



TRANSFORMING DISABILITY ACCESS for Indigenous Australians

SUBMISSION TO QUEENSLAND PRODUCTIVITY COMMISSION
INQUIRY INTO THE NATIONAL DISABILITY INSURANCE SCHEME
MARKET IN QUEENSLAND

INSTITUTE FOR URBAN INDIGENOUS HEALTH
OCTOBER 2020

RECOMMENDATIONS

The continued structural Access Pathway and Plan Development Pathway barriers in the NDIS preventing equitable outcomes for Indigenous people with disability

remain at odds with the government's commitments to place responsibility for program design in Indigenous hands.

IUIH considers that the experience of the Indigenous NDIS Pilot Project of National Significance should be a primary driver to shape reforms which address this national priority, including as a successful and 'real life' example of the kind of systemic and structural transformation deemed necessary to closing the gap.

Recommendations:

1. Progress the government's National Agreement on Closing the Gap (2019-2029) commitments to:
 - Improve cultural accountability by systematic and structural transformation of the NDIS, including through genuine shared decision-making between government and Indigenous communities
 - Give preference to and ensure priority NDIS funding of Indigenous organisations, acknowledging the evidence-base that Indigenous designed and delivered services will close the gap faster
2. In line with and to give practical application to the above commitments, draw on the experience of the NDIA funded Institute for Urban Indigenous Health's Pilot Project of National Significance to:
 - 2.1 Establish specific and Indigenous-led Access and Plan Development Pathways into the NDIS for Indigenous people with disabilities - operating in parallel to 'mainstream' NDIS 'Partners in the community' for Early Childhood Early Intervention (ECEI) and Local Area Coordinator (LAC) Partners in Community. These pathways:
 - should assign ECEI and LAC roles and functions to competent and culturally appropriate community-controlled organisations and intermediaries who are trusted by Indigenous people
 - must reflect structural changes to the way NDIS is accessed by Indigenous people, rather than front-end 'connector' or 'referral' type solutions
 - should be introduced as part of the upcoming refresh of current LAC and ECEI contract arrangements in 2021, and on a regional scale across NDIS Service Areas
 - 2.2 Formally incorporate the involvement of a Participant's chosen advocate, intermediary or support in the development of Participant Plans, both at the pre-Plan Meeting stage to assist the Participants to clearly articulate their Goals, as well as during the formal Plan Meeting with the NDIA's Planner/Delegate
 - 2.3 Integrate NDIS access, coordination and service provision with primary health care. This could be achieved through leveraging the already established national network of 150 Aboriginal Community Controlled Health Services (ACCHSs), including:
 - building on trusted and already established culturally safe ACCHS client relationships to ensure seamless navigation through the health, aged and disability care systems
 - extending the community-controlled delivery model to support an extant 'thin' market of culturally appropriate disability providers, including in urban settings
3. Implement priority and targeted strategies to improve access and service delivery services in urban regions - where the majority (80%) and fastest growing Indigenous population resides. Contrary to common misconceptions, proximity to 'mainstream' services does not translate into better access or outcomes for Indigenous people
4. Introduce enhanced transparency and accountability measures, including:
 - incorporating Indigenous specific NDIS targets and reporting requirements into all NDIS programs
 - publishing quarterly Indigenous access and plan data at the NDIS Service Area level

Executive Summary

The Institute for Urban Indigenous Health (IUIH) welcomes the opportunity to provide input to the Queensland Productivity Commission's Inquiry into the National Disability Insurance Scheme (NDIS) market in Queensland.

IUIH's submission is anchored in several key policy and practice initiatives, including:

- IUIH's NDIA funded NDIS Pilot Project of National Significance
- The National Agreement on Closing the Gap 2019-29

Pilot Project of National Significance

In April 2019, the National Disability Insurance Agency (NDIA) funded the Institute for Urban Indigenous Health (IUIH) to conduct a National Disability Insurance Scheme (NDIS) Pilot Project of National Significance (NDIS Pilot).

In contracting IUIH for the NDIS Pilot, the NDIA made, what was at the time, an unprecedented commitment to a partnership aimed at reforming Access and Plan Development pathways into the NDIS for Indigenous people with disability in South East Queensland (SEQ) – pathways which would run in parallel to the NDIA's 'mainstream' Local Area Coordination (LAC) and Early Childhood Early Intervention (ECEI) Partners.

Importantly, the NDIS Pilot was aptly ascribed as having 'nationally significant' objectives, viz. to build the requisite evidence to reshape NDIS program architecture so that the needs of Indigenous people with disabilities across Australia could, for the first time, be systematically supported in an accessible and culturally safe manner.

Alignment with Closing the Gap

This imperative to enact transformative change in the way Indigenous Australians access and benefit from services, including in the disability space, remains a national priority.

For example, in its refreshed Closing the Gap strategy, the National Federation Reform Council (formerly COAG) has committed to placing the design and delivery of programs into Indigenous hands. This was poignantly accentuated in the Prime Minister's February 2020 Closing the Gap Statement to Parliament which underscored the need for radical changes to the way programs were implemented, and that a genuine partnership with, and the devolution of program responsibility to, Indigenous people were critical to achieving any real improvement in the lives of Indigenous Australians. In July 2020, all levels of government committed to the new Partnership Agreement on Closing the Gap (2019-29) which, for the first time, requires a preference and priority for Indigenous organisations to deliver services, in addition to a requirement for systemic and structural transformation of mainstream government organisations to improve cultural acuity.

Aligned to these commitments, and intrinsic to the design of the NDIS Pilot, is the fundamental recognition that Indigenous led, designed and delivered solutions are essential to addressing the lack of success in meeting previous closing the gap targets. Compellingly, the NDIS Pilot provided the NDIA with a propitious opportunity to translate the Prime Minister's call to action into a contemporary and ground-

breaking reality and marks a watershed for disability policymakers and NDIS program custodians to make real gains in redressing access inequity for Indigenous Australians.

The NDIS needed an urgent redesign for Indigenous Australians

In commissioning the NDIS Pilot, the NDIA, including with NDIA Board support¹, had identified significant design flaws in the current 'mainstream' NDIS rollout - manifest through the persistent and substantive fragmentation and lack of cultural safety experienced by Indigenous people in attempting to access the NDIS. These barriers have been further substantiated by several recent research studies:

- The Lowitja Institute commissioned research by the University of Melbourne's Centre for Health Policy (May 2019), which found significant impediments for Indigenous people accessing NDIS²
- The government-commissioned Tune NDIS Review (December 2019), which had a key recommendation to refocus efforts to address serious inequities in Indigenous access³.
- The Australian Social Policy Commissioned research by the University of Melbourne and Western Sydney University, which found significantly higher rates of discrimination and avoidance of service access experienced by Indigenous people with disability (compared to Indigenous without disability)⁴.

The Pilot Model and Successes Observed

The NDIS Pilot was co-designed in direct response to these challenges and represents a 'recast' of the current NDIS LAC and ECEI partner arrangements. For example, the NDIS Pilot replaces the LAC model through the establishment of alternate teams of Indigenous staff engaging with potential Participants through the engagement, eligibility testing, pre-planning and Plan build stages. Critically, this new approach is built on cultural integrity, trusted relationships and complete integration with the health care, family support, aged care and disability systems operated by IUIH.

For noting, this scope and approach differ substantively from other access initiatives such as:

- Assessment and Referral Teams (ART) under the Queensland Government's Disability Connect and Outreach Program (DCOP)

¹ The NDIS Board indicated strong support for the PPoNS in a face to face meeting with IUIH in May 2019.

² Ferdinand et al. Understanding disability through the lens of Aboriginal and Torres Strait Islander people – challenges and opportunities. Melbourne, Australia: Centre for Health Policy, University of Melbourne; 2019

³ Review of the National Disability Insurance Act 2013, *Removing Red Tape and Implementing the NDIS Participant Service Guarantee*, David Tune AO PSM, December 2019

⁴ Temple et al. *Exposure to interpersonal racism and avoidance behaviours reported by Aboriginal and Torres Strait Islander people with a disability*. Aust J Soc Issues

⁵ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. Commissioners present: Indigenous Commissioner Andrea Mason OAM, Commissioner, The Honourable Roslyn Atkinson AO and Commissioner Alistair McEwan AM

- ‘Community Connectors’ under the NDIA’s national contract with the National Aboriginal Community Controlled Health Organisation (NACCHO)

Differentially to these approaches, and as recommended by the research above, the NDIS Pilot is anchored in culturally trusted health providers (the IUIH Network) as part of a seamlessly navigable service system, as well as providing support during the critical plan building stage. These have both proven to be critical success factors in achieving outcomes.

The NDIS Pilot set a goal of 500 Indigenous people reaching “access met” into the NDIS and 500 Indigenous people having Plans lodged with the NDIA during the initial project period (April 2019 to June 2020). NDIS Pilot progress was to be surveilled by a quarterly high-level joint IUIH/NDIS Monitoring Committee aimed at distilling ‘real-time’ learning and was also to be the subject of an independent, practical evaluation.

The Pilot has now engaged 900 Indigenous clients in South East Queensland.

Significantly, analysis by the NDIA has shown that the NDIS Pilot achieved an astonishing 3 times better ‘access met’ rates and 10 times better ‘plan approval’ rates compared to standard NDIS arrangements.

This represents cogent validation of the proposition that efforts to realise improve NDIS participation will fail for Indigenous people unless there are a cultural adaptation and apposite Indigenous-led program redesign.

Notwithstanding these findings, the NDIA has decided not to evaluate or transition the Pilot following cessation of funding in June 2020, despite the Pilot’s original design construct being to inform potential for national replicability.

This now has sobering implications in terms of how the Commonwealth and Queensland Governments will meet their commitments under the recently (July 2020) signed National Agreement on Closing the Gap, where there is an imperative for all government agencies, including the NDIA, to implement Indigenous-led solutions through structural and systematic transformation of existing program design architecture.

This need for urgent reform has been accentuated by the latest data indicating only 45% of the Queensland Indigenous NDIS participation target for 2019 met - compared to 75% for all Queenslanders.

The Need

Rates of Disability

The barriers faced by Indigenous Australians with a disability in accessing life-changing care are well known. Compared with non-Indigenous Australians, Indigenous Australians are:⁶

- 1.8x as likely to have disability
- 2.0x as likely to use disability support provided under the NDIS

⁶ AIHW Disability Support for Indigenous Australians, 2019

For Indigenous Australians, it is often more complex in terms of more than one disability or health issue occurring together, and it is compressed within a shorter life expectancy.

