community networks as means of information dissemination supported, and not led, by online platforms. Ensuring that Aboriginal staff lead engagement with communities, to build trust, is also vital to ensuring the culturally appropriate delivery of information and materials relating to the NDIS.
- **Adequate resourcing of engagement plans and strategies.** Engagement and information strategies must be resourced to respond to both place and culture so people are provided with information about what is possible and relevant; and who they can talk to locally to find out more. Engagement with the NDIS must be broadened beyond 'disability services' alone, to include others engaged in the health and wellbeing of communities, including Aboriginal Medical Services and trusted local general practitioners.
- **Ensure quality planning.** This should be holistic and inclusive, taking into account a person's culture and addressing their needs and aspirations in the context of their wider family and kinship network. Planning processes should dedicate the time needed to deliver a quality plan that the person is satisfied with.
- **Recognise that additional work is required to ensure that Aboriginal people and local communities can engage most effectively with the NDIS.** Dedicate additional resources to addressing inequities in access and optimal support for Aboriginal people with a disability, recognising that there are unique historical factors and contemporary realities for Aboriginal people. This could include through additional face-to-face workshops and intensive community engagement once people develop a plan, to ensure they are deriving maximum benefit from that plan and related supports.
- **Demonstrate leadership and inclusion by getting the timing right.** Strategies for developing NDIS processes, implementation plans, procurement and roll out planning must, from the earliest stages, map how Aboriginal people and communities will be engaged and their needs responded to as a matter of priority. This will overcome any perception that these matters are dealt with retrospectively and will demonstrate a genuine commitment to inclusion and culturally responsive practice.
- **Enable continual improvement of NDIS processes and service delivery.** Make sure that resourcing is available to implement suggestions made through consultation(s) and continue to work closely with people in local communities.



PLAN FIRST, DON'T 'RETROFIT'

THE ANSWERS – MAKING CHANGE WORK

What we now know

The transition to the NDIS offers opportunities to do things differently, more efficiently, and more effectively. In its full-form, it engenders the potential to address entrenched barriers in the lives of Aboriginal and CALD people with a disability, by giving them greater choice and control over their lives. The NSW Minister for Disability Services, the Hon. John Ajaka has articulated the purpose of the NDIS as enabling people with a disability to “participate confidently in a disability system based on self-directed supports and individualised budgets.”⁷⁸ This report demonstrates that whilst the promise of the NDIS exists, there is still significant work to be done to ensure that this promise is *realised* in the lives of both Aboriginal and CALD people in NSW.

For Aboriginal people, the barriers that characterised their engagement with disability services in the state, as well as the NDIS itself, were tied to historical experiences of marginalisation and intergenerational disadvantage. Many participants recounted the experience of people living with a disability who received patchy services, rather than comprehensive services based on the needs they have in their lives and more importantly, their aspirations for the future. This can compound to produce disadvantage across the life-course, and for generations.⁷⁹

Aboriginal controlled organisations in the disability sector provide a critical counterpoint to this tendency, and reported spending significant time building durable relationships with families and communities, particularly in disseminating information concerning the NDIS, as well as in providing planning support. However, due to their size, tendering processes, particularly around planning support, can leave these same organisations vulnerable to being sidelined and deemed ‘not competitive.’ We heard from some participants that even where ‘partnerships’ were entered into, for the purposes of a tender, adequate brokerage did not take place, leaving the organisations expected to perform or contribute to the work, without adequate recognition or remuneration. This can have a marked impact on the planning process for some Aboriginal people, and affect people’s ability to seek a review of a plan once it has been finalised, through a lack of awareness about where to go to seek a review. This remains an issue because seeking a plan review is an option available to participants under the NDIS access pathway, in cases where their plan is inadequate to their needs, goals and aspirations.