Urban Need

It is also clear that proximity to mainstream services in urban areas has not translated into better health access and outcomes. For example:

- In SEQ, the Health Adjusted Life Expectancy (HALE) Gap is 1.5 times greater than in remote Queensland ⁷
- In SEQ, the rates of under 65-year-old Indigenous people with profound or severe disability in the major urban region of SEQ are higher than the Indigenous rates in Queensland (6.9% and 5.5% respectively).
- Nationally, according to AIHW Burden of Disease data:
 - The relative disadvantage between Indigenous and non-Indigenous people is greater in urban areas, with Indigenous people in major cities experience 2.1 times the rate of health disadvantage compared to non-Indigenous people in the same area. For a similar comparison in very remote areas, Indigenous people experience 1.9 times the rate of disadvantage
- Nationally, according to the latest (2015) Aboriginal and Torres Strait Islander Social Survey⁸:
 - Indigenous people in non-remote areas were more likely than those in remote areas to feel that they had been treated unfairly in the last 12 months (35% compared with 28%). Indigenous people in non-remote areas further reported that in the last 12 months their GP or specialist did not always show them respect (15%), listen carefully to them (20%) or spend enough time with them (21%)
- Nationally, according to the latest (2019) Aboriginal and Torres Strait Islander Health Survey:⁹
 - The proportion of people with one or more selected chronic conditions was higher for people living in non-remote areas (48%) than in remote areas (33%)
 - the proportion of people with a mental or behavioural condition was around three times higher for people living in non-remote areas (28%) than remote areas (10%)
 - the proportion of people who did not see a General Practitioner when needed in the last 12 months was higher for those living in non-remote areas (14%) compared to remote (8%)

The above data highlight that the clear implications for ensuring that a priority focus is on urban setting as well as remote. This imperative to give priority attention to the needs of urban regions has not, however, been reflected in NDIS policy and program development.

Further, the challenges which are emerging through Indigenous population trends are not well understood. These trends reveal some dramatic demographic changes:

- There is a continued urbanisation of the Indigenous population, with 79% of Australia's Indigenous people living in urban areas
- There is a slowed or, in some cases, declining remote Indigenous population

⁷ Queensland Health 2017. *The burden of disease and injury in Queensland's Aboriginal and Torres Strait Islander people 2017 (2011 reference year) Hospital and Health Service profiles*, Queensland Health, Brisbane.

⁸ As reported in Australian Health Ministers' Advisory Council (AHMAC) 2017. *Aboriginal and Torres Strait Islander Health Performance Framework 2017 Report*, AHMAC, Canberra.

⁹ Australian Bureau of Statistics (2019). *National Aboriginal and Torres Strait Islander Health Survey, 2018-19*, cat no 4715.0, ABS, Canberra

Figures 1, 2 and 3 highlight these population shifts.

Figure 1. National Indigenous urban population trends 1971-2016 by size of town or city (Source: Markham and Biddle, 2018)

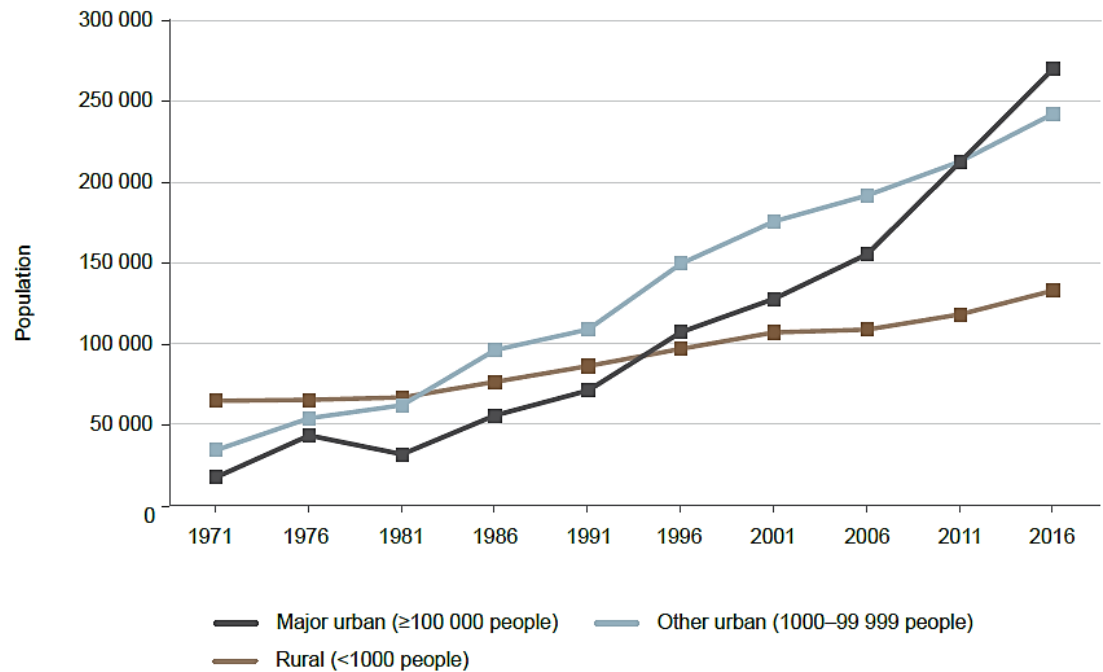


Figure 2. Projections of Indigenous Population to 2031, by Indigenous Region, ABS

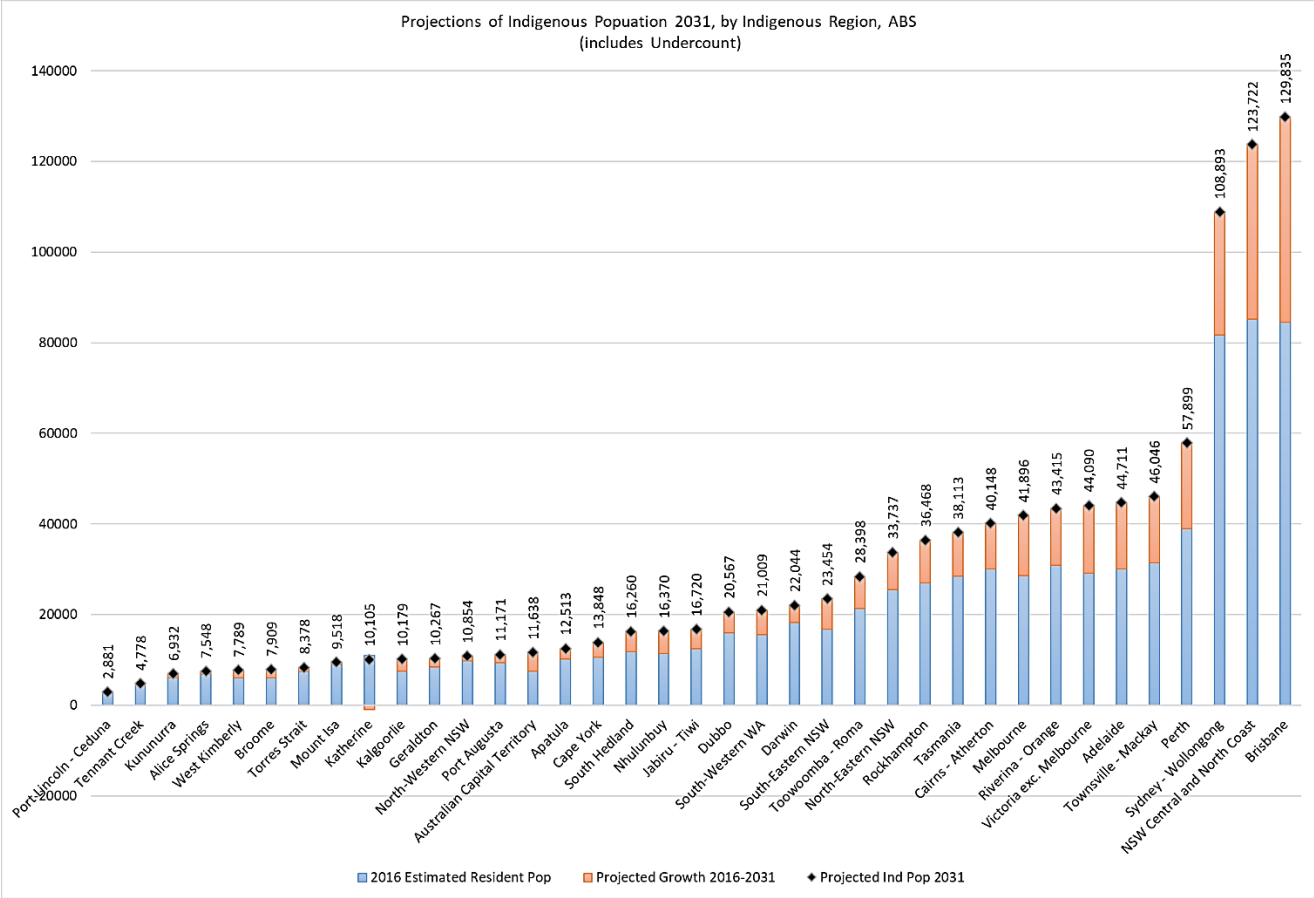
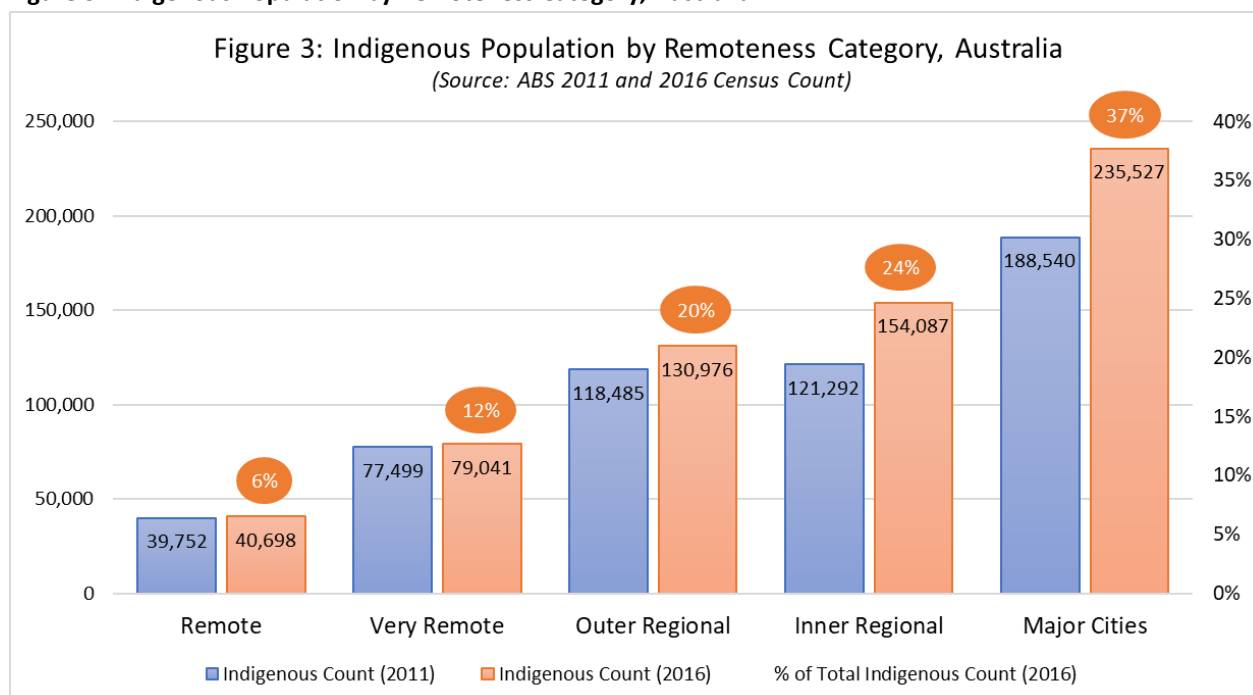


Figure 3. Indigenous Population by Remoteness Category, Australia



Lack of Culturally Safe Pathways and Thin Markets

Compounding this baseline ‘disability gap’ is the double disadvantage of inadequate ‘mainstream’ program responses which inherently fail to incorporate cultural safety and lack any real accountability to meet disability gap targets.

For example, a recent study (August 2020) published by the Australian Social Policy Association in the Australian Journal of Social Issues¹⁰ makes a poignant case to urgently address this lack of cultural safety. The study, undertaken by the University of Melbourne and Western Sydney University, found Indigenous people living with a disability were 1.6 to 1.8 times more likely to be exposed to racism and almost twice as likely to avoid certain situations because of past experiences of discrimination. It further reports that 42% of Indigenous people with a disability experienced racism compared to 32% of those without a disability and that 20% of Indigenous people with disability avoided settings such as healthcare or social services (including disability) because of instances of racism, compared with 11% of Indigenous people without a disability. Following repeated experiences of discrimination, “Apprehended discrimination” may result: the fear of becoming exposed to discrimination, leading to avoidance behaviours as a form of self-protection. As a result, fear and mistrust of healthcare are major deterrents to use. By contrast, the one exception was within the Aboriginal communities themselves, where disabled Indigenous individuals

¹⁰ Temple JB, Wong H, Ferdinand A, Avery S, Paradies Y, Kelaher M. *Exposure to interpersonal racism and avoidance behaviours reported by Aboriginal and Torres Strait Islander people with a disability*. Aust J Soc Issues. 2020;00:1–20. doi: 10.1002/ajs4.126.

are much more included, and participate in community and cultural events at the same rate as Indigenous people without a disability.

These findings provide for a compelling case as to why it is critical to ensure there are culturally safe pathways constructed, including to be delivered by community controlled Indigenous who provide the trusted relationships to support Indigenous people with a disability to access the NDIS. Unlike other sectors such as health, the study highlights the current absence of an overarching self-determining framework guiding the policy and program development of the NDIS and the urgent need to privilege Indigenous voices in the redesign of the NDIS. **Text Box 1** refers.

TEXT BOX 1: Excerpt from ‘Exposure to interpersonal racism and avoidance behaviours reported by Aboriginal and Torres Strait Islander people with a disability’, Australian Journal of Social Issues, August 2020, Temple et al

Understanding the nature of discrimination toward Aboriginal and Torres Strait Islander people with disability across all settings improves the capacity of support services to respond to racism, which is especially important given Australia’s National Disability Insurance Scheme (NDIS) and the challenges faced by Aboriginal and Torres Strait Islander people in accessing this programme (Ferdinand et al., 2019). It is important to recognise that the NDIS is being rolled out to Aboriginal and Torres Strait Islander communities amidst a context characterised by Aboriginal and Torres Strait Islander people’s fear and mistrust of governmental agencies due to experiencing intergenerational and historical racist treatment, exclusion and discrimination (Biddle et al. 2014; First Peoples Disability Network 2017).

Engaging with Aboriginal and Torres Strait Islander communities therefore requires the incorporation of trauma-informed approaches, as well as a high level of cultural competency in order to foster relationships based on trust (Ferdinand et al., 2019). Unlike many other sectors (e.g. health, education), there is currently no overarching framework for self-determination, working with Aboriginal and Torres Strait Islander people or cultural safety in the disability sector.

*This study provides further support to research calling for Aboriginal and Torres Strait Islander people with disability to lead the development of frameworks and approaches for the disability sector (Avery, 2018) It is imperative that policy in Aboriginal and Torres Strait Islander and disability address discrimination and provide greater support to Aboriginal and Torres Strait Islander people with disability. **This process needs to privilege the voices of Aboriginal and Torres Strait Islander people with disability who have been notably absent from policy development to date (Avery, 2018).** With the continued roll-out of the NDIS, addressing these issues is becoming more urgent.’*

The need for this cultural is includes urban settings, where the challenge of a ‘thin’ culturally secure market (both in relation to Partners in Community and Service Provision) remains just as acute as in remote regions. For example, at the commencement of NDIS transition arrangements in SEQ in 2017, there were no Indigenous community-controlled disability providers, despite this region being home to almost 40% of Queensland’s and 11% of Australia’s Indigenous population.

IUIH’s experience with the NDIS Pilot has overwhelmingly confirmed this, with the 900 Indigenous people engaged in the project having had no previous success in accessing the NDIS system through available mainstream pathways.

The aforementioned December 2019 Tune NDIS Review brought this into sharp focus, as highlighted in its Review consultations (**Text Box 3** refers).

TEXT BOX 3: Excerpts from Tune NDIS Review, December 2019

"The consultation revealed a deep frustration and angst with how the NDIS was being implemented in Aboriginal and Torres Strait Islander communities. The barriers to access and difficulties with the processes were widespread, chronic, and were showing no signs of improvement. The prevailing sense from the workshop was that cultural and social issues affecting access to the NDIS by Aboriginal and Torres Strait Islander people had been placed in the 'too hard basket' by the NDIA, and that they were not taking the issues of Aboriginal and Torres Strait Islander people seriously."

First Peoples Disability Network, Consultations Final Report

"There is a sizeable group who may not even realise the NDIS exists and they may be eligible for support. They are likely to have other forms of social disadvantage and may have limited interaction with other government systems. They may be people who have good reasons to fear government bureaucracies".

National Disability and Carer Alliance

"Unfortunately, many Aboriginal and Torres Strait Islander people's engagement with the NDIA is inflexible, inaccessible and not culturally safe. Engaging in the 'proper way' with Aboriginal and Torres Strait Islander participants requires respectful, sensitive and participant led relationships."

National Legal Aid

"The NDIS relies heavily on people finding their own way to the door. That is not easy for a whole range of people – people who have multiple forms of disadvantage, people who come from a culturally or linguistically diverse background, people who come from an Aboriginal or Torres Strait Islander background. Then there are those who have a very good reason to fear government services. We need to use trusted networks and organisations to reach these people..."

Every Australian Counts

Regrettably, the abundance of evidential Indigenous-led solutions to these barriers - already demonstrated for more than 40 years in the Aboriginal community controlled health sector - were not incorporated into the initial design and rollout of the NDIS, with the current policy and practice of the NDIS access and delivery architecture fundamentally out of step with these key CTG Agreement commitments. For example, there is no systematic or structural funding, capacity building or support for Indigenous led, designed and delivered NDIS access and care pathways. Given that the NDIS is the single biggest reform measure since Medicare, this represents a remarkable national policy design failure.

This failure was evident from the beginning. For example, the 2017 *Australian Government Plan to Improve Outcomes for Aboriginal and Torres Strait Islander People with Disability* had intent to articulate principles and strategies to ensure equitable access to the NDIS by Indigenous Australians. In reality, the Plan fell short in addressing key access barriers. Notably, in relation to supporting potential Indigenous Participants, there was:

- A focus on market development of service providers, rather than the importance of also building access and plan building pathways
- Reference to the 'thin' market of rural and remote settings, with an incorrect assumption that 'in urban areas there is generally greater access to disability services'
- No strategies to overcome structural barriers through promoting Indigenous-led solutions such as leveraging already established community-controlled health programs, workforce and infrastructure

Of note, these design flaws also mirror those evident in the aged care sector, including the structural access barriers experienced by Indigenous Elders in accessing MyAgedCare. In its Interim Report recommendations, the Royal Commission into Aged Care Quality and Safety's Interim Report not only

highlights the inherent barriers manifest in the current MyAgedCare system, but promotes expanded and integrated health, aged care and disability services for Indigenous people which are delivered through community-controlled organisations.

This has driven the need to ‘retrofit’ the NDIS architecture - which was the focus of the NDIS Pilot. In doing so, the NDIS Pilot also presented an opportunity to progress key Tune Review recommendations that it ‘develops a comprehensive national outreach strategy for engaging with people with disability who are unaware of, or are reluctant to seek support from the NDIS, with a dedicated focus on Aboriginal and Torres Strait Islander peoples’.

The Solution: NDIS Pilot Project

Involvement of IUIH

The genesis of the NDIS Pilot goes back to 2017. From November 2017 through to March 2019 IUIH negotiated with the NDIA and the Commonwealth Department of Social Services (DSS) to establish distinct Aboriginal and Torres Strait Islander ‘pathways’ for Access Determinations and Plan Building in SEQ. This was to build on a related IUIH NDIS Readiness Project previously funded by the Queensland Government and announced by the Queensland Minister for Communities, Disability Services and Seniors, the Hon Coralee O’Rourke in April 2018.

The rationale for SEQ was established and conceded early on. SEQ is the region in Australia with the fastest growing Indigenous population and is now the region with the largest number of Indigenous people. The estimated SEQ Indigenous population in 2020 is 100,000, which is almost 40% of the entire State’s Indigenous population and 11% of the entire Australian Indigenous population.

This population aligns with IUIH’s regional SEQ footprint, where IUIH was ideally placed to take on the NDIS Pilot. IUIH was established in 2009 as a strategic response to the significant growth and geographic dispersal of Indigenous people within the SEQ region. As the regional lead of a network of five Member Aboriginal and Torres Strait Islander Community Controlled Health Services (ACCHSs) in SEQ, IUIH has driven the development and implementation of transformational change to the way health care services are delivered for urban Indigenous Australians in the SEQ region.

Through pioneering ground-breaking Indigenous designed and delivered services, this has led to unprecedented improvements in health access and outcomes – with IUIH recognised as having made one of the most significant impacts of any Indigenous health organisation in Australia, in the shortest period, and with a national best standard of care¹¹.