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In relation to CALD people accessing disability services, and consistent with the literature, we found that the quality and quantity of information greatly influenced their knowledge of how to navigate not only disability services, but the NDIS too. Too much focus was placed on (re)producing resources that may make little sense, even in English, and too little focus was placed on translating, in real explanatory ways, what terms like 'goals' and 'aspirations' mean in everyday settings for people with a disability, and their families and carers, which may be one and the same. Because the information base is so poor, and because institutional commitments to full CALD inclusion and participation are often lacking, the planning process – which is central to the NDIS – can sometimes fail CALD families, and we heard stories to this effect from participants we spoke to. Moreover, eligibility issues were raised by two participants, particularly in relation to residency criteria, which curtail the ability of people who currently receive service under bulk-funding arrangements, to be able to receive such services in the near future. To remedy some of these issues, participants suggested drawing on existing models of best practice, some of which involved, at least as far as the trial-sites were concerned, interagency collaboration, and active models of hands-on workshops to build capacity for people themselves, as well as their circle of support.

New ways of working – system leadership

Change often starts with conditions that are undesirable, but artful system leaders help people move beyond just reacting to these problems to building positive visions for the future.⁸⁰

Systems need to be supported and set up so that families can support one another in culturally appropriate ways and find out what this is all about (CALD participant).

Tailoring support to the person means significant changes to the ways that most organisations operate and how staff carry out their roles. Without discovering the ways that the organisation can tailor the support to people, person-centred approaches cannot be achieved.⁸¹

Realising the promise of the NDIS in NSW necessitates new ways of working that break down silo thinking and place the needs and aspirations of people with a disability first. For CALD and Aboriginal people, the need for innovation, and replicating what currently works best, is greatest. As this report has noted, both population groups have been disadvantaged historically in access to disability services, and Aboriginal people more specifically through persistent socio-economic disparities across key indicators of economic security, health and wellbeing. While barriers are often articulated as an individual's problem, they are often also structural – shaped by, and through, systems - which can either work well or fail people. While the stories of people with a disability from both Aboriginal and CALD backgrounds may appear to present opportunities to examine 'culture', they equally speak to limited or diminished opportunities, of historical marginalisation in the case of Aboriginal people, and sub-standard access to essential supports and services, relative to other Australians.



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As a result of this legacy, achieving change requires 'system leadership'. As described by Senge, Hamilton and Kania, system leadership characterised by specific capacities, such as 'helping people see the larger system', 'fostering reflection' and 'shifting the focus from reactive problem solving to co-creating the future'. Many participants expressed a desire for such system leadership, stressing the need for a collective focus on improving outcomes, including optimising access to the full gamut of services and supports, as well as strengthening existing systems and improving practices, to be able to fully and effectively engage Aboriginal and CALD people in the NDIS. It is increasingly recognised that "[t]ailoring support to the person means significant changes to the ways that most organisations operate and how staff carry out their roles."⁸²

At the heart of this was an aspiration – shared by both Aboriginal and CALD people – for high-level strategic leadership and clear definitions of what cultural competency means *in practice* and at a range of levels within agencies and organisations, including those providing services directly. Whilst cultural competency is increasingly a focus within the sector, it is often articulated in vague and abstract terms, which participants felt did not approximate optimal responses to the needs of CALD or Aboriginal people. When asked to articulate what cultural competency meant in a practical sense, two CALD participants framed it as:

...the capacity of organisations to deal with ambiguity and the complexity of CALD clients. The organisation should have, at the top level, the policies to support this cultural competency. It is not only [about] using bilingual workers.

....being more self-reflective in your practice and being aware of your own bias and your own cultural position and being appropriately curious about, and knowledgeable about other cultures.

Another participant, who had worked in the disability sector with CALD people for decades, remarked that the diversity that notions such as cultural competency seek(s) to address requires a key virtue - introspection. The participant stressed that cultural competency had been 'over-simplified,' including through training models, reducing the skills people needed to engage on a daily basis to a few dot points, and stated that the standard needs to be raised in this regard: "[i]n order to respond to some complexity in the world, you actually need to use your brain."

The need for this level of commitment to cultural competency across the disability sector, and not just within the main organisations working with either Aboriginal or CALD people, was underscored by other participants, who recognised that multiple agencies, not all of them specialist, would be engaging with both Aboriginal and CALD people as the NDIS roll-out occurred across NSW. For instance, an Aboriginal respondent commented on the need for people in the sector to work together:

We've recognised there's not the capacity in the Aboriginal-controlled service sector to meet all of the need and that mainstream organisations will have to take up the slack in some locations (Aboriginal provider, statewide).