For example, in just 10 years:

- Regular clients annually accessing life-changing comprehensive primary health care in SEQ have dramatically increased from 8,000 to 35,000 – supported by an expansion of clinics from 5 to 20 across the region

¹¹ Citation in IUIH’s joint win of Reconciliation Australia’s 2018 National Indigenous Governance Awards

- Through peer-reviewed published research, IUIH is receiving national and international acclaim for its system of care which is closing the gap 2.3 faster than standard care
- IUIH is now the largest employer of Indigenous people in SEQ, with over 1400 staff, of which half are Indigenous. IUIH's comprehensive workforce strategy has made a major contribution to building this Indigenous workforce, including through extensive tertiary and certificate level training programs supporting its expanded service reach into the health, education, aged care and disability sectors, including to support IUIH's entry into the NDIS service provision space
- Through its regional 'ecosystem', IUIH is able to: harness data to set targets and drive continuous improvement outcomes across all its member services; broaden the scope of interconnected service offerings including addressing the determinants of health; realise significant efficiencies in program operations through scaled-up solutions; provide what is arguably Australia's most extensive range of allied health and specialist disciplines for an Indigenous client population
- Over 3,200 Indigenous Elders are, for the first time, receiving culturally safe community aged care services through brand new access, assessment and service pathways developed and delivered by IUIH. Having demonstrated a solution to the failing mainstream aged care system (and access barriers like those confronting the NDIS), IUIH's model is now the subject of growing government and Aged Care Royal Commission interest for national replication. Now supporting more Elders to access community aged care services than any other provider in Australia, this model serves as a highly relatable blueprint for the NDIS Pilot to also forge new pathways for Indigenous NDIS Participants.

At its core, IUIH's demonstrated successes have not been a response to, or product of, government policies or programs, but rather showcase a new paradigm where empowered communities created the catalyst for change and led the design and delivery of solutions for their people. This also represents the fundamental value proposition being demonstrated by the NDIS Pilot.

Further background information on IUIH is included in **Attachment A**.

NDIS Demand

A realistic minimum size of the potential NDIS Participant client market in SEQ was pitched at 7% of the Indigenous population.

This is based on AIHW's estimate of 7.3% of the Indigenous population with a severe or profound disability¹². AIHW's estimate references a range of relevant statistical collections. For example, among Indigenous Australians aged 15 and over living in non-remote areas, the rate of severe or profound disability was:

- 7.2%, according to the ABS 2015 Survey of Disability, Ageing and Carers (SDAC)
- 7.8%, according to the ABS 2014-15 National Aboriginal and Torres Strait Islander Social Survey (NATSISS)
- 8.5%, according to the ABS 2016 Census

¹² AIHW Disability Support for Indigenous Australians, September 2019

As indicated earlier, these data reflect prevalence rates of Indigenous people with a severe or profound disability are almost twice those of non-Indigenous Australians based on age-standardised rates.

Based on these considerations, and using the 7% target, the estimated potential Indigenous NDIS Participants in the NDIS Pilot target region (SEQ) was 6,054 (as at June 2020).

This is consistent with SEQ's share¹³ of the Queensland Audit Office (QAO) projection of 14,500 Indigenous people being eligible for the NDIS in Queensland by 2019¹⁴. This QAO projection equates to approximately 7% of the Queensland Indigenous Estimated Resident Population (0-64) in 2016. Growth over the last 4 years would now make this target higher by an additional 14.4%, based on intercensal growth rates.

Latest NDIS data (as at June 2020) reports 6,514 Indigenous NDIS clients in Queensland¹⁵. This indicates only 45% of the Indigenous participation target for 2019 has been met (compared to 74% for all Queenslanders) and highlights the urgent need for new approaches to be implemented to address access barriers for Indigenous people such as that trialled under the IUIH NDIS Pilot. Unfortunately, Indigenous access data is not published at the NDIS Service Area level, despite representations made by IUIH to the NDIA. Future granular reporting of this kind will be essential to support the enhanced accountability measures required to monitor closing the gap objectives.

Figure 1 shows the potential NDIS Indigenous Participant distribution across the target NDIS Pilot NDIS Service Areas. The NDIS Pilot target region is the IUIH's SEQ footprint and includes the following NDIS Service Areas:

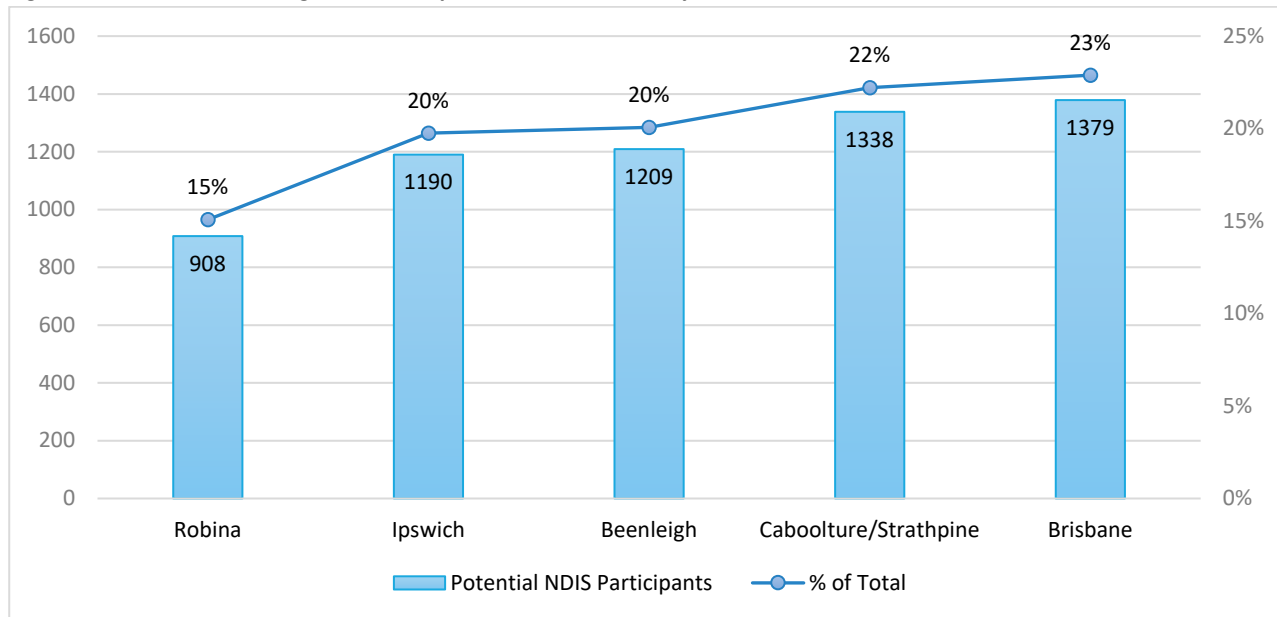
- Brisbane
- Robina
- Caboolture/Strathpine
- Ipswich
- Beenleigh

¹³ SEQ's Indigenous population represents 38% of Queensland's Indigenous population

¹⁴ Queensland Audit Office: The National Disability Insurance Scheme (Report 14: 2017–18). QAO quotes ABS estimates of 14,500 based on ABS 2016 212,534 Estimated Indigenous Population in Queensland 0-64 years

¹⁵ NDIS Quarterly Performance Dashboard, Queensland, June 2020

Figure 1: Potential NDIS Indigenous Participants at 30 June 2020, by NDIS Service Area



NDIS Pilot Architecture

Following previously unsuccessful advocacy by IUIH to establish Indigenous access pathways as part of the LAC and ECEI tendering processes, the NDIA ‘belatedly’ agreed to fund IUIH to conduct a place-based pilot project in South East Queensland to reengineer the way disability services are accessed by Indigenous people. In a collaborative co-design process facilitated by then NDIA Deputy Chief Executive Officer Michael Francis and IUIH’s CEO Adrian Carson, the intent was that the pilot would have the status of a ‘project of national significance’, with evaluation of project outcomes to inform NDIS program reforms, including to support Closing the Gap objectives.

Commencing in April 2019, the pilot built on IUIH’s preceding Queensland Government (Department of Community Services) funded NDIS Readiness Project and was designed to replace the existing Local Area Coordinator (LAC) and other NDIS planning arrangements with new access and plan building pathways for Indigenous people

In developing the NDIS Pilot, several underpinning propositions were agreed:

- Equitable Indigenous access and participation in the NDIS required the ‘navigation’ support of competent Indigenous organisations which are known to and trusted by their local communities
- Indigenous Australians constitute a ‘thin market’ for access, plan development and for service delivery everywhere – in urban areas as much as in regional, rural and remote areas. Critically, this also notes the limited number of Indigenous community organisations available to support access and delivery, and the need to allow these culturally trusted providers to undertake both functions – in contrast to a purist separation of roles to address perceived ‘conflicts of interest’
- Significant demographic changes to the Indigenous population had occurred which required policy and program responses. These included:
 - 79% of Indigenous Australians are now living in urban environments
 - The percentage of Indigenous Australians living in remote locations continues to decrease

- There are nodes where the growth rates of Indigenous Australians are most pronounced – those urban areas and regions are known and include SEQ, which is the largest and fastest-growing Indigenous region in Australia. By 2031, the Indigenous population in SEQ is projected by the ABS to be 129,000.

Framed by the above propositions, the core design of the NDIS Pilot was to achieve equitable access to and participation in the NDIS by Indigenous persons with disability, including in urban regions, where the fastest growing and largest Indigenous population cohorts live. To this end, pathways were developed which were separate from, and would replace, standard engagement and access NDIS processes for 0 to 6-year-olds (the ECEI cohort) and for 7 years and above (the LAC cohort).

Specifically, the Pilot design needed to address the structural barriers inherent in the NDIS systems design which, unlike the well-developed community-controlled health sector, was framed around a single 'one size fits all' and 'siloed' approach and are structurally fragmented:

- The 'gateway' for the necessary steps to gain access to the NDIS are mainstream providers chosen by the NDIA. These ECEI Providers and LAC 'Partners in the Community' have the sole legitimate authority to employ staff who are responsible to organise the dissemination of information in their 'service areas' – of which there are five in SEQ – as well as the sole right to function as 'gatekeepers' for assistance with collecting the relevant evidentiary documentation and submitting via email individuals' Access Request Forms to the NDIA's National Access Team. These ECEI and LAC providers have no accountable targets or reporting metrics to ensure equitable and culturally appropriate access by Indigenous applicants
- The decisions to approve access, to deny access, or to delay access pending provision of further information are the sole prerogative of staff of the NDIA's National Access Team. These staff are unknown to the Applicants
- A separate program takes over from the National Access Team for those individuals granted access, to organise Plans that authorise what the NDIS will offer. These are regionally based Service Delivery Centres
- The staff employed by the ECEI Provider or the LAC Provider receive notification of 'access met' decisions by the National Access Team. These staff are responsible for coordinating a meeting between the individual Participant and an NDIA Planner/Delegate at the relevant Service Delivery Centre. The Planner/Delegate uses this meeting as the mechanism to construct the Participant's Plan and then allocates a dollar value budget to this Plan.

The specific measures which IUIH embedded into the Indigenous Pilot Project of National Significance in order to redress structural barriers in the NDIS Access Pathway and the Plan Development Pathway included the following:

- The NDIA agreed that a small, dedicated Project Team employed by IUIH would be funded with the sole remit of securing 500 'access met' outcomes from the NDIA National Access Team and 500 "Plans directly submitted to NDIA Planners" for Aboriginal and Torres Strait Islander people with disability principally from four 'service areas' in SEQ.
- IUIH would submit to the NDIA, as the 'trigger' to pay against monthly invoices, monthly Progress Reports containing a data section and a narrative section; the narrative section would identify

and discuss key success factors as well as obstacles to implementation for consideration at meetings of a Joint Monitoring Committee between senior NDIA and IUIH management.

- An independent, external practical evaluation of the Indigenous NDIS Pilot Project of National Significance would be undertaken, with a methodology and contractor jointly agreed, in order to validate key success factors and advise on the potential for replicability and sustainability.
- Approved Plan for Indigenous Participants would automatically include funding for Coordination of Supports for at least one hour per week and two hours a week for more complex Plans.
- IUIH would secure signed Consent Forms from Indigenous Applicants nominating an IUIH Project Officer as the person the Applicant wanted to have continuing involvement during their Access Pathway and Plan Development Pathway. This arrangement was intended to ensure that IUIH could follow-up on outcomes from Access Request Form Applications with the National Access Team and could legitimately be involved with those who achieved an 'access met' outcome in providing support to the Participant prior to their Plan Meeting as well as at their Plan Meeting.

A schematic at **Attachment B** provides further detail in relation to the process flows for IUIH's NDIS Pilot.

These alternate access and plan build pathways would, however, operate within the overall structural design parameters of the NDIS, which included:

- A National Access Team silo, a Plan Approvals silo, a Service Delivery Silo and Quality & Safety Standards which at the time of the Pilot launch were set by each jurisdiction pending installation of a National set of Quality & Safety Standards
- Use of the template NDIS Access Request Form and Supplementary Evidence as mandated compliance front-end processes for authorised entry into the NDIS
- Use of Planning Meetings led by NDIA-approved Planners with NDIS Participants as the valid process for framing customised Plans responding to the exercise of the choice-and-control principle by the Participant.

Two key performance metrics were identified: IUIH and NDIA contracted that IUIH would achieve for the target group in SEQ:

- 500 "access met" outcomes– this is the metric for the Access Pathway, controlled by the National Access Team; and
- 500 "plans directly lodged with NDIA Planners" – this is the metric for the "Plan Development" Pathway, controlled by NDIA Regional Offices in Brisbane. It is not necessary that these 500 would all be the same 500 as the "access met" outcomes.

The parties agreed that:

- A Joint Monitoring Committee (JMC) would monitor the pilot through analysis of key success factors in real-time. The JMC was to be co-chaired, at Deputy Chief Executive Officer level in the NDIA and Chief Executive Officer level in IUIH
- An independent, practical evaluation of the NDIS Pilot be conducted that would furnish NDIA with valuable data and insights for adaptation and appropriate replication.

The Contract documentation was signed in March 2019 and the agreed arrangements for the Pilot Project would run from April 2019 to 30 June 2020.

NDIS Pilot Achievements

Key Pilot Data

Notwithstanding some considerable implementation challenges impacting on supporting system change of this magnitude, IUIH has demonstrated significant success in mobilising community engagement in the NDIS. For example, by the end of August 2020, the NDIS Pilot had engaged with close to 900 (895) Indigenous South East Queenslanders along the NDIS eligibility testing and plan building journey.

The overwhelming theme emerging from these 900 Indigenous Queenslanders is that that cultural and related barriers in the current mainstream NDIS system would have prevented them from any chance of accessing NDIS support. Their collective stories bear testimony to the power and importance of relationships built on trust and pathways designed and delivered by community-controlled entities.

In terms of the Access Met pathway, **Table 2** below outlines the engagement achieved.

Table 2. Access Pathway Data - April 2019 to August 2020

Access Met	Access Not Met	Determinations Pending	Records Currently under Review	Further Information Required	ARFs Ready/ Soon Ready	'Pipeline' Awaiting Consultation
388	69	52	5	27	110	244

In terms of the Plan Build pathway, **Table 3** below outlines the engagement achieved

Table 3. Plan Building Pathway Data – to August 2020

Plans Approved	Planning Meetings Booked
313	341

Data received from the NDIA Brisbane Regional Manager has provided comparisons between a cohort of NDIS Pilot participants who had effectively gone through the 'standard' NDIS pathway in the first period of the project (due to the NDIA not implementing the agreed NDIS Pilot processes) and a cohort of more recent NDIS Pilot participants who are now benefiting from the agreed 'project' pathway. The NDIA describes the difference as 'stark', noting that 'effective engagement (leading to an Access Met decision, or an approved plan) drops off sharply at each step in the 'standard' pathway'.

Table 4, supplied by the NDIA, highlights the NDIS Pilot achieving an **astonishing 3 times better 'access met' rates and 10 times better 'plan approval' rates when agreed operational arrangements have been implemented.**

Table 4: Access Requests Submitted by IUH (October to December 2019). Status as of 23 January 2020. Comparison of participants supported through standard or project pathways (NDIA supplied)

	Submitted	Access Met	Access Met %	Approved	Approved %
IUIH Pilot Pathway	66	59	89%	49	74%
Standard Pathway	90	26	29%	6	7%

Success Factors

The design characteristics supporting the above outcomes can be summarised as follows:

- Central to the success factors supporting these results is that the NDIS Pilot dispenses with the LAC model through establishment of alternate teams of Indigenous staff engaging with potential Participants through the eligibility testing, pre-planning and Plan build stages. Similar to Indigenous-led community health services, a ‘black LAC’ was trialled
- Critically, this new approach is built on cultural integrity and trusted relationships, where potential NDIS participants are mostly already known clients of IUIH. This significantly enhances the chances of successful navigation into and within the NDIS, with culturally enriched engagement the key to addressing the multiple barriers experienced by Indigenous people to access services, including even the perspective and understanding of what ‘disability’ and carer support means. For example, there is no equivalent word for ‘disability’ in many Aboriginal and Torres Strait Islander languages, resulting in underreporting of disability and underutilisation of disability services.
- Indigenous people with disability are much more likely to come on board the NDIS if they are approached by a person or organisation they trust and with whom they have an existing relationship. It's also important they can get the information and help they need easily and quickly from an organisation that is based in their community and which understands and values their cultural identity. For Indigenous people, a collective legacy of negative experiences with mainstream agencies and services has led to a significant degree of fear and mistrust.
- The NDIS Pilot offers complete integration across the health, family, aged care and disability domains. For example, IUIH’s established infrastructure of community-based, multi-functional clinics across SEQ provide the base for comprehensive integrated primary health care, in-home aged care, preventative health, and can readily sustain community-based NDIS engagement and support for the Access and Plan pathways. This results in a more seamless approach to supporting both clinical and functional needs, with substantial opportunities for increased efficiencies and effectiveness.

These design characteristics align with recommendations made in the Lowitja Institute commissioned research referred above. The research, undertaken in May 2019 by the University of Melbourne’s Centre for Health Policy, specifically sought to understand disability through the lens of Aboriginal and Torres Strait Islander people, including to explore the challenges and opportunities brought by the NDIS. Of relevance, key recommendations of this research included:

- Cultural brokerage to facilitate access
- Strengthening existing provider-participant relationships in engagement and planning processes, including to capitalise on these relationships to build trust with participants (such as Aboriginal Community-Controlled organisations)

Further, these design characteristics also corroborate the above mentioned study on the exposure to interpersonal racism and avoidance behaviours reported by Indigenous people with a disability undertaken by the University of Melbourne and Western Sydney University published by the Australian Social Policy Association in ¹⁶ makes a poignant case to urgently address this lack of cultural safety. The report found Indigenous people living with a disability were 1.6 to 1.8 times more likely to be exposed to racism and almost twice as likely to avoid certain situations because of past experiences of discrimination. It further reports that 42 percent of Indigenous people with a disability experienced racism compared to 32 percent of those without a disability and that 20 percent of Indigenous people with disability avoided settings such as healthcare or education because of instances of racism, compared with 11% of Indigenous people without a disability. By contrast, the one exception was within the Aboriginal communities themselves, where disabled Indigenous individuals are much more included, and participate in community and cultural events at the same rate as Indigenous people without a disability.

Lessons from Aged Care Reforms

IUIH's NDIS Pilot success builds on its experience in transforming Indigenous access to the aged care system. Five years ago, there were less than 200 Indigenous Elders receiving culturally safe community aged care services in SEQ. Growing to become Australia's largest provider of Indigenous-led community aged care services, IUIH now supports 3,200 Indigenous Elders across the Cabool, Brisbane North, Sunshine Coast and Wide Bay Aged Care Planning Regions.

This exponential growth has been premised on a model of community control and integration with the health care system, where - like the NDIS Pilot - new pathways needed to be created to address the structural barriers faced by Indigenous Elders in navigating the Aged Care System.

This included:

- Targeted and deliberative assistance for Indigenous Elders to enter the Aged Care System through obtaining the consent of each individual Elder to interact with MyAgedCare on their behalf, as a trusted, culturally appropriate intermediaries
- Structural coordination with entry level Regional Assessment Services (RAS) whereby IUIH qualified Assessors conduct individual assessments under the auspices of the RAS
- Comprehensive integration of culturally safe community aged care and primary health care service provision to support a seamless client journey.

The success of this model has received national attention as an emerging best practice approach to be replicated nationally.

Included in several initiatives being funded by the Commonwealth Department of Health is the Systems Navigator Measure, with IUIH chairing an Indigenous "communities of practice" collective of nine System Navigators nation-wide who are working with Indigenous Elders under this initiative. Importantly, there is acknowledgement that IUIH's leading role as an Indigenous Systems Navigator is not an impediment to

¹⁶ Temple JB, Wong H, Ferdinand A, Avery S, Paradies Y, Kelaher M. *Exposure to interpersonal racism and avoidance behaviours reported by Aboriginal and Torres Strait Islander people with a disability*. Aust J Soc Issues. 2020;00:1–20. doi: 10.1002/ajs4.126.

IUIH also providing in-home aged care services. As is the case in the NDIS space, there is a need for community-controlled aged care access, assessment and service provision pathways to be co-delivered as an appropriate response to what is clearly a culturally 'thin market'. Any perceived 'conflict of interest' and 'program separation' arguments can and have been readily managed in the context of supporting higher order closing the gap objectives.