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Participants articulated a range of potential solutions, not all of which entailed additional funding, but which centred on better, and more strategic, use of existing funding mechanisms, and clearer guidelines around tendering processes. For instance, one Aboriginal participant suggested that agencies and services in the disability sector ensure that in sites where the full roll-out of the NDIS will commence, engagement with Aboriginal communities should commence six months prior to the delivery of services, and not once a shop-front has been established, and community discussions had begun. The participant remarked:

I would be looking at basically taking what you have to do in a particular area out to the community. Get community together, have a conversation, form your networks and your stakeholder groups now....not just in the service provider space, not just in the community space, but integrate them both and have the conversation about here is the NDIS we need to roll out, here's what are the core pillar areas we need to take care of in the next six months....how can we go about it? Commence that community consultation and the accountability at the start.

The danger in leaving discussions to the late stage is that community members, on the basis of available information, which can include rumours, arrive at their own conclusions about what the NDIS means in their lives, or the lives of their community, as this report has already demonstrated. In this environment, counter-narratives, or what Scott has termed 'hidden-scripts', can emerge within communities which serve to entrench attitudes and amplify suspicions, and thereby exacerbate existing barriers to service access.⁸³

Others suggested that whilst generalist disability services needed to become more culturally appropriate, tendering processes, particularly those concerning planning support services, should be strengthened to ensure that local Aboriginal-controlled organisations are adequately remunerated for their contributions, including through human resources. This situation could be improved through the adoption of stronger guidelines concerning tendering in this area; guidelines that actually increase the likelihood of achieving relevant outcomes by enabling those successful in securing a tender to reach the relevant population group(s).

Both Aboriginal and CALD participants, many of whom had worked in their communities for years, and some for decades, advocated models to improve engagement. Some of these models involved sector-wide collaboration between agencies that work in the disability sector and more broadly, including people working in health and wellbeing, citing the siloed nature of discussions to date:

The conversation about the NDIS is only occurring in the disability space effectively. So it's not an agenda that's really being pushed and a conversation that's really being had...they're not integrating and building partnerships across those areas very well (Aboriginal provider, statewide).

CALD participants reported that they were already doing this, through re-orienting the way they're working. One participant remarked that this involved changing the language they use to frame the NDIS and access to services, particularly for families who are not accustomed to talking about 'disability':



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We've found it more useful sometimes in some communities to frame our workshop as 'health', to try and get around that stigma around disability and get more people to come.... (CALD provider, state-wide).

As an example of more entrenched cross-sectoral work with CALD communities, in the Hunter region a committee was convened, comprising of representatives from key CALD and disability groups, to provide practical advice, guidance and support for the roll-out of the NDIS trial. A participant recounted how this initiative arose:

We came across this issue [access barriers] and we wanted to tackle it... we raised this with NDIA in Hunter, with ADHC in Hunter, we raised this with Ethnic Communities Co-operative...so we effectively raised with this all the key stakeholders in the sector....and everyone came together and a group was set up called the Hunter CALD Disability Engagement Group.... and they organised an ethnic community leaders forum. And at that forum... they came up with a list of recommendations about how to address these issues of access and information and inclusion at large. On the basis of that engagement, they came up with a project design and the project design is to have a project officer who will individualise information around the NDIS and capacity building of individual communities around NDIS and then be a communication flow between the Hunter CALD Disability Engagement Group and the individual communities...and then this project officer will train individual communities or provide information to individual communities....so there would be reciprocal communication going on (CALD provider, roll-out site).

Another participant in a non-trial site provided a similar example of effective person-centred practice, based on partnerships with established local organisations and caseworkers in rural and regional areas:

In Wagga, for example, we worked with their local caseworkers who do all that settlement work and have one on one meetings with families and there was an interpreter present, the caseworker that already knows that family...and we kind of introduced a lot of this information. And then we ran sessions of train-the-trainer with all of those caseworkers and equipped them with the materials on person-centred planning....and in their regular catch-up they were able to keep implementing that throughout the year.

These are prime examples of co-design - they actively involve members of communities, and those providing funding and delivering supports to participants in the design, delivery and monitoring phases in a manner that accords with the goals of the NDIS.



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In terms of improving the quality and availability of resources, participants also provided a range of ideas, ranging from stronger training for planners that move them beyond old models of working to the development and provision of iconographic resources for young people and their families. A case study of innovative practice, related primarily to CALD communities, is provided below.