This approach has been taken up by the Royal Commission into Aged Care Quality and Safety with Commissioners proactively engaging with IUIH and its model of care to help shape their Interim Report's key priorities in respect to Indigenous Elders. The Royal Commission's recommendations include the need for enhanced flexibility, adaptability and cultural safety in the provision of aged care for Indigenous Elders, including:

- providing accessible aged care assessment pathways
- integrating aged care with other services, such as primary health, mental health and disability services, including services provided by Aboriginal Community Controlled Health Organisations and other existing Aboriginal health and community organisations
- devising culturally appropriate assessment processes to access aged care
- greater provision of Aboriginal and Torres Strait Islander-specific services in cities and regional areas'

Most recently (October 2020), at the Aged Care Royal Commission's Final Hearing, Counsel Assisting's Final Submissions and Recommendation¹⁷ were tabled. The recommendations strengthened the above Interim Report priorities through proposals to make transformational and systemic change in the way Indigenous people access and receive aged care.

Noteworthy in these recommendations are:

- The establishment of 'Specific Aboriginal and Torres Strait Islander Service Arrangements'. This is a clear acknowledgement that the mainstream system alone CANNOT support culturally safe pathways for Indigenous Elders
- Requirements for Indigenous assessors to be recruited in any new Aged Care Assessment Agency and for local Indigenous people to be employed as Care Finders to help navigate access
- Priority and financial support to increase the number, capacity and viability of community-controlled aged care providers, including leveraging the existing Aboriginal Community-Controlled Health Service network to support expansion/integration into aged care and disability services. This includes provisions for flexible arrangements and capacity building to encourage new Indigenous entrants into the disability sector.

These aged care reform directions are also directly relevant to reshaping the NDIS architecture for Indigenous Australians, where similar structural barriers require systemic change.

Closing the Gap

The NDIS Pilot success is consistent with the well-documented and strong evidence supporting dramatic improvements in the health and aged care domains, where community-controlled arrangements have led the design and delivery of programs.

¹⁷ Sourced at: <https://agedcare.royalcommission.gov.au/hearings-and-workshops/final-hearing>. For noting, the final report of the Aged Care Royal Commission is due in February 2021.

The imperative to progress these reforms has been given a priority focus in the recently signed (July 2020) National Agreement on Closing the Gap (2019-2029). In this new CTG Agreement, all levels and jurisdictions of government have committed to redress significant past failures through a new approach to closing the gap. For the first time, there is now an explicit commitment to the following principles and outcomes:

- **Shared decision-making between government and Indigenous people**, including through formal partnerships, ‘where the voices of Indigenous people hold as much weight as the governments’
- **Preference for, and an increase in funding to and the number of, Indigenous organisations delivering services**, including an acknowledgement of the evidence base that community-controlled services ‘achieve better results’ to close the gap faster
- **Systemic and structural transformation of mainstream government organisations** to improve accountability and respond to the cultural needs of Indigenous people, including ‘that when government agencies change, design or deliver policies and programs they do so in line with the above priorities’.

These principles reflect the Prime Minister’s earlier (February 2020 CTG Statement to Parliament) commitment for fundamental change in the government’s approach to closing the gap, which was to give responsibility for program design and delivery back to Indigenous people. Relevant excerpts from this Statement are included in **Text Box 2**.

Text Box 2: Prime Minister’s Closing The Gap Statement to Parliament, Feb 2020

"Despite the best of intentions; investments in new programs; and bi-partisan goodwill, Closing the Gap has never really been a partnership with Indigenous people."

"We also thought we understood their problems better than they did. We don't. They live them. We must see the gap we wish to close, not from our viewpoint, but from the viewpoint of indigenous Australians before we can hope to close it and make a real difference."

"And that is the change we are now making, together with indigenous Australians through this process."

"It must be accompanied by a willingness to push decisions down to the people who are closest to them. Where the problems are, and where the consequences of decisions are experienced. That is what we must do."

"Our new approach to Closing the Gap provides some of the answers to this question. An approach that is built on partnership. On giving back responsibility. An approach of listening. Of empowering."

"We know that when Indigenous people have a say in the design of programs, policies and services, the outcomes are better - and lives are changed."

It is now incumbent on the NDIA, and the Commonwealth and Queensland Governments, as signatories to the Bilateral NDIS Agreement¹⁸, to translate their respective obligations under these priority commitments into a transformative re-engineering of the NDIS architecture – through a codesign process with Indigenous people, including to be informed by the clear outcomes of IUIH’s NDIS Pilot.

Future Directions

A practical first step in honouring these Closing the Gap commitments is to ensure that the outcomes of IUIH’s NDIS Pilot translate into ‘structural and systemic transformation’ of the NDIS. This was clearly the intent of the NDIS Pilot, which was funded by the NDIA to be a ‘project of national significance’.

Unfortunately, despite multiple representations made by IUIH to the NDIA Board and Senior Management, the NDIA has shown no interest in developing a transition plan to progress any system change beyond the Pilot end date of June 2020. Further, [REDACTED] the NDIA has not facilitated any external evaluation of the Pilot. Such an evaluation is deemed critical to ensure learnings from what could be regarded as the largest and most impactful Indigenous disability trial undertaken in Australia can inform future NDIS directions.

Rather than deference to the remarkable outcomes of the Pilot, the NDIA has decided to fund ‘Community Connector’ positions¹⁹ as its solution to improve system navigation for potential NDIS Indigenous Participants. However, this approach is at odds with the evidence base of ‘what works’ and as clearly demonstrated by the Pilot – viz that:

- Access and engagement pathways - as currently delivered by LAC and ECEI providers - must themselves be replaced with and operated by culturally safe Indigenous operated entities, rather than just a ‘front end’ linkage back to mainstream which would only increase system fragmentation and where there is no accountability of LAC or ECEI Partners to meet Indigenous targets
- Trusted Indigenous intermediaries have a critical role to not only evoke trust in the NDIS processes but in providing a continuum of support at every stage along the information sharing, eligibility testing, pre-planning and plan building client journey, including to provide a contact point between NDIS delegates/planners and the Participant
- Building on existing provider-participant relationships (such as that formed through Aboriginal Community Controlled Health services) is critical to ensure an integrated health and disability care model, to harness efficiencies through a joined-up service and workforce response and to ensure cultural framing and meeting of Participant needs/goals. The latter is important in the context of a culturally thin market, with most Indigenous Participants not empowered to navigate ‘consumer directed’ care through a culturally unsafe ‘choice’ of mainstream providers

A similar critique can be made of the Assessment and Referral Teams (ART) under the Queensland Government’s Disability Connect and Outreach Program (DCOP).

By contrast, and as indicated above, there are emerging and ground-breaking reforms in the aged care space which have the potential to represent a watershed in creating new care pathways for Indigenous

¹⁸ Bilateral Agreement between the Commonwealth of Australia and Queensland on the National Disability Insurance Scheme - 09 July 2019

¹⁹ Funding auspiced by the National Aboriginal Community Controlled Health Organisation (NACCHO)

Elders. Championed by the Aged Care Royal Commission, these reforms would give real substance to the key principles of shared decision-making and community control – demonstrated as the only way to make any progress in closing the gap.

It is hoped that the disability sector can leverage this reform momentum to address similarly intractable cultural barriers which are manifest in mainstream NDIS architecture. Both the Queensland Productivity Commission's Inquiry into the National Disability Insurance Scheme market in Queensland and the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability offer an ideal opportunity to progress this reform agenda.

Deliberative action now will also take advantage of the anticipated Partners in Community (LAC and ECEI) refresh tendering process which is anticipated to be promulgated in early 2021. This presents, for example, an opportune window to allow community-controlled entrants into the market.

NDIS Service Delivery

IUIH's NDIS Pilot experience has laid the foundation to support its evolution into an NDIS accredited community-controlled service provider. Having received accreditation under the NDIS Quality and Safeguards Commission, IUIH is in an advanced business development stage, with planned delivery architecture will be aligned to its nationally acclaimed community aged care delivery model - reflecting an integrated and seamless health and disability service pathway for Indigenous NDIS clients.

A delayed focus on 'supply' of services reflects a strategy of first creating a 'demand' pipeline through IUIH's access and plan development Pilot. This demand and supply approach will, in turn, address some of challenges of the existing thin market for culturally safe NDIS supports. Leveraging its already established health and aged care services into disability supports, is also a viable template for other community-controlled health services to enter the NDIS market.

Recommendations

The continued structural Access Pathway and Plan Development Pathway barriers in the NDIS preventing equitable outcomes for Indigenous people with disability [REDACTED] [REDACTED] remain at odds with the government's commitments to place responsibility for program design in Indigenous hands.

IUIH considers that the experience of the Indigenous NDIS Pilot Project of National Significance should be a primary driver in efforts to address this national priority, including as a 'real life' example of the kind of systemic and structural transformation deemed necessary to closing the gap.

Accordingly, the following recommendations are made:

1. Progress the government's National Agreement on Closing the Gap (2019-2029) commitments, including to:
 - Improve cultural accountability by systematic and structural transformation of the NDIS, including through genuine shared decision-making between government and Indigenous communities

- Give preference to and ensure priority NDIS funding of Indigenous organisations, acknowledging the evidence-base that Indigenous designed and delivered services will close the gap faster
2. In line with and to give practical application to the above commitments, draw on the experience of the NDIA funded Institute for Urban Indigenous Health's Pilot Project of National Significance to:
 - 2.1 Establish specific and Indigenous-led Access and Plan Development Pathways into the NDIS for Indigenous people with disabilities - operating in parallel to 'mainstream' NDIS 'Partners in the community' for Early Childhood Early Intervention (ECEI) and Local Area Coordinator (LAC) Partners in Community. These pathways:
 - Should assign ECEI and LAC roles and functions to competent and culturally appropriate community-controlled organisations and intermediaries who are trusted by Indigenous people
 - must reflect structural changes to the way NDIS is accessed by Indigenous people, rather than front-end 'connector' or 'referral' type solutions
 - should be introduced as part of the upcoming refresh of current LAC and ECEI contract arrangements in 2021, and on a regional scale across NDIS Service Areas
 - 2.2 Formally incorporate the involvement of a Participant's chosen advocate, intermediary or support in the development of Participant Plans, both at the pre-Plan Meeting stage to assist the Participants to clearly articulate their Goals, as well as during the formal Plan Meeting with the NDIA's Planner/Delegate
 - 2.3 Integrate NDIS access, coordination and service provision with primary health care. This could be achieved through leveraging the already established national network of 150 Aboriginal Community Controlled Health Services (ACCHSs), including:
 - building on trusted and already established culturally safe ACCHS client relationships ensuring seamless navigation through the health, aged and disability care systems
 - extending the community-controlled delivery model to support an extant 'thin' market of culturally appropriate disability providers, including in urban settings
 3. Implement priority and targeted strategies to improve access and support in urban regions - where the majority (80%) and fastest growing Indigenous population resides. Contrary to common misconceptions, proximity to 'mainstream' services has not translated into better access or outcomes for Indigenous people
 4. Introduce enhanced transparency and accountability measures, including:
 - incorporating Indigenous specific NDIS targets and reporting requirements into all NDIS programs
 - publishing quarterly Indigenous access and plan data at the NDIS Service Area level

Contact

Adrian Carson

CEO, Institute for Urban Indigenous Health

Mobile: 0448 865 618 Email: Adrian.Carson@iuih.org.au



A focus on urban Indigenous populations is essential to closing the health gap

A rapidly increasing majority of the Indigenous population is now in urban areas:

- Nationally, 79% of Indigenous people live in urban areas, with the largest cohort (41%) of Indigenous people living in major urban cities (over 100,000). The fastest growing Indigenous populations are in major urban cities, with population decline or slowed growth in remote and very remote regions

Proximity to mainstream services has, however, not translated into better health outcomes for Indigenous people due to significant barriers in accessing culturally safe care. National data show that:

- 73% of the total Indigenous burden of disease and 74% of the total health gap is in urban areas
- The relative disadvantage between Indigenous and non-Indigenous people is greater in urban areas: Nationally, Indigenous people in major cities experience 2.1 times the rate of health disadvantage compared to non-Indigenous people in the same area. For a similar comparison in very remote areas, Indigenous people experience 1.9 times the rate of disadvantage
- There is lower access to Community Controlled Health Services in urban areas (26%) compared to remote areas (97%)



"With the opportunity of being able to directly impact 11% of Australia's and 38% of Queensland's Indigenous population, IUIH is in a unique and pivotal position to make a significant national impact in closing the gap faster"

Institute for Urban Indigenous Health

1.