CASE STUDY 5: STORIES FROM UNDER THE PLUMTREE

“The Plumtree Family Storytelling project collated the stories of families who have a child with a disability. Families were interviewed and coached to tell their stories on video. The interviews focused on the process they went through to receive individual funding, the use they make of it to assist their family in for instance purchasing resources or services, the impact that the funding had on their child and by extension on the whole family.

The families reflected on their experience with caring for a disabled child, from the time they received the diagnosis, through to making contact with Plumtree and commented on the lessons learned along the way. These lessons were analysed thematically and the interviews were post-processed so that these lessons be easily shared with other parents. A trailer introduces the project and provides the context relevant to Plumtree present and future audience. In total, just over an hour of video materials were produced.

Implications and future uses: This project reinforces our experience that families learn best from each other – and provide engaging content for their peers - potential Plumtree new clients who search for relevant services via the internet. Parents have clearly stated that they receive not only new information, but also knowledge, from other parents: that is, information about what is available, but with the added value of a genuine evaluation from someone like them who has tried and tested the resource or service in question. It is this knowledge that sets apart the Plumtree Family Storytelling project!

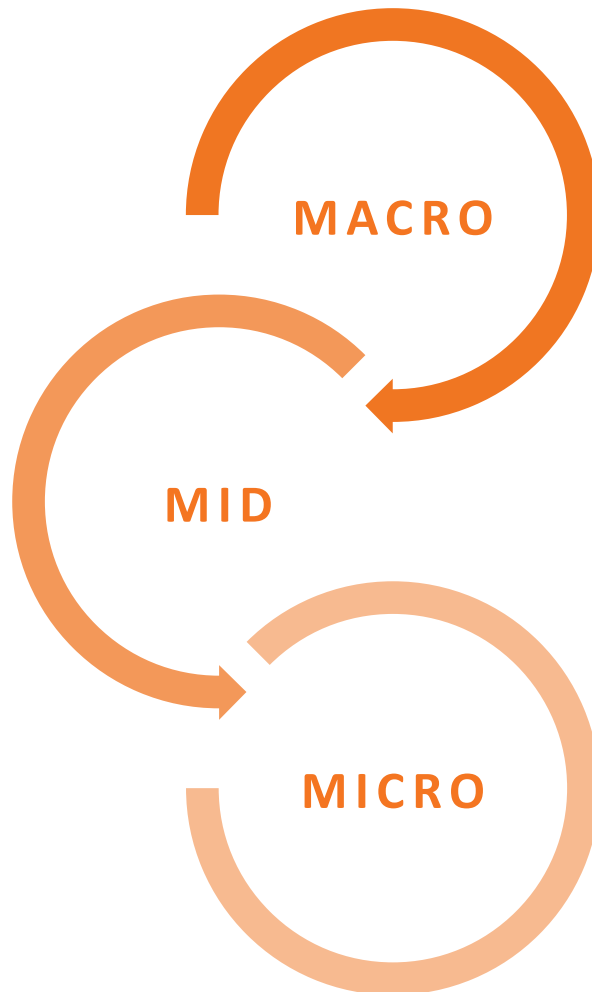
The Storytelling project provides unique learning materials for other professionals. The potential to develop relevant and appealing staff training programmes from parents’ stories is great, as families reflect on their reactions to the services provided by Plumtree. Additionally, these parents’ experiences with the system can offer valuable insight for NDIS policy and implementation.”

Source: Plumtree online.

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Implementing these new models of business will require drivers of change – including *individuals* accessing services and supports, who vote with their feet, *organisations* who provide services, and *agencies*, who fund, resource and exercise oversight in the disability sector. This change will, however, be driven at different levels. In the following section, we outline recommendations for change at these levels, drawing on a macro, mid and micro-level framework, depicted below.

Figure Four: Drivers of change – levels of action



RECOMMENDATIONS

Macro level (Structural level factors)

Tendering

- Ensure that tendering processes, both within the NDIS and at state-level within the disability sector are informed by principles of local knowledge and connection, and require lead agencies to apportion adequate funding to support listed partner agencies (co-applicants) where their tenders are successful, particularly those that purport to be working with Aboriginal communities and responding to local community diversity.
- Insert clauses in funding agreements that make it necessary to employ and train, where necessary, Aboriginal people to deliver services locally and ensure that similar clauses are included requiring improved data collection to measure the effectiveness of funding provided.