The Institute for Urban Indigenous Health's (IUIH) response in South East Queensland

IUIH's footprint is an amplification of these demographic and health challenges for Indigenous people in SEQ:

- SEQ is Australia's largest and equal fastest growing Indigenous region, with census count growing 33% between 2011 and 2016 (compared to 18% national Indigenous growth)
- SEQ is home to 11% of Australia's and 38% of Queensland's Indigenous people. SEQ's Indigenous population is projected to grow from 100,000 in 2020 to 129,000 by 2031
- In 2009, only a fraction of this population was accessing community controlled comprehensive primary health care
- The Health Adjusted Life Expectancy (HALE) gap is 1.5 times greater in SEQ (11.6 years) compared to remote areas of Queensland (7.6 years)

The imperative to address these challenges shaped the blueprint for a new regional community governance architecture and the formation of IUIH. As the backbone organisation of a regional IUIH Network of member Community Controlled Health Services (CCHSs) in SEQ, IUIH was created by the existing four CCHSs to drive the development and implementation of transformational change to the way health care services were delivered for urban Indigenous Australians. The IUIH Network is outlined in Table 1 and Figure 1.

Table 1. IUIH Network

IUIH NETWORK	
Local Government Areas of IUIH Network	Brisbane, Gold Coast, Logan, Redland, Moreton Bay, Ipswich, Laidley, Somerset and Scenic Rim
Institute for Urban Indigenous Health (IUIH)	South East Queensland Regional Backbone organisation Directly operates: - the Moreton Aboriginal and Torres Strait Islander Health Service (Moreton ATSICHS), with clinics in Caboolture, Morayfield, Strathpine, Deception Bay and Margate - the Goodna clinic - the Salisbury Mums and Bubs hub
The Aboriginal and Torres Strait Islander Community Health Service Brisbane (ATSICHS Brisbane)	Headquartered in Woolloongabba with additional clinics in Browns Plains, Northgate, Logan and Loganlea
Yulu-Burri-Ba Aboriginal Corporation for Community Health (Yulu-Burri-Ba)	Headquartered on North Stradbroke Island, with additional mainland clinics in Capalaba and Wynnum
The Kalwun Development Corporation (Kalwun)	Headquartered in Miami with additional clinics in Coomera and Bilinga
The Kambu Aboriginal and Torres Strait Islander Corporation for Health (Kambu)	Headquartered in Ipswich with additional clinics in Laidley and Booval

"SEQ's Indigenous population is projected to grow from 100,000 in 2020 to 129,000 by 2031."



Figure 1: IUIH Network Clinic Map



Institute for Urban Indigenous Health

3.

IUIH's recognition as current joint winner of Reconciliation Australia's national Indigenous Governance Awards includes:

'Through strengthened community self-determination, an entrepreneurial business model, and pioneering a brand new regional health 'ecosystem', IUIH has now been able to make the biggest single health impact of any Indigenous organisation in Australia, in the shortest time period, and with a national best practice standard of care'.

For example:

- ✓ Recent peer-reviewed publications have showcased IUIH's System of Care as international best practice, including having Australia's only validated model which is closing the Health Adjusted Life Expectancy (HALE) gap 2.3 times faster than predicted trajectories

- ✓ IUIH has dramatically improved access to services:

300% growth in clinics, from **5** in 2009 to **20** in 2020

312% growth in regular Indigenous client numbers from **8,000** in 2009 to **33,000** in 2020

4,583% increase in Annual Health Checks from **500** in 2009 to **23,419** in 2020

- ✓ IUIH can leverage its regional strength to generate significant efficiencies of scale and reach. With close to a \$100 million annual budget, IUIH is now the largest community controlled health and aged care provider in Australia, and also the largest comparable mainstream community health provider

- ✓ IUIH has 670 employees. Across the IUIH Network there are over 1400 employees, including 700 Indigenous employees - now considered the largest Indigenous employer in SEQ. This is making a major contribution to improved employment and household income levels for Indigenous people in SEQ, and a key social determinant in meeting the interdependent health, education and employment closing the gap targets

- ✓ IUIH's Birthing in Our Community (BiOC) program has delivered stunning and internationally acclaimed perinatal results – halving the national preterm birth rate (6% compared to 14%) and, for the first time in Australia, almost closing the gap altogether in comparison with non-Indigenous pre-term birth rates. In addition: low birth weights half national rate (6% compared to 11%); admissions to neonatal unit half national rate (10% compared to 22%)

- ✓ IUIH's flagship Deadly Choices engagement and health promotion program is now considered the most recognised Indigenous brand in Australia – described as 'the jewel in the crown of Indigenous health'. The current rollout is throughout Queensland and in selected sites in all States/Territories, including school programs, media campaigns, sports ambassador program and partnerships with 16 NRL, AFL and other sporting clubs across Australia, including a Deadly Origin campaign. For the January to June 2020 period, Deadly Choices had a national reach of over 2 million through its social media platform

- ✓ The Deadly Kindies campaign is increasing early childhood education attendance, directly contributing to achieving closing the gap education targets

- ✓ IUIH is considered the largest Indigenous community aged care provider in Australia - providing care to 3,278 Elders in SEQ, Sunshine Coast and Wide Bay and operating under a unique and nationally recognised service delivery and financial model integrating aged care with comprehensive primary health care. IUIH is leading a national COVID-19 Elders response in every capital city of Australia to provide critical welfare checking, meals and other supports

- ✓ Following the establishment of a health/justice partnership, IUIH is the first CCHS in Australia to be registered as a Community Legal Centre, addressing rights and responsibilities as a core component of the health system and recognising the important intersection between legal matters and health

- ✓ IUIH has spearheaded a project of national significance to pilot new culturally safe NDIS access and plan building pathways to better support Indigenous people with a disability in SEQ. IUIH is also an accredited NDIS service provider



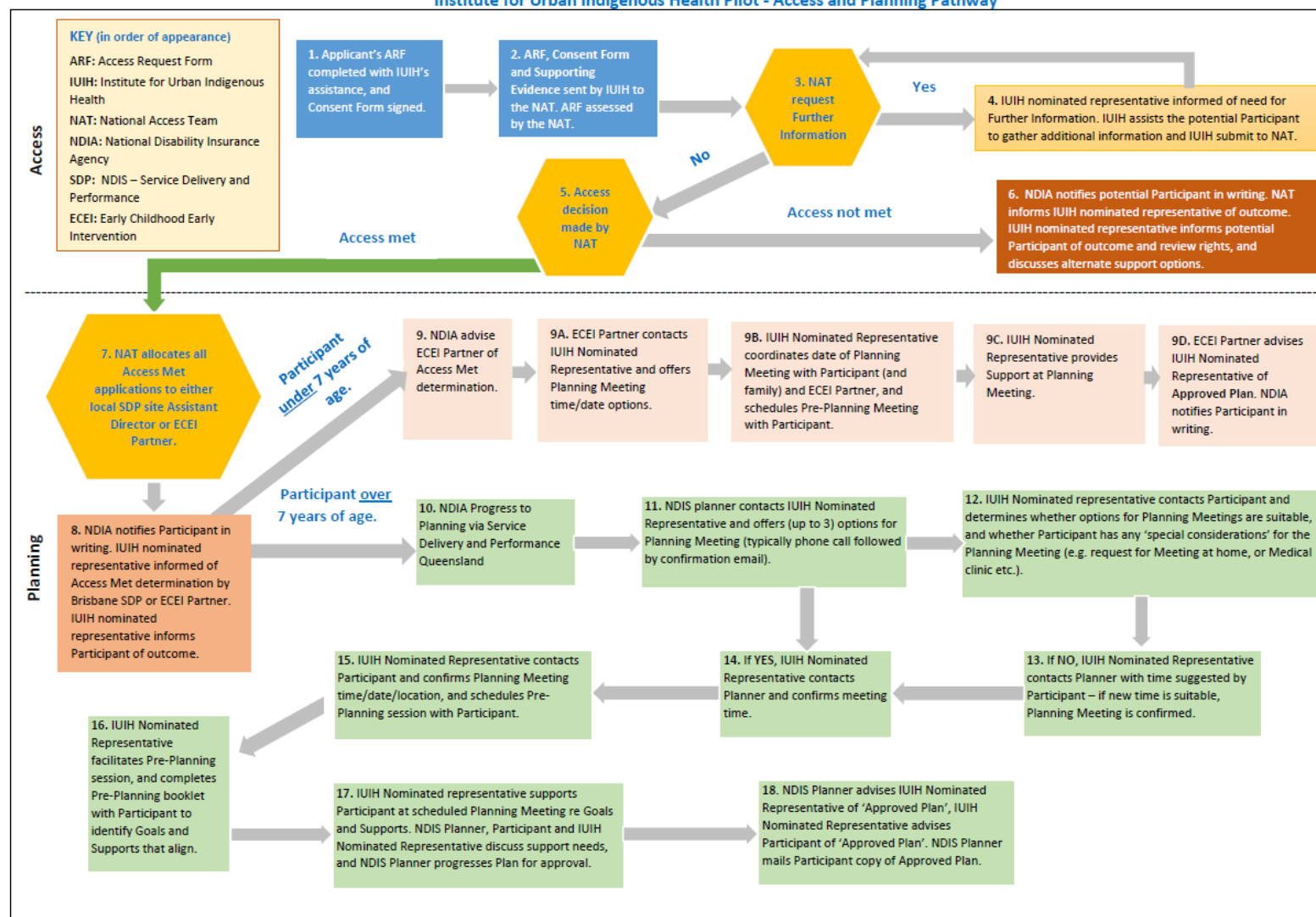
🏠 22 Cox Road, Windsor

☎ (07) 3828 3600

🌐 www.iuih.org.au



Institute for Urban Indigenous Health Pilot - Access and Planning Pathway



NDIS Pilot Design Features

The following design features are deemed to have contributed to achieving successful outcomes to date.

(1) IUIH leveraged its community-based, multi-functional Clinic network

The fundamental strategic proposition that IUIH put to the NDIA from November 2017 through to March 2019 was that IUIH could activate a network of between 15 to 20 community-based clinics which already enjoyed public recognition, had the trust of local community members and Elders, could call upon a personnel cadre of hundreds of doctors-specialists-allied health professionals to input into Access Request Forms (ARFs), and could function as an infrastructure for community engagement activities as well as more intimate face-to-face individual/family encounters in culturally safe spaces.

This leveraging strategy is considered a foundational efficiency for achieving equitable participation by Indigenous Australians who are “out of the line of sight” of government agencies, NGOs and mainstream NDIS “LAC and ECEI Partners”.

(2) IUIH ‘Socialised’ multiple clinical disciplines into the NDIS

IUIH was fully cognisant of Applicants for the NDIS having their Access Request Forms (ARFs) rejected because treating clinicians would not comply with the ‘functional impact’ requirement when describing the individual’s disability at “PART F” in the ARF. Accordingly, IUIH understood that the success of its leverage strategy for the network of community-based clinics depended upon ‘socialising’ up to 12 clinical clusters into compliance with ‘functional impact’ descriptors. Hence, concurrent with the initial community engagement activities, IUIH launched a sustained, three-month-long ‘socialisation’ campaign of face-to-face meetings, briefings and information dissemination in and out of normal working hours, targeting groups of clinicians in their professional clusters, locally as well as regionally, jointly led by IUIH’s Disability Services Manager and IUIH’s Clinical Director and mandate by the IUIH Chief Executive Officer.

This ‘socialisation’ campaign was successful in securing behavioural change from the 12 clinical professions in compliance with ‘functional impact’ language in “PART F” of the ARFs.

(3) IUIH established a systematic regional team approach

IUIH has always acknowledged that the NDIS constitutes a massive ‘systems change’. The NDIS was touted publicly as the biggest policy change by the Australian Government since the introduction of Medicare. IUIH recognised from the beginning in March-April 2019 that it is essential for the Indigenous Access Pathway and Plan Development Pathway to be implemented consistently, systematically, across all 15 to 20 locations within the SEQ NDIS’s Service Areas. Consequentially, when utilising the NDIA’s funding for the “Pilot Project of National Significance”, IUIH notionally allocated Project Officers to clusters of clinics and/or to Service Areas, but always on the basis that the Project Officers comprised a flexible, regional ‘pool’ such that Project Officers could be deployed in what IUIH called “response blitzes” where local community engagements generated ‘demand hot spots’.

This flexible deployment of Project Officers was successful in maximising the Project Officers' productivity and, concurrently, kept faith with the 'early adopters' in the local communities who took the leap of faith to work with IUIH to try to access the complex, daunting system that is the NDIS.

(4) IUIH could communicate with over 35,000 registered Indigenous clients

The IUIH network of community-based clinics had been progressively developed in the decade 2009 to 2019, in a planned strategic response to the rapid and continuous population growth Aboriginal and Torres Strait Islander people in south-east Queensland. By March 2019, the clinics and community health programs were delivering professional services to over 35,000 Aboriginal and Torres Strait Islander people in all age cohorts, and every individual's biodata had been recorded onto an electronic patient information records systems (PIRS). Tapping into this electronic database was the logical, efficient starting methodology for IUIH to establish initial information dissemination about the NDIS and its potential relevance and benefits to these existing clients and/or to their children or family members.

This initial approach proved successful, both as a mobilisation strategy to engage the 15-20 clinics as well as a targeting strategy to focus in on the first wave of clients most likely to have NDIS eligibility.

(5) IUIH launched a 'slow burn' strategy of community engagement activities

An integral component of IUIH's business case to the NDIA had always been that Aboriginal and Torres Strait Islander people who were potentially eligible for access into the NDIS but who were "out of the line of sight" of mainstream NGOs and government agencies, required a culturally trusted and accepted intermediary organisation to initiate a communication dialogue with them. IUIH linked the NDIA-funded Project Officers to the 15-20 Clinics as well as to IUIH's community-based programs including the renowned "Deadly Choices" Program to launch carefully planned and locally-customised community engagement activities aimed at raising awareness of the NDIS, explaining the key design parameters of the NDIS for Access and Plan Pathways, and registering interest from individuals, parents and grandparents in more intensive, one-on-one consultation to secure access. In contrast to other initiatives being promoted at this time which trumpeted herding together scores of people and 'registering' them in one 'hit', IUIH's community engagement activities focused on small-scale, intimate sessions in community locations, with morning tea breaks provided for informal conversations to complement the formal presentations and Q&A sessions. IUIH ensured that an Aboriginal or Torres Strait Islander "Champion" with a disability who was a household name spoke at these early community engagement meetings. IUIH established from the very first community engagement activities that the Community was confused about the NDIS, that mainstream disability providers were targeting the Indigenous community to harvest service delivery contracts and were uninterested in the front-end process for the Access Pathway and the Plan Development Pathway, and that achieving a successful outcome along those Pathways was a 'slow burn' not a 'quick sprint'.

IUIH was successful in implementing a methodology for community engagement which communicated essential NDIS messages in a language that Aboriginal and Torres Strait Islander people understood, that respected their concerns, that dispelled their confusion, and which encouraged them to continue with the necessary Access steps for entry into the NDIS.

(6) IUIH developed customised Tools

The first Tool which IUIH had to develop was a set of single-page documents printed back-and-front containing text and flow diagrams for the 15-20 clinics and the 12 clinical disciplines which explained three separate ways that they could 'channel' Aboriginal and Torres Strait Islander people with disability into the community engagement activities or directly to a Project Officer. These documents were generated in close consultation with senior managers in the IUIH clinical network. The second Tool which IUIH developed was to make the NDIS "Access Request Form" into a writable pdf format, which meant that its constituent PARTS could be progressively completed over time and by several parties – such as the Applicant, the Project Officer, and the treating clinicians across 15-20 dispersed locations. The third Tool which IUIH developed was a Primary Contact Consent Form, signed by the Applicant and designating a specifically named Project Officer as the person whom the NDIA was to contact at each step along the Access Pathway and the Plan development Pathway. The Primary Contact Consent Form had multiple purposes, namely to ensure that the Indigenous Applicant (a) did not 'get lost' or 'disappear' into the mainstream LAC/ECEI Providers, (b) did not become excluded from the "Pilot Project of National Significance", (c) did not miss out on continuing support and assistance with Pre-Plan Meetings, (d) was supported to insist on a minimum of one hour of Coordination of Supports in their Plans; and (e) was counted towards the two Metrics in IUIH's Contract with the NDIA.

The NDIA's own data, provided by the Brisbane Regional Office, has demonstrated the extraordinary level of success of these Tools in streamlining efficient, beneficial journeys along the Access Pathway and the Plan Development Pathway, compared to journeys of Indigenous Applicants/Participants when these Tools are not utilised.

(7) IUIH established a 'pipeline' of potential Applicants

The 'slow burn' approach described previously generated as months went by increasing demand from Aboriginal and Torres Strait Islander people with disability and/or their parents/families for assistance in making their applications into the NDIS. Rather than sacrifice quality in a dash to register Indigenous Applicants, IUIH concentrated on continuously improving its systems and processes with the 15-20 Clinics and IUIH's community programs for screening and completing the Access Request Forms. IUIH's decision was taken in the interests of securing 'access met' outcomes and minimising 'access not met' outcomes or 'further information required' decisions from the National Access Team. Re-work and rejections arising from these latter two outcomes constitute inefficiencies and as such should have no place in a "Pilot Project of National Significance" seeking to demonstrate the systemic key success factors for sustainability, adaptation and replication. Consequently, IUIH built-up over time a 'pipeline' of people who were awaiting their detailed face-to-face consultation and then support with their Access Request Form completion and Supplementary Evidence.

(8) IUIH developed a computerised Applicant-Participant NDIS database.

IUIH 'mapped' the key milestones along the Access Pathway as well as the Plan Development Pathway in the NDIS as a system. Initially, IUIH linked these milestones into the dominant PIRS electronic records system used in south-east Queensland and this worked well in the early months of the "Pilot Project of National Significance". But, as the numbers of Indigenous Applicants and Participants began

to increase, and as the 'pipeline' numbers expanded, IUIH decided to establish a discrete electronic database to record and monitor the milestones in the "Pilot Project of National Significance". IUIH was able to leverage some of its existing information technology systems infrastructure to build this database in FIXUS. Each Project Officer received training in FIXUS, and each Project Officer was given responsibility for entering Applicant and Participant milestone data directly into the individual's FIXUS record. A FIXUS Administrator maintains the integrity of the database and generates reports for the IUIH Chief Executive Officer and IUIH Manager for Aged Care and Disability Services, as well as for the Project Team.

IUIH has been successful through FIXUS in: (a) monitoring the progress of individuals along every milestone of the Access Pathway and the Plan Development Pathway; (b) conducting 'case conference' reviews to address blockages or delays in milestones whether originating from within IUIH or within the NDIA; (c) re-deploying Project Officers to communities demonstrating either blockages or higher levels of demand; (d) engaging with the NDIA Brisbane Regional Office on resolving a number of matters.

(9) IUIH has implemented effective Project monitoring and reporting systems.

Internally, IUIH implemented regular Project Team Meetings: (a) as a forum which enabled IUIH senior management to keep Project Officers informed of the broader issues around the "Pilot Project of National Significance"; (b) as the authoritative forum for Project Officers to express issues of concern – of which there were many in the period April to December 2019, as the NDIA is aware; and (c) as a process to ensure quality, consistency and timeliness in all aspects of Project implementation. The COVID-19 pandemic created the opportunity to transition these Project Team meetings to a video-conferencing format using "Microsoft Teams" technology. Externally, IUIH has provided comprehensive "Monthly Progress Reports" to the NDIA, comprised of two sections – a Data Section which addresses the two performance Metrics as well as a Narrative Section which addresses key success factors, blockages and case studies. The intent of the "Monthly Progress Reports" was that they were linked to payments of monthly invoices submitted by IUIH to the NDIA. Additionally, the substance of the Narrative Report sections would be considered at periodic meetings of the Joint Monitoring Committee.

Project Team Meetings even in a COVID-19 environment continue to be a success in achieving their three original intents.