Engagement

- Ensure forward planning for rolling out the Scheme in each location includes the development of consumer engagement strategies for both Aboriginal and CALD communities.
- Develop consumer engagement strategies in consultation with Elders and members of Aboriginal and CALD communities, and resource them at levels that allow effective community engagement to occur.
- Ensure that Aboriginal community engagement with the NDIS occurs at least six months prior to the implementation of the Scheme in each site.

Workforce development

- Be aware that the workforce to deliver effective community engagement with Aboriginal and CALD communities may need time to scale up—so early engagement with Aboriginal and CALD community organisations and realistic processes of co-design will be key to delivering against the recommendations noted above.
- Employ Aboriginal and CALD staff at senior levels within organisations, including managers of Local Area Coordinators, and not just as frontline workers, to ensure accountability for both expenditure and outcomes at an organisational level.
- Ensure that organisations working in the sector can demonstrate high-level commitments to genuine inclusion for Aboriginal and Torres Strait Islander peoples, as well as CALD people.

Mid-level (Institutional systems and processes)

Recruitment and development

- Adequately remunerate staff members that undertake translation work, either through a payment-for-service approach, additional to base salaries, or through more attractive salary packages.
- Develop, and fund, project officer roles within existing organisations, whose function would be to work across agencies, individualise NDIS-related information for participants and their families and problem solve where current systems are not responsive to cultural needs. A cross-agency approach would broaden the reach of continuous improvement and assist Aboriginal and CALD people who are already engaged in the NDIS to get better outcomes from NDIS processes.

Outreach

- Develop scaffolding approaches to ensure that there is meaningful and ongoing engagement with peripheral service providers that interact with people with disability, such as Aboriginal Medical Services and trusted local general practitioners, to ensure that the NDIS is widely known and accessible to the people who need it most.
- Implement workshops that provide ongoing engagement with Aboriginal and CALD NDIS participants who already have a plan and experience in the system, to identify any systemic and ongoing barriers that may prevent them from accessing the full benefits of the scheme. These workshops should also focus on building people's capacity to access remedial systems, such as plan reviews and provide a forum for them to feedback to the NDIS as the Scheme evolves, enabling continuous improvement.

Information and resources

- Develop more flexible, including iconographic, approaches to ensure that those who are non-verbal have adequate opportunity to participate fully in disability support planning. Ensure that these resources are developed in consultation with, and allow for some evaluation by, CALD and Aboriginal people.
- Actively promote Aboriginal and CALD resources and informational materials to potential participants, and include easily-digestible information relating to the planning process in particular, as well as opportunities for plan review. This could take the form of a plain language charter of rights, for example, that lets people know what they can expect when they engage with the NDIS and related services.
- Use consumer engagement strategy development processes for Aboriginal and CALD people (as recommended above) to assess how people in each site access information and develop information resources that can be delivered through these channels (i.e. through community radio or local networks).⁸⁴

APPENDIX ONE: SEMI-STRUCTURED INTERVIEW SCHEDULE



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Background

1. Could you please tell me a little bit about your organisation and your role in it?
2. Are you working in the disability area more broadly? If so, how are you working with/interfacing with the National Disability Insurance Scheme (NDIS) in your area?
3. Is this work funded? If so, by whom? What is the funding period for the project?
 - a. Are you funded by the NDIA or the NSW state government?

Available information

4. In relation to the work you're doing and the people you're working with, how much information currently exists for Aboriginal /or CALD consumers, about disability services in general and the NDIS in particular? [Could you please provide a little bit more detail for me?]
 - a. Do you know if the information is reaching people?
 - i. How is this information reaching people? (i.e. word of mouth, online etc.)?
 - ii. If it is not reaching people, why do you think that is?
 - b. Have consumers shared their thoughts with you and, if so, what is their thinking about the available resources? Are they useful for them?
 - c. What are your thoughts on the available resources and/or information?

Service barriers and enablers

5. Could you please talk me through the way in which a person comes into contact with you and what happens once they indicate that they are seeking access disability services or the NDIS? (Prompt, as necessary, for further information).
6. Are there any specific barriers you see for Aboriginal /or CALD people in attempting to access disability services or the NDIS in your area?
 - a. Are other agencies involved in trying to address these barriers and, if so, how?
7. How do you think these barriers can be effectively addressed within the transition to the full roll-out of the NDIS? What support would be helpful in addressing these barriers?
 - a. What strategies are you using to improve access?
 - b. How successful have these strategies been, in your view?
 - c. Once people are involved with the NDIS scheme, what strategies are used to maintain their interest and involvement?
 - d. Are there any other examples of specific practices in other areas that have worked for CALD or Aboriginal groups, and which you think may be useful in the context of the NDIS?
 - i. Do people have access to necessary and reasonable supports once they are in the system? What approaches do you use to ensure that this happens?
8. If you were designing the NDIS rollout, particularly in your area, what would you do differently?
 - a. What would your first priorities be and in what order would other priorities fit?
9. Is there anything else that you would like to add?

APPENDIX TWO: PARTICIPANT CONSENT FORM

Participant Information Statement

NCOSS Disability Project 2015



The National Disability Insurance Agency (NDIA) delivers the National Disability Insurance Scheme (NDIS). The NDIA has a number of processes and systems with which Aboriginal people with disability and people with disability who are culturally and linguistically diverse (CALD) must engage in order to maximise the benefit they get from the NDIS. How people with disability are supported to engage with the NDIS and the NDIA will determine the quality from the NDIS.

Objectives

This project aims to develop an evidence base about the needs for support with engaging with the NDIA of Aboriginal people with disability and CALD people with disability who may confront a range of barriers to doing this. The project will focus on various processes relating to the NDIS, including information about the NDIS, application, assessment, planning and reviews. The project will investigate the experiences of a range of agencies involved with supporting people with disability to engage with the NDIA, and provide feedback to the NDIA, NSW Family and Community Services, and the non-government sector about how to support people with disability to overcome these barriers. The project aims to use this evidence base to build capacity amongst agencies involved with people with disability to support access and ongoing engagement with the NDIS.

Methodology

The project involves three modes of data and analysis collection. Firstly, a scoping review of other studies and research on the NDIS will be undertaken, as well as a review of the idealised 'access pathway' to the NDIS. Secondly, 15-20 interviews with people engaged in disability services, as well as the NDIS itself, will be conducted. It is expected that interviews will be conducted with organisations currently working in the Hunter NDIS Trial Site, as well as in the Nepean-Blue Mountains area, to support people with disability and families to participate in the NDIS. The interviews may also involve people with disability and families participating in the NDIS. Finally, data source triangulation will be undertaken to assess the extent to which idealised notions of access are reflected in current practice. The project will produce a research report, and findings will be presented publicly.

Your participation

Interviews are being conducted with 15-20 people engaged in disability services and with the initial roll-out of the NDIS in NSW (including the Hunter, and Nepean-Blue Mountains). Your participation will take the form of a semi-structured interview, lasting between 20 and 30 minutes, which will be audio-recorded. When the report arising from this project is written, your personal details (including your name, and place of work) will not be disclosed and a pseudonym will be assigned to you instead, with a general descriptor of the nature of your work. Audio-recordings will be destroyed as soon as the report is finalised. You will not be directly reimbursed for your participation in this study.



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APPENDIX TWO: PARTICIPANT CONSENT FORM

Consent Form

NCOSS Disability Project 2015

- I have had the chance to read the participant information statement and to discuss this project with the researcher(s). I am satisfied with the answers I have been given.
- I acknowledge that my decision to participate in this study is voluntary and that I may withdraw from the study at any time without having to give a reason.
- I know that my real name, and that of my organisation, will not be used in any report arising from the interview and that anything I disclose will be reported in a way that I cannot be directly recognised.
- I know who to contact if I have any questions about the study.

I agree to have my interview recorded. I know the recording will be cared for respectfully by the researchers and destroyed as soon as the final report is released	Yes	No
I wish to receive a copy of the final report once it is released	Yes	No

Your signature indicates that, having read the information provided, you have decided to participate.

I, (please PRINT name), consent to take part in the NCOSS Disability Project.

.....
Signature of Research Participant

...../...../.....
(date)

For further information, contact jed@ncoss.org.au, or call (02) 8960 7930

